



UNIVERSITY OF
BIRMINGHAM



EVALUATING ADVANCE CARE PLANS

Listening to Families and Professionals

FINAL REPORT

Dr Karen L Shaw and Jenna L Spry on behalf of the Research Team
September 2020

Evaluating advance care plans: Listening to families and professionals.

- This Report outlines the main findings from a project entitled: A multi-perspective qualitative study to understand the experience and impact of the Child and Young Person's Advance Care Plan – CYPACP.
- It describes a qualitative study that focused on the lives of different families to understand what the CYPACP means to them and the role that professionals and services play in this.
- This involved interviews and surveys with 19 parents and 127 multi-disciplinary professionals who had experience of the CYPACP in the West Midlands (October 2017 to February 2020). This provided detailed insight about how families and professionals work together to make and advance care plans and the factors that shape experience and outcomes.
- These findings were combined with learning from end-of-project stakeholder events and other research findings to generate a detailed list of recommendations and research priorities.
- This report is intended for those involved in the commissioning, design, implementation and use of care services for children with serious condition and their families.
- For more information, please visit our study website at www.birmingham.ac.uk/acp-study

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Karen Shaw and Jenna Spry (Authors)

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Executive Summary

Advance care planning is considered an important mechanism to drive-up standards in care for babies, children and young people with life-limiting or life-threatening conditions.¹ This involves making a formal care plan that sets out agreed actions to be taken in the event of deteriorating health, emergencies or end of life. The Child and Young Person's Advance Care Plan (CYPACP)² is one such plan; endorsed by the National Institute for Health and Care Excellence (NICE).¹ This has been adopted by a large group of NHS and private sector organisations across the UK.

This report provides the first in-depth examination of the CYPACP. It brings together learning from (i) a research study to provide in-depth understanding about the CYPACP in all of its particularities – from the perspectives of families and professionals in the West Midlands, (ii) stakeholder events held at the end of the study to disseminate and discuss our findings, and (iii) other related research. From this, we have produced a number of key messages about advance care planning, including important recommendations for policy and practice.

Key Messages

- **Advance Care Planning is a valuable component of high quality care.** The findings demonstrate that the CYPACP is relevant to a diverse range of children and families and makes sense to them as a resource to plan care. Parents and professionals described the CYPACP as an improvement on previous ways of working and described numerous positive outcomes and anticipated benefits (e.g. clarifying goals of care, thinking more broadly about wishes for life and death, increased recognition of unmet needs, care in preferred places and improved wellbeing). As such, the evidence supports the inclusion of advance care planning as a quality standard for children's health care and NICE endorsement of the CYPACP.¹ However, the findings also highlight areas where progress can be made.
- **Families need more choice and support.** Making a CYPACP has many emotional implications for parents who describe the process as challenging, distressing and draining. While no participants in our study regretted making a plan, they called for more choice about how plans are made (timing, location, who is involved) and improved information, support and aftercare.
- **The CYPACP is a complex intervention that requires support to implement.** Professionals and organisations have undertaken significant work to promote and adopt the CYPACP. Many staff have also developed considerable expertise in its implementation. However, parents and professionals reported too many instances where care providers lacked awareness about the CYPACP or failed to use it without prompting. As such, families and care providers may fail to capitalise on the potential benefits of the CYPACP because it is not fully embedded and integrated into routine practice. Several interrelating issues were identified:

- **Many professionals feel underequipped to deliver key aspects of the CYPACP;** having received little formal education in advance care planning. Unmet training needs included the general principles and skills that underpin advance care planning such as: how to discuss sensitive topics with families, respond to distress and meet non-clinical needs (e.g. spiritual care, wishes and memory-making). Professionals also needed support to understand and implement the CYPACP as intended. This included improved clarity about policy, eligibility, and the individual and collective actions required to create, share and review plans.
- **A ‘whole pathway’ approach is needed** to ensure that all professionals who deliver care to children and families can incorporate the CYPACP at every stage of their journey – from diagnosis to end of life and into bereavement. This will involve engaging all members of the care team, including those providing specialist and universal services. Consistency will be further increased by adopting a national approach that will unify advance care planning across regions and settings; reflecting that care for children with complex or rare conditions is often provided across organisational boundaries.

- **The CYPACP has room for improvement.** The CYPACP is largely fit for purpose, although several aspects can be improved to support safety and make it more family-centred. This includes changes to the CYPACP documentation to support accuracy, clarity and relevance of information; particularly in non-clinical sections. The findings also suggest that more can be done to optimise existing resources (e.g. website, policy, leaflets) and develop new materials (e.g. family-centred resources, profession-specific factsheets, e-learning).
- **Greater priority needs to be given to the long-term resourcing of the CYPACP.** The CYPACP has developed rapidly through the expertise and commitment of individual champions and multi-agency collaboratives. However, the sustainability of the CYPACP is precarious while it remains dependent on ‘special interest’ groups who offer their time on a goodwill basis. In addition to dedicated funding, development strategies will also benefit from (i) ongoing access to evidence-based information on what works to promote beneficial outcomes and (ii) co-production models of involvement to ensure the CYPACP takes account of all stakeholders.
- **Greater societal awareness of advance care planning and the CYPACP is needed.** Lack of public awareness hinders conversations about advance care planning and reduces opportunities for social support.

Implications for Policy and Practice

- **Guidance:** We call on NHS England and NHS Improvement (NHSE/I) to make clear to NHS commissioners that they should specify advance care planning in the children's palliative care services that they commission from local providers, including hospitals, community services and children's hospices. The new NHSE/I service specification does have a section on advance care planning, but does not refer to the CYPACP, which perhaps it usefully could.
- **Funding:** We call on NHSE/I to fund the CYPACP to make sure it is sustainable, can be developed further and remain as a valuable resource for families, professionals and services.
- **Education:** We call on Health Education England to develop a core skills education and training framework for children's palliative care which explicitly refers to advance care planning. We also call on education providers to make sure that children's palliative care is embedded in undergraduate and postgraduate medical and nursing courses, including advance care planning.
- **Children's palliative care professionals, networks and provider organisations:** We call on them to offer advance care plans to all families of children who need palliative care and make sure professionals have the skills and knowledge to undertake advance care planning; arranging education and training opportunities if needed.

