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Care and support  
through terminal illness

# Evaluating advance care plans

Listening to families and professionals



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# Evaluating advance care plans: listening to families and professionals

**T**his short report summarises findings from the project, *A multi-perspective qualitative study to understand the experience and impact of the Child and Young Person's Advance Care Plan – CYPACP*. It includes the key messages from the research. The full report and recommendations are available at [birmingham.ac.uk/acp-study](http://birmingham.ac.uk/acp-study)

together to make and use advance care plans, including 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.

## What we found

### **Advance care planning is a valuable component of high-quality care.**

The CYPACP is relevant to a diverse group of children and families as a resource to plan care. Research participants described numerous positive outcomes and anticipated benefits. 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. Many describe the process as challenging, distressing and draining. While no participants in our study regretted making a plan, they wanted more choice about how plans are made (timing, location, who is involved) and improved support.

### **The CYPACP is a complex intervention that requires support to implement.**

Many professionals and organisations have undertaken significant work to adopt the CYPACP and many staff have also developed considerable expertise. However, parents and professionals reported too many instances where care providers lacked awareness about the CYPACP or failed to use it without prompting.

## About the research

Over 86,000 babies, children and young people have a life-limiting or life-threatening condition in England alone, and this figure is set to increase.<sup>1</sup> Advance care planning is considered an important aspect of care for these children and their families.<sup>2,3</sup> This is the use of formal plans that set out agreed actions in the event of deteriorations, emergencies or the end of life. The Child and Young Person's Advance Care Plan (CYPACP)<sup>4</sup> is one such plan, endorsed by NICE.<sup>3</sup> This has been adopted by a large group of NHS and private sector organisations across the UK. This study, funded by Marie Curie, is the first in-depth examination of the CYPACP. The aims were to understand the experience and impact of the CYPACP, from the perspectives of families and professionals.

## What we did

In-depth qualitative methods (including interviews, focus groups and surveys) were used to reveal the lived experiences of 19 diverse parents and 127 multi-disciplinary professionals in the West Midlands. Analysis provided detailed insight about how families and professionals work

**Advance care planning is a valuable component of high quality care.**

### **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. The CYPACP documentation needs to be updated to improve accuracy, clarity and relevance. Supportive resources for families and professionals are also needed.

### **Greater priority needs to be given to the long-term resourcing of the CYPACP.**

The CYPACP has developed through the commitment of individual champions and multi-agency collaborations. However, the sustainability of the CYPACP is precarious while it remains dependent on 'special interest' groups who offer their time on a goodwill basis.

### **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**

We've made a number of detailed recommendations for the CYPACP processes and documents, available at [birmingham.ac.uk/acp-study](http://birmingham.ac.uk/acp-study)

In addition, we're making the following calls to the NHS, Health Education England, education providers and children's palliative care professionals.

### **Guidance**

The new NHS England and NHS Improvement (NHSE/I) service specification does have a section on advance care planning, but it doesn't refer to the CYPACP.

We call on NHSE/I to ensure that NHS commissioners specify advance care planning in children's palliative care services that they commission. These can include hospitals, community services and children's hospices.

### **Funding**

We call on NHSE/I to fund the CYPACP so it can be sustainable, 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, and includes advance care planning.

### **Care providers**

We call on children's palliative care professionals, networks and provider organisations to offer advance care plans to all families of children who need palliative care. Also providers must make sure professionals have the skills and knowledge to undertake advance care planning. Education and training opportunities should be created, if needed.

## **Conclusion**

Evidence from this project supports current policy and practice guidelines<sup>2,3</sup> which assert that advance care planning helps to drive up standards in children's healthcare. The recommendations in this report overlap with the NICE recommendations for advance care planning for children and their families.<sup>2</sup> However, this new understanding about the CYPACP highlights additional strategies to improve advance care planning for children, families and professionals.

## Further reading and references

1. Lorna K Fraser et al. *Make Every Child Count'. Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*. Final Report. February 2020. [togetherforshortlives.org.uk/wp-content/uploads/2020/04/Prevalence-reportFinal\\_28\\_04\\_2020.pdf](https://togetherforshortlives.org.uk/wp-content/uploads/2020/04/Prevalence-reportFinal_28_04_2020.pdf)
2. National Institute of Clinical Excellence. *End of life care for infants, children and young people with life-limiting conditions: planning and management*. 2016. [nice.org.uk/guidance/NG61/](https://nice.org.uk/guidance/NG61/)
3. *Together for Short Lives. A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions* 3rd Edition, Together for Short Lives, February 2013. [togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Core-Care-Pathway.pdf](https://togetherforshortlives.org.uk/wp-content/uploads/2018/01/ProRes-Core-Care-Pathway.pdf)
4. *The Child and Young Person's Advance Care Plan (CYPACP)* [cypacp.nhs.uk](https://cypacp.nhs.uk)

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