1. Introduction

- Over 86,000 babies, children and young people have a life-limiting or life-threatening conditions in England alone and this figure is set to increase.³ Improving care for these children and their families is a national priority.¹ This recognises that care is often suboptimal and crisis driven, which can be distressing for children and families, and place increased pressures on the NHS.¹
- Advance care planning is a cornerstone of the national improvement strategy for children's palliative and end-of-life care and is considered a 'core element of their palliative care'.¹ This involves working with families to make 'a formal care plan that includes details about the child or young person's condition, decisions made with them and their parents or carers (for example about managing symptoms), and their wishes and ambitions'.^{1,4}
- There is a strong impetus for using advance care plans. Advances in treatment mean that children with life-limiting/threatening conditions are surviving longer and requiring increasingly complex care over longer durations.³ However, predicting death in children can be difficult, as many have recurrent episodes where death seems likely.^{5,6} Unfortunately, prognostication difficulties and concerns about communicating bad news means that discussions happen too late and families miss opportunities for appropriate care.^{6,7} This is concerning; earlier discussion and recognition of end-of-life is associated with less suffering among children and better outcomes for families,^{8,9} whereas lack of support places bereaved parents at increased risk of long-term psychological and physical morbidity.^{10,11} Advance care planning is therefore considered an important means of managing uncertainty and ensuring more responsive care.^{1,4}
- The Child and Young Person's Advance Care Plan (CYPACP)² is a set of resources endorsed by the National Institute for Health and Clinical Excellence.¹ This was developed by the CYPACP Collaborative (NHS and private sector organisations) to consolidate the best features of existing advance care plans and unify the approach across regions and settings.² The CYPACP proforma:
 - Sets out an agreed plan of care to be followed should a child's condition become unstable or deteriorate, or if they develop potentially life-threatening complications of their illness.
 - Is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service
 - Remains valid when parent(s) or next of kin cannot be contacted
 - Is supported by a policy document and leaflets for parents and young people
- At the time of the study, use of the CYPACP was fairly widespread; adopted by 3 large regional paediatric palliative care networks, and 15 NHS Trusts and Children's Hospices.² However, evaluation of the CYPACP was limited to just a few audits and service evaluations, making it difficult to know if the CYPACP was performing as intended and had benefits for families. This study aimed to address this knowledge gap and the calls of others. Indeed, Marie Curie and the James Lind Alliance had also identified advance care planning as a key research priority¹² and others working in children's healthcare noted that "Guidelines, strategies and policies for advance care planning are being produced faster than the evidence base to support them".¹³

- This project therefore represented the first in-depth examination of CYPACP implementation. The aim was to understand the perceptions, experiences and impact of the CYPACP on children, families and professionals, in order to inform improvements in supportive and palliative care. It was intended that this would provide detailed information that would support further development of the CYPACP. However, it was also hoped that the findings would results in broader learning for advance care planning, such as identifying core components of best practice and desired outcomes, including which ones matter most to families.

2. Co-created research

Before discussing the specific research methods and findings, it is important to explain the approach used.

The project was based on a model of co-creation,^{14,15} with an explicit aim to keep families at the heart of every decision. Thus, the research was co-operative endeavour where academics, clinicians, parents and charities worked together to share their different knowledge, skills and visions for the project; conceptually develop ideas; solve problems; facilitate engagement and share decision-making. This happened through a number of collaborative and connective activities:

■ **Family Involvement Day:** The study started with a public engagement event, to (i) sense-test key assumptions that underpinned the research proposal, (ii) identify effective strategies to engage with families throughout the study and (iii) offer further opportunities for involvement. It was held at a local Children's Centre to facilitate involvement and was attended by parents, children with complex medical conditions and their siblings, members of the public, including young people (n=18). The day was facilitated by the research team, and staff members from the Children's Centre, with support from Acorns Children's Hospice, who worked collaboratively with mixed participant groups to co-develop art. Activities included making simple mood boards, collages, tapestry, instant-photography and games that were aimed to support communication about thoughts, feelings or experiences that did not rely exclusively on language, age or ability. It was also important that activities enabled participants to highlight issues that reflected their experiences and needs, without being personally intrusive (i.e. did not require people to tell personal stories, unless they wished to) and enabled children to participate through natural play. These activities helped shape the research by informing: priorities for the project, appropriate and effective ways to communicate with families at different stages of the research; different ways in which families could be involved and their possible support needs. Several parents expressed a wish to remain involved in the project (as steering group members) and feedback demonstrated that the day had been enjoyable and useful (e.g. enabling them to build new relationships with one another and the Children's Centre).



■ **Public Face of the Research** Families were instrumental in developing the public face of the Research, including a family-friendly project title and set of logos. These were developed through interactive activities at the Family Involvement Day (above), with support from a graphic designer. It was used on all project materials and communications to raise the profile of the research and aid communication. Given the sensitive nature of our research, use of the logo on our study envelopes also provided an extra layer of safety for participants, enabling them to choose an appropriate time to open the contents. As requested by families, the title reflects the importance of 'listening' and the design is positive, and resonates with childhood, without being childish. The planes represent the important message that parents gave us; that every family has their own unique journey which may be long or short, uncertain, with ups and downs – but is also full of joy. It also reflects the idea that the Advance Care Plan is created from sheets of paper that can be transformed into something more valuable.



- **Steering group** Parents, carers and members of the public provided ongoing advice and problem solving as part of the Project Steering Group. Involvement was supported with an Involvement Handbook and Welcome Session to enable parents to meet one another, orientate them to the project, identify personal support needs and ask questions. Other members of the steering group included academics, health professionals and key charity groups, including those with expertise in public engagement and working with 'hard to reach' families. Together, the group shared the decision-making, designed public facing materials and data-collection tools, and helped to plan and deliver dissemination events and publications.



- **Patient and Public Involvement (PPI) groups** We also collaborated with existing public engagement groups outside the core team e.g. The Young Ambassadors and Parent and Carer Champions at Acorns Children's Hospice Trust. Members of these groups supported the team to develop the research strategy, particularly in relation to data collection with families, and established ongoing connections (e.g. by joining the Steering group) to enhance the reach and impact of the research within relevant communities.

- **Knowledge transfer** An explicit intention of the project was to rapidly transform the findings into benefit. The steering group worked with organisations in the local community to design and deliver dissemination events for families and professionals - that would offer two-way learning between the research team and attendees. This included a free Study Day for professionals that included (i) keynote talks from parents (see photo), national groups, researchers and health professionals and (ii) interactive sessions to support training needs identified in the study and develop further learning about advance care planning. A Family 'fun' Day was also held to disseminate findings, show how they were being used to improve care and enable them to 'have the last word' by co-creating artwork to illustrate what matters to them. Dissemination is also happening through usual academic routes e.g. conferences and peer-reviewed articles (co-authored with parents in some instances).



- **Re-investment:** Where possible, our policy has been to invest the research funding back into local charities that have a similar mission statement to our own, and able to support and widen engagement. This has included:
 - *The Springfield Project – supported our initial stakeholder event.* The Springfield project delivers children's centre services for families with young children and was an ideal place to hold the initial Family Launch Event. Its location ranks amongst the top 20% most deprived areas in Birmingham and has a population that is rich in cultural and religious diversity. This facilitated the inclusion of 'seldom heard' voices (i.e. groups who are often underrepresented in healthcare decision-making and research).
 - *TouchBase Pears – supported our dissemination events.* Touchbase Pears is a pioneering centre for the whole community in Birmingham and beyond. This is run by Sense; a national charity that supports people who are deafblind, have sensory impairments or complex needs, to enjoy more independent lives. This provided conference facilities for the end-of-project study day for professionals and an accessible and family-friendly venue for the Family Dissemination event, allowing us to facilitate access to support beyond the project. It includes a community café, children's library, family activities and access to information and support.

3. Research methodology

Aims and rationale: The aim of this project was to understand the perceptions, experiences and impact of the CYPACP on young people, parents and healthcare professionals, in order to inform improvements in supportive and palliative care. Specific objectives were to understand:

- How the CYPACP is perceived and experienced by families and professionals.
- The impact of the CYPACP on families and professionals, focusing on the extent to which it promotes 'humanised' care.
- The processes by which the CYPACP is operationalized and sustained in practice.

Design: The CYPACP involves (i) dialogue over extended periods (ii) input from many people, (iii) varied settings and (iv) change over time. A pluralistic qualitative design¹⁶ (integrating various data collection methods and analyses) was used to provide a multi-layered understanding of this complex intervention.

Conceptual frameworks: The study was informed by several theoretical frameworks relating to humanised care¹⁷ and implementation.¹⁸ These guided the initial data collection (i.e. indicating important topics to explore within interviews/surveys), but were applied 'lightly' to ensure participants were not constrained in revealing how they experience and understand the CYPACP. The intention was not to test or develop theories, but to use existing constructs and frameworks to better explain the data and translate them into patient/family benefit.

Methods: Overall data were synthesised from:

1. ***In-depth qualitative interviews with families*** (on 2 separate occasions, where possible) to provide detailed understanding about how families experience and understand the CYPACP, and whether it responds adequately to their evolving needs.
 - a) Initial family interviews asked participants to describe: their beliefs about advance care planning; the context in which they are made (e.g. nature of the child's condition, relationship with services); their experiences of making/revising/withdrawing a plan (e.g. appropriateness of timing, communication, decision-making) and its impact on care (including experienced and anticipated outcomes).
 - b) Follow-up interviews were timed to capture important developments in families' care needs (e.g. change in health status/prognosis, acute/inter-current health episodes and review/use of CYPACP). Questions explored adequacy of the CYPACP to address families' experiences and evolving needs, (e.g. did the CYPACP promote: recognition of individual needs, right care at right time, appropriate clinical management, psychological wellbeing).

2. **Case-based interviews with professionals named in these families' CYPACPs** to develop a better understanding of how families and staff work together to actualise the CYPACP and how organisations and working practices influence implementation. Professionals were invited if they had: (a) helped participating families to complete their CYPACP, or had been sent a copy and potentially required to implement it (e.g. GPs, ambulance staff). Participating professionals were asked to reflect on the adequacy of the CYPACP to meet this family's needs, their own roles in implementing it and lessons learnt from perceived successes/failures.
3. **Online qualitative questionnaires** to widen participation and provide a wider set of data to verify, refine and augment emerging theories about how the CYPACP shapes the experience and quality of care. The questioning frame was similar in scope to the interviews, but had a greater focus on service improvement (e.g. how the CYPACP is embedded in practice; experience of initiating, introducing and co-constructing plans; information sharing/management across settings; use of plans in deteriorations, emergencies, end-of-life; perceived risks, benefits and outcomes; examples of best practice, suggestions for improvement).

The research was undertaken in the West Midlands (which has been using formal advance care planning documents, including the CYPACP since 2011). Working with 17 Research and Development Trusts, recruitment was facilitated by ACP Co-ordinators (typically senior nurses who ensure that CYPACPs in their regions are completed, reviewed and copied to relevant parties). Eligibility criteria for families included (i) having experience of the CYPACP (ii) contact was confirmed to be appropriate by their care team, (iii) ability and willingness to participate, with support where required (e.g. interpreters). Professionals were invited to participate if they were named in a child's CYPACP. Having consulted widely, it was believed that CYPACPs are generally completed with parents. However, provision was made to include children/young people who had been involved in making their own CYPACP by developing youth-friendly versions of the interview and questionnaire.

Analysis: Analysis began with open coding of family interview transcripts to ensure the research remained centred on user needs. Transcripts were analysed individually, across families and longitudinally, using Interpretative Phenomenological Analysis.¹⁹ This process produced a master-list of themes derived from families' unique and shared experiences. Data from the case-linked professional interviews were then analysed using thematic content analysis²⁰ to refine the emerging 'theory'. Thematic content analysis⁶ of the online survey data was used to examine 'theoretical transferability' (i.e. the extent to which our emerging theory explained the experiences and outcomes of other families and professionals), and to develop more nuanced understandings. Finally, corpus linguistic analysis²¹ was used to examine language use in relation to the CYPACP; this is important given that plans are completed and understood through dialogue.

Outcomes: These findings were subsequently presented and discussed at two dissemination events, including a study day for professionals and a family day. The former included an interactive session with other researchers working in paediatric advance care planning to compare our collective findings using different methodologies, across a range of different regions and settings. New learning from these events and activities were used to develop a detailed set of recommendations for policy, practice and research.

4. Research Findings

Participants: In total, 146 individuals participated in the study. This included:

- In-depth qualitative interviews (n=17) undertaken with 12 parents (with 5 having a second interview) and 37 professionals named in their CYPACP.
- Additional questionnaire data was provided by 7 parents and 90 professionals.

Participants were recruited from across most regions of the West Midlands with variations in environment (rural and urban) and access to healthcare services (primary, secondary, tertiary care - including respite and out of hours care). Participant characteristics are shown in Tables 1 and 2. One child sadly died during the study.

Table 1: Family characteristics (n=12)	Interviews (n=12)	Questionnaire (n=7)
Parents		
Mothers , Fathers	12 , 0	6 , 1
Living with partner	9	-
Ethnicity		
White British	10	4
Asian/Asian British	1	1
Mixed/multiple ethnic groups	0	1
White, Other	1	1
Children with CYPACP		
Male, Female	9 , 3	-
Age (range, years)	2-14	7-11
Condition at study entry (using ACT Categories, Together for Short Lives)		
Category 1: Life-threatening, where curative treatment is feasible but can fail	2	-
Category 2: Premature death is inevitable	3	-
Category 3: Progressive, without curative treatment options	3	-
Category 4: Irreversible but non-progressive, causing severe disability	4	-
Stage of illness at study entry (The Spectrum of Children's Palliative Care Needs)		
Green: Life-limiting condition, but survival to adulthood is likely	1	-
Yellow: May live for many years, but death before adulthood is not unexpected	4	-
Amber: Increasing instability or progressive deterioration	6	-
Red: Critically ill	1	-
Details of CYPACP		
Length of time CYPACP in place (range, months)	1 – 96	-
Resuscitation instructions		
Full resuscitation	7	-
Modified resuscitation	1	-
Do not attempt CPR	4	-
Professional who led initial CYPACP completion		
ACP Co-ordinator (often jointly with speciality or community consultant)	6	0
Hospital Speciality Team	2	3
Children's Community Nurse (not ACP Co-ordinator)	1	2
Community Paediatrician	0	1
Hospital Palliative Care Team	1	0
Hospice Team	2	0

Table 2: Professional characteristics questionnaire (n=90)	Interviews (n=37) Count (%)	Questionnaire (n=90) Count (%)
Community Children's Nurses	7	21 (23.3)
West Midlands Ambulance Service	8	19 (21.1)
Nurse, Other (including nurse specialists)	4	14 (15.6)
Consultants, hospital (including PICU)	5	10 (11.1)
General Practitioners (GPs)	0	5 (5.6)
Community Consultants	2	4 (4.4)
Palliative Care Nurses	1	4 (4.4)
Respite (including heads of care, managers)	1	4 (4.4)
Family workers/coordinators	3	2 (2.2)
Physiotherapists	0	2 (2.2)
Medical Secretaries Emergency Care	0	2 (2.2)
Consultant, other	0	1 (1.1)
Team lead (community)	6	1 (1.1)
Education (Head Teacher)	0	1 (1.1)

Analysis of the interview and survey data (phenomenological, thematic and linguistic) provided detailed understanding of how families and staff work together to actualise the CYPACP, similarities and discrepancies in their views, and organisational factors that influence implementation - summarised here:

How the CYPACP was perceived and experienced by families.

- Making a CYPACP had significant emotional implications for parents; forcing them to contemplate and articulate their greatest concerns and fears. Indeed, the experience remained etched in parent's memories as a difficult and distressing event.

“...it was a really difficult conversation...it's still a massively sensitive subject and yeah, it was a really overwhelming day.” (Mother)

Parents also expressed feelings of guilt, especially in relation to actively planning for a child's end of life care. It is therefore understandable that most parents in this study had initial reservations about the CYPACP. That said, no parent expressed regret; considering the CYPACP to be in the best interests of their children. They also described how it supported them to have more 'control' in their children's care and offered reassurance in the face of uncertainty.

“I think in an emergency you don't know how you're going to handle it, if I was going to fall to pieces, I didn't know how I would be in a real difficult emergency. So having that care plan in place is peace of mind...” (Mother)

- Parent motivations for making a CYPACP was the need to protect their children from harm; in life and in death. However, this was conceptualised differently between participants and could change over time. For example, the primary function of a CYPACP could be to protect a child from unwanted interventions at the end of life or, alternatively, to ensure that 'everything' would be done to preserve life. Thus, parents were most receptive to making a CYPACP when it aligned to their parental imperatives to protect their children in meaningful ways.

“I wouldn’t want her to suffer but I think the whole point about this...” (Mother)

- Few families in this study had involved children in completing the CYPACP and many children (and siblings) were unaware of the document. In many cases, this related to children’s capacity to understand – but also reflected parental protective strategies to minimise distress. However, it was evident that parents felt more comfortable with the CYPACP when it reflected children’s identities and their known wishes, values or decisions.

“I’ve spent every minute with [my son] apart from when he was either in the operating theatre, unconscious, at school, at nursery or when he’s been out and about. So when you spend that amount of time with someone, you learn a lot about them. I had to write it as if I was asking him what he wanted.” (Mother)

How the CYPACP was perceived and experienced by professionals.

- Professionals expressed a strong commitment to delivering compassionate and high quality care, and felt that the CYPACP contributed positively to this agenda. They outlined a number of benefits, describing the CYPACP as helping them to initiate and structure conversations about advance care planning, clarify families’ wishes and organise more responsive and timely care provision. The CYPACP was also felt to support professional wellbeing, by reducing events that could cause personal or moral distress (e.g. conflicts, inadequate care).

“I think they’re a good thing ...it enables the conversations to be opened up with families.” (Community Children’s Nurse)

- While some professionals demonstrated significant expertise in using the CYPACP, it was also evident that many professionals felt vulnerable in relation to advance care planning. Many felt under-trained and were unsure if they implementing the CYPACP appropriately. This was particularly evident in professional groups less orientated to the provision of palliative care (e.g. emergency departments). Even those with clear responsibilities for advance care planning lacked confidence in many aspects of the CYPACP and were unclear about how roles and responsibilities should be delineated in relation to implementation. Concerns included how to: identify the right children at the right time, initiate plans with families, have difficult conversations, complete non-clinical aspects of the CYPACP, support families, and work collaboratively to ensure timely and appropriate use.

The impact of the CYPACP, focusing on the extent to which it promotes ‘humanised’ care.

- We found many practices related to the CYPACP that worked to humanise (or dehumanise) families’ experiences of care. It was particularly important that the CYPACP was not seen as a ‘tick box’ exercise; with the aim of full completion. The better approach was to use the CYPACP to facilitate conversations about what mattered to families and to use this information to guide/prioritise completion. Indeed, parents valued practices where professionals took time to understand families’ journeys and show how the CYPACP related to their history and future hopes.

“I know that [the Children’s Community Nurse] had gone through everything with me and given me plenty of confidence in the plan so I was more than happy to fill it in...[She] the sort of person that you could tell your whole life story to and she’s very empathetic and she’s great to listen to you.” (Mother)

- Parents particularly valued practices that helped them make sense of the CYPACP in relation to their child’s unique self. They wanted to see how the CYPACP could support aspects of life that were valued by children (e.g. going to school) and align to children’s agency (e.g. what children wanted, or were believed to want, for themselves).
- Parents also appreciated practices that showed how the CYPACP: (i) fitted in with their own sense of self (e.g. ‘worrier’, ‘control freak’), (ii) facilitated important parenting roles (protecting their child, advocating for them) and (iii) increased the visibility and legitimacy of their expertise and decision-making. The importance of agency was also highlighted, including genuine choice about how plans were made (i.e. when, where, who is involved), freedom to change plans, and honest information about the document’s limitations.

“We weren’t given that choiceIf we were asked that question, I would definitely have taken one of my friends with me.” (Mother)

- The psychosocial components of the CYPACP (e.g. wishes for life, spiritual care, bereavement care) were particularly relevant to humanising care. These could transform the CYPACP from being perceived as a clinical document for end of life, to a holistic plan for life. Done well, these sections could add value to families’ lives (e.g. by prompting them to consider new horizons, improving quality of life, facilitating memory making and supportive relationships).

*“...for us it was important to be able to make sure that, as well as medically, he is looked after holistically too and the family as a whole.”
(Parent, Survey)*

However, it was clear that these sections were often poorly completed, with insufficient detail to be acted upon. A key factor was professionals’ lack of confidence, with many describing themselves as lacking the necessary expertise to complete these sections and expressing uncertainty about whose responsibility it was to enact them.

- We found that the CYPACP was often discussed in detail at the time of completion, but parents had few other opportunities to discuss it in meaningful ways. If subsequent discussions did occur, the emphasis was often placed on updating existing information, rather than on more general explorations of whether the CYPACP was helping to meet needs, and if not, what else could be done. We found that the process of interviewing parents provoked them to think more widely about the role of CYPACP and as a result, some decided that changes were needed to their plans reflect new needs or add further detail. However, it was clear that many parents have few supported opportunities to reflect on the CYPACP.

“Once a plan is done, that’s it. You’re left to deal with it. That’s it, until it’s reviewed the following year.” [Mother]

- The nature of the experience could also impact on therapeutic relationships. When done well, parents' relationships with professionals/healthcare teams could be strengthened, but even long-standing relationships could be undermined when the CYPACP was handled insensitively. Where possible, parents wanted to make plans with people they 'knew well'; not necessarily the most senior or lead person in a team.

“It was a negative experience. I wasn't told by right [people] at the right time...I should have had that conversation with someone whom I had been meeting on more day to day basis locally. I would have been more comfortable... to pass on such info [to] my daughter's special school nurse, or her community nurse.” (Parent, Family Survey)

The processes by which the CYPACP is operationalized and sustained in practice.

- It was evident that having a CYPACP could facilitate high quality care and positive outcomes, and we identified many examples of excellent practice, effective processes, reflection and innovation. For example, professionals had set up system to help to identify children on caseloads who might benefit from a CYPACP, flag up CYPACPs on hospital admission data and prompt annual review dates. They had also undertaken steps to ensure children with CYPACP are regularly discussed at team meetings, developed new training opportunities and audited practices.
- Unfortunately, there were also instances where the CYPACP did not work as expected, mainly because the CYPACP was not embedded in routine care. This could result in missed opportunities to offer plans to families and delays to reviews of existing plans; potentially resulting in out-of-date information informing care. Indeed, parents recurrently described how they had needed to prompt professionals to use the CYPACP. This was problematic. One of the anticipated benefits for parents was that the CYPACP would protect them from having to repeatedly explain difficult decisions and relay complex information. Lack of professional use therefore served to devalue the plan (as an important/essential document); increasing parent distress and reducing the potential of the CYPACP to have a humanising impact.

“They don't have a copy. None of her consultants or every time she goes for an operation, they don't have a copy of it. This is the one thing that I get really angry about.” (Mother)

While many 'interested' professionals were attempting to mitigate this by taking on significant teaching and championing roles, much needs to be done to normalise the CYPACP and extend the benefits to a wider set of families.

- Role delineation and collaborative working was a recurrent issue. This could be a source of tension with individuals/organisations sometimes perceived to be assuming too little responsibility for CYPACPs, acting as barriers to their completion and review, using the CYPACP in inappropriate ways, or making unilateral decisions. At the same time, individuals and organisations could feel that others were better placed to take on the responsibility (e.g. more relevant expertise, closer relationships with families, more resources) or could assume that others were more involved than they actually were. Blurring of roles and responsibilities was particularly evident between hospital and community settings.

“If I’ve written an Advance Care Plan, whether it’s for everything or nothing, no one else will update it.... They’ll say, ‘Well, I didn’t write it. I can’t update it” (Specialist Nurse)

However, without clear understanding and agreement of roles, professionals felt it was difficult to explicitly question, challenge or reconfigure existing ways of working. Parents were also be unsure who to contact regarding different issues in the ACP.

- Education, support and training in advance care planning (generally) and the CYPACP (specifically) was considered beneficial. Although some high quality provision exists, few professionals in this study had received formal training and were often reliant on support/mentoring from ‘special interest’ colleagues or self-directed learning. Those less orientated to palliative care also felt that it would be hard to justify training time, where their use of the CYPACP was infrequent. This said, a number of generic support needs were identified. These are described in great detail in the **Recommendations Document** available on the project website at: <http://www.birmingham.ac.uk/acp-study>, but are summarised briefly here:

- *Eligibility and validity.* Professionals understood that the CYPACP was designed for children with a life-limiting or life-threatening conditions, but were unsure about the limits of eligibility (e.g. complex conditions where threat to life was low but children had significant care needs, use in perinatal settings) and validity of the CYPACP when transferred to adult care.
- *Role delineation and collaborative working,* including the specifics of their own role and how roles/responsibilities should be transferred or shared at different implementation points.
- *Processes:* Few professionals understood the entire CYPACP process and how they fit within it.
- *Compatibility with existing practice.* Ways of working do not always fit easily into existing systems or can duplicate work.
- *Using the CYPACP document:* Professionals were generally confident about the clinical aspects of the CYPACP. Other sections, however, (wishes for life, spiritual/cultural care, organ donation, bereavement care) could be more challenging.
- *Reviews and version control:* Ensuring timely reviews was also an area of concern and many professionals lacked robust systems to ensure version control.
- *Supporting families:* Professionals could lack confidence in key aspects of implementing the CYPACP, including: introducing the CYPACP, talking about death and dying, spiritual/cultural issues, responding to distress, knowing when/how to involve other professionals or external organisations

Research Limitations

The number of participants in this study was small compared to the overall population that the CYPACP is relevant to. However, the total number of participants (n=146) is larger than most qualitative studies and families had diverse characteristics (see Table 1). This enabled us to identify a number of themes that were relevant across participants, settings and contexts. However, the scope of this study meant that it was focused on the West Midlands and included parents who had a CYPACP (as opposed to those who had not been offered a plan or who had declined one). The lack of long-term follow-up also meant that we had limited insight into the impact of the CYPACP on longitudinal outcomes, including bereavement. There were also a number of under-represented groups including fathers, children and young people, and important professional groups, including GPs and educational professionals – despite much effort to include them. Further investment in this research would look to build on this report by exploring these issues.

Given these potential limitations, we took several steps to ensure the findings were trustworthy. This included triangulating with results with other research findings and seeking feedback from a wider set of professionals (as part of the end-of project study day for professionals – see next section). Thus, while participants' views may not be representative of all families and professionals caring for children with serious conditions, we are confident that a number of statements and recommendations can be made about the CYPACP that have relevance across participants, settings and contexts.

5. Turning research into action

An explicit purpose of the project was to ensure rapid benefit for families and professional by providing practical outcomes. As such, two dissemination events were held as soon as the research data were analysed, including a study day for professionals and family event. These sought to:

- Disseminate the research findings
- Offer visible thanks for their involvement
- Address unmet needs identified in the study and facilitate support beyond the project
- Provide opportunities for stakeholders to comment on the findings and generate additional learning to inform the final recommendations
- Provide opportunities for 'closure'.

Taking Off! Turning Research into Action. A free study day for professionals

A free study day for health and care professionals was held on 4th February 2020 at TouchBase Pears, Birmingham; a community/family centre with conference facilities and easily accessible by rail/road. We hoped this would support attendance, raise awareness of local support for families and provide a relaxed atmosphere to promote open and honest discussion.

The aim was to rapidly transfer the findings into improved service delivery, by providing education, training and support for multi-agency and multidisciplinary staff involved in advance care planning. Attendance was open to any professional involved in advance care planning, regardless of whether they had participated in the study or not.

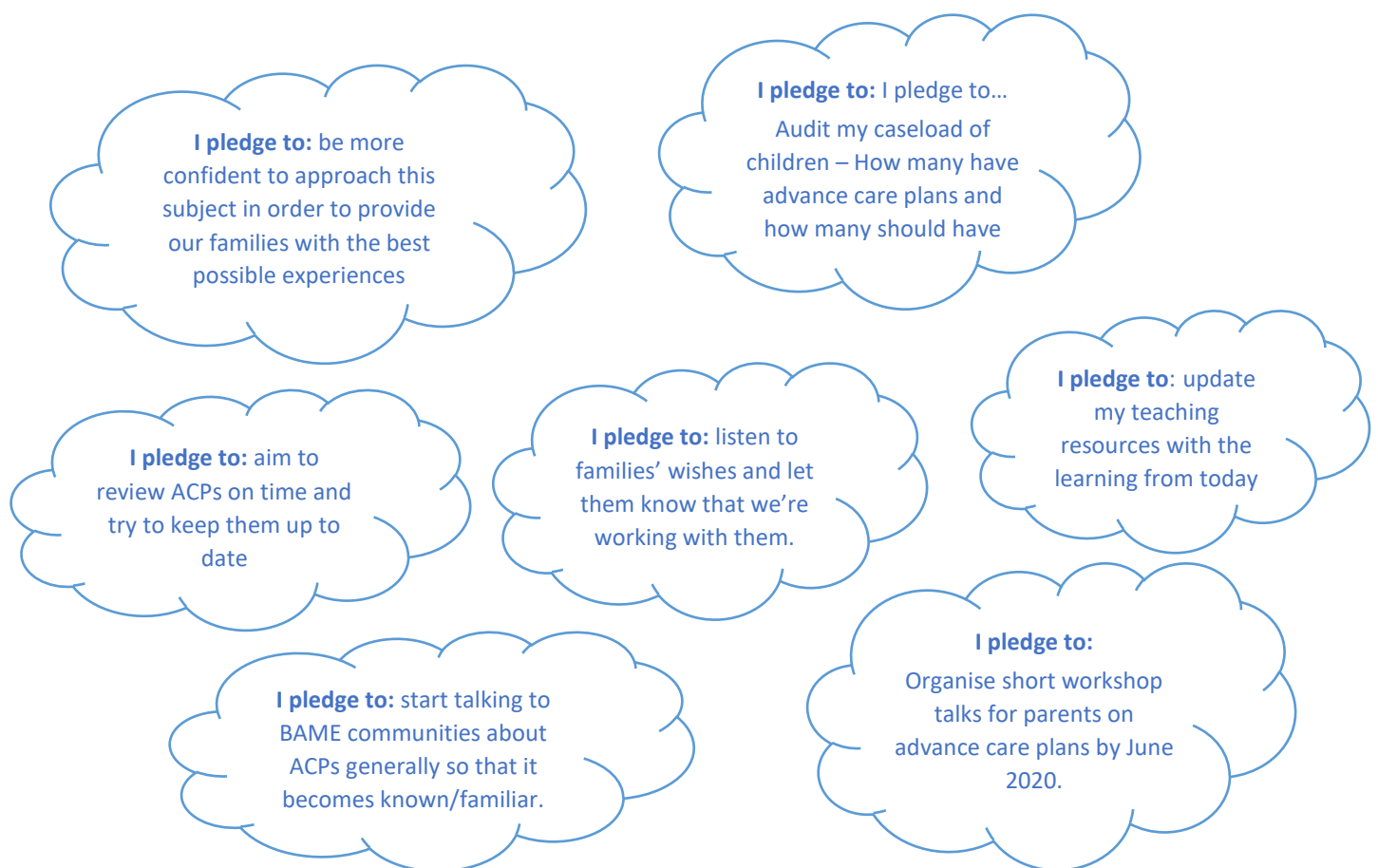


Photos by Nick Robinson Photography (consent given by presenters and attendees)

The study day was approved by the Royal College of Paediatrics and Child Health for Continuing Professional Development, and was attended by 75 multi-disciplinary/multi-agency professionals.

The agenda was co-developed with parents, professionals and charities to disseminate the research findings and target information and training needs identified in the study, including suggestions made by participants. The format was designed to be solution-focused; supporting attendees to understand how they can optimise advance care planning by using their existing skills, knowledge and resources – rather than focusing on problems. It included keynote talks from the research team, parents on the steering group and local/national leaders in advance care planning. This was followed by a series of interactive workshops, with facilitated discussions and expert panels to field questions. These were purposively designed to provide a supportive environment in which professionals could raise concerns, ask questions, and build relationships. Indeed, the study had shown that many professionals have expertise, but have limited opportunities for knowledge exchange and peer support. The study day also provided the first opportunity for the Child and Young Person's Advance Care Plan Collaborative Working Group to use the study recommendations to plan their development strategy. It also brought together researchers with a special interests in advance care planning (nationally) in order to share results across studies, settings and populations, and discuss future research priorities and collaboration. This helped the project team to further refine their thinking and recommendations for policy and practice.

The positive and collaborative ethos was reflected throughout the day, with attendees contributing peer support during the event and making personal pledges (e.g. individuals offered to provide additional training through the West Midland's Paediatric Palliative Care Network, researchers agreed to write a joint publication to disseminate shared learning).



Family Dissemination Event.

This was held on Saturday 15th February, 2020 for families who had been involved in the research as participants, steering group members or advisors. TouchBase Pears, in Birmingham, is a pioneering centre run by Sense; a national charity that supports people who are deafblind, have sensory impairments or complex needs, to enjoy more independent lives. As such, it provided an accessible and family-friendly venue, where parents, children and young people could also find out more about the ongoing play, advice and support activities offered by TouchBase Pears, allowing us to facilitate support beyond the project.



Photos by Nick Robinson Photography (parental and adult consent given)

The day included: artwork to summarise the research findings; information to show how the results are improving practice (including pledges written by professionals who attended the study day); play opportunities and sensory story-telling; opportunities for parents to meet one another and seek specialist support (e.g. Palliative and Bereavement Care Team from Birmingham Children's Hospital). A graphic facilitation artist assisted us to produce a visual representation of families' key messages from the research and give families 'the last word' (see next). This will be used as a lasting legacy of the project which we can share widely to promote the views of families.

6. Recommendations

A list of detailed recommendations have been made in a separate **Recommendations Document** available at: <http://www.birmingham.ac.uk/acp-study>, but are briefly summarised here in 4 broad sections: Family Support; Support for professionals; CYPACP Process & Documents; Wider changes. Many of these are general principles. Others are more specific to the CYPACP document and processes. However, nearly all can be easily made into SMART goals (Specific, Measurable, Assignable, Realistic, Time-related) and used to plan future development strategies. Many are also encapsulated in this artwork co-produced with families (at the end-of-study Family Day). This shows what matters to them, in their own words, and incorporates some of the many pledges made by professionals who attended the Study Day.



Family Support

Support families when *introducing* the CYPACP

- Identify the best person to introduce the CYPACP to the family.
- Where possible/appropriate, introduce the CYPACP as a plan for life.
- Show how the CYPACP relates to the family - personally.
- Explain how the CYPACP can grow and change to fit children's current and future needs.
- Talk about what might stop families wanting to have a plan.
- Discuss the range of options for completion and agree next steps.
- Reinforce their right to change their minds about the CYPACP at any time.
- Declining a CYPACP should not be seen as poor choice (if decision-making is informed).

Support families when *making* the CYPACP

- Help families to prepare for making a CYPACP by helping them understand the range of topics that might be covered and that sections are optional.
- Build on previous conversations and information already established to demonstrate that families have already begun to think about some of the issues in the CYPACP.
- Optimise choice as much as possible. This should include *who* should be involved in making the plan; *where* and *when* plans are made, and *how* (e.g. one event or a staged approach)
- Facilitate families to utilise their own support systems
- Provide aftercare by facilitating access to supportive services and organisations.
- Provide opportunities to reflect on the CYPACP and follow-up activities.

Support families to involve children and young people

- Explore parents' views about involving children and young people in the CYPACP.
- Ensure that children's views, values and preferences are incorporated in the CYPACP.
- Consider using (or developing) developmentally appropriate resources and techniques to elicit what matters to children and young people.
- Consider the involvement of other professionals to support children's voices to be heard. e.g. play workers.

Develop and use family-centred information about the CYPACP

- Develop family oriented information, co-produced with families to ensure it is meaningful and user-friendly.
- Consider the language, communication and cultural needs of families.
- Think carefully, and be clear, about what messages to give in relation to the CYPACP.

Give families more spaces to talk about the CYPACP

- Use naturally occurring opportunities to broadly enquire about the CYPACP.
- Check action plans to see if they are progressing as intended.
- Provide opportunities for families to discuss the CYPACP with other parents.
- Perhaps include some carefully selected case studies (e.g. on the CYPACP website) that shows how a range of families have used their CYPACP and a varied range of impacts.
- Provide families with an impartial contact for general questions, concerns or complaints.

Support for professionals

- Emphasise the message that the CYPACP is everyone's business.
- Clarify the criteria for being the 'lead' professional(s) for the CYPACP.
- Develop a competencies and training framework to support advance care planning (generally) and the CYPACP (specifically).
- Clarify eligibility about who should be offered a CYPACP and why.
- Clarify processes. Help professionals to understand the whole CYPACP process, how it aligns to existing work and who/what might be involved at different stages.
- Develop a practice-based manual for (i) Advance Care Plan Co-ordinators and (ii) professionals who make plans with families.
- Develop 'quick reference guides' for use when making plans with families (that can be customised locally).
- Develop profession-specific fact-sheets to support involvement of different groups (e.g. paramedics, teachers, GPs).
- Set up systems to ensure two-way information exchanges between the CYPACP Working Group and Adoption leads/Regional ACP co-ordinators (e.g. to cascade national updates, identify local issues, share best practice).
- Increase support and visibility of Regional ACP Co-ordinator who provide critical roles in the regional management and audit of the CYPACPs.
- Further develop the CYPACP website to provide a national repository of information and to provide a central hub for the CYPACP.
- Consider having a CYPACP training lead.
- Consider national data reviews to develop wider evidence base to support development.

CYPACP Process and Documentation

- Clarify the legal status of the CYPACP, professional duty and the limits of honouring wishes.
- Manage family expectations appropriately when the plan is originally written.
- Clarify issues around ownership and what this means in practice.
- Ensure that families understand the process to make changes to the CYPACP.
- Consider a new section in the CYPACP where parents can note non-urgent changes/issues.
- Make the document more child/family centred by adding space to include information about the child (e.g. likes/dislikes), key moments in the family journey, photographs etc.
- Provide more guidance about appropriate completion, especially in relation to (a) high risk and (b) non-clinical sections.
- Include prompts to promote detail, action-planning, task allocation and time-frames.
- Add hyperlinks/signposting to national organisations that parents can choose to follow.
- Provide guidance about how services can build collaborative links with supportive organisations (e.g. organ donation, wish granting charities, local religious leaders)
- Develop guidelines (and process charts) for managing and sharing CYPACP data.
- Develop guidelines about how patient data can be linked to the CYPACP to benefit care.
- Be aware of system risks (e.g. CYPACPs may be taken off systems if out of (review) date).
- Consider how CYPACP could be built into current and future data management systems.
- Clearly mark pages/sections most relevant to those responding to an emergency.

Wider Changes

- Develop activities and resources to support better public awareness of advance care planning (in general) and the CYPACP (specifically)
- Take steps to normalise the CYPACP as part of routine care.
- Include advance care planning and the CYPACP in the undergraduate education of health professionals and Continuing Professional Development.
- Flag up the fact that CYPACP is endorsed as part of national policy and promote the CYPACP as part of more general social actions (e.g. Dying Matters)

7. Where next?

Dissemination: We continue to disseminate the findings and support their translation into practice, working with the CYPACP Collaborative Working Group, Marie Curie, Together for Short Lives and a range of parent, professional and educational groups. For example, the findings are being incorporated in both the under-graduate (nursing) and post-graduate (interprofessional) teaching modules on paediatric palliative care at the University of Birmingham, and will inform the UK and Ireland Children's Palliative Care Education Standard Framework and Audit. This aims to standardise inter-professional children's palliative care education.



Research Priorities: The findings suggest a number of areas that warrant further study. These were discussed at the Study Day for professionals, which brought together researchers with a special interest in advance care planning for children and young people. Several priorities for future research and service development were agreed.

- **Advance Care planning at the beginning and end of childhood:**
 - Perinatal and Neonatal Care (i.e. how to advance care plan during pregnancy or soon after birth)
 - Transitional Care (i.e. how to support young people's advance care planning as they move from paediatric to adult orientated services).
- **Staff training and intervention development** (i.e. how can staff training needs be met in ways that raises standards universally, given the complexity of advance care planning and limited resources in children's palliative care).
- **Unheard voices:** Our study widened involvement in advance care planning research and included data from groups not previously represented (e.g. Ambulance Service). However, there is still work to be done to better understand the perspectives and needs of some groups including children and young people, fathers, looked after children, eligible families not offered an ACP or who decline one, GPs, educational professionals.
- **Eligibility and reach:** It will also be important to quantify the extent to which professionals may be under-utilising the CYPACP and other similar resources, given that most families with a life-limiting/threatening condition do not appear to have an advance care plan. Understanding how to reach and support all families equally, who can benefit from the CYPACP, will be important.
- **Novel research methods and methodologies:** Recruitment and data collection in this field was challenging in our study and for those researchers attending the Study Day. The use and development of better ways to engage with families and staff is warranted (e.g. using technology, social media, art, play and peer research).
- **Outcome measures:** Our study highlights many outcomes that matter to families and the professionals who care for them. However, work now needs to be done to determine if these can be developed into meaningful outcome measures to support ongoing evaluation (e.g. patient/carers reported outcome measures) and benchmarking of ACP (e.g. criteria by which providers can rate their performance and target improvement).

New Funding: During the course of the study, it was apparent that the CYPACP was beginning to be used in the perinatal period, (i.e. in pregnancy and soon after birth) where a baby was recognised to have a confirmed or probable life-limiting condition. However, some participants expressed uncertainty about whether this was appropriate. Given the lack of evidence in perinatal advance care planning, we have secured funding from Birmingham Women's and Children's Hospital Research Foundation to undertake the following project: *How should we implement advance care planning in perinatal settings? A mixed methods study using normalisation process theory. Dr KL Shaw (PI), J Spry, Prof A Ewer, Prof M Kilby, Dr C Cummins. Birmingham Women's and Children's Hospital Research Foundation (BWCHRF579).*

8. Conclusions

Evidence from this project supports current policy and practice guidelines^{2,3} that assert advance care planning (generally) and the CYPACP (specifically) are important mechanisms to drive-up standards in children's health care. Indeed, the recommendations made in this report have a high degree of overlap with the NICE recommendations for advance care planning for children and young people available at www.nice.org.uk/guidance/NG61 and should therefore be read together to provide a comprehensive guide to best practice. What this project adds, however, is new evidence about how the CYPACP can be used and developed to contribute more positively to this agenda.

Use of resources like the CYPACP are important. This project shows that, when used well, they can help to support families at the most existentially challenging moments of their lives by helping to provide more humanised and family-centred care. The need to optimise palliative care is also underscored by recent research that shows that the number of babies, children and young people with life-shortening conditions is much larger than initially thought and increasing annually.³ This will have an impact upon palliative care services and all other settings that care for children and their families. Indeed, families' journeys involves a myriad of care settings, communities, and individuals, all of whom need to engage with the CYPACP in some way. The CYPACP therefore has the potential to support these working partnerships in ways that not only align to families' wishes, but lead to better planning and targeting of resources. However, the benefits described here will require initial investment to raise awareness of the CYPACP and develop professional competencies to ensure that the different disciplines and agencies can channel their practices effectively - for the benefit of children and their families.

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