

## Marie Curie Research Grants Scheme

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A multi-perspective qualitative study to understand the experience and impact of the Child and Young Person's Advance Care Plan (CYPACP)

**Duration of project:** 24 months

**Start date:** 1st May 2017

**Budget:** £141,764

### **Abstract**

#### **Background**

Advance care planning for children and young people with life-limiting/threatening conditions has undergone significant development in the last 8 years, with similar strategies evolving across the UK. This has recently culminated in the Child and Young Person's Advance Care Plan (CYPACP); a set of resources produced by the CYPACP Collaborative Working Group (<http://cypacp.nhs.uk>) to consolidate the best features of existing plans and unify the approach across regions and settings. The resources are free to download and comprise a CYPACP:

- Pro forma; to record in advance the wishes of a child or young person and/or those with parental responsibility for them
- Policy document
- Guide for professionals
- Leaflets for parents/carers
- Leaflet for young people

As a 'plan for life', the CYPACP:

- Covers clinical, psychosocial and spiritual issues
- Sets out an agreed plan of care to be followed when the child/young person develops (a) potentially reversible intercurrent illnesses or (b) potentially life-threatening complications of their condition
- Is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service
- Can be used as a resuscitation and/or end-of-life care plan
- Remains valid when parents/next of kin cannot be contacted.

Initiating a CYPACP involves several steps to establish that it is appropriate and is completed by a senior paediatrician or appropriately trained senior nurse who knows the family well (resuscitation section requires paediatrician discussion/signature). It usually involves dialogue over extended periods to allow the family time to make informed decisions, with input from the core and wider multidisciplinary team. Once agreed, Local CYPACP Co-ordinators (usually senior paediatricians, advanced/consultant nurses) ensure that plans in their area are completed appropriately, reviewed and copied to relevant parties. Local Lead

Clinicians for Advanced Care Planning also act as the primary link between their organisation and the CYPACP Collaborative.

Rapid uptake of the CYPACP in the West Midlands and other regions suggests an unmet need. However, there is little evidence to determine whether it performs as intended and has benefits for families. This study will address this gap by examining how the CYPACP is implemented from the perspectives of families and professionals involved in their care.

### **Aim**

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.

### **Design**

Qualitative study, underpinned by an interpretative framework. Data will be collected using case-based serial interviews and questionnaires with families and staff who have experience of the CYPACP in the West Midlands.

### **Methods & participants**

Stepwise recruitment will begin by inviting approximately 15 purposively selected families to participate in two in-depth interviews over 9-months. Interviews will subsequently be undertaken with the (i) clinical staff involved in completing their CYPACP (approx. n=15), and (ii) health/social/educational professionals named in their CYPACP who may be called upon to implement it (e.g. GP, ambulance services; n>45). Participants will be invited to describe their experience of completing a CYPACP (or reasons for declining/withdrawing one) and how families and professionals: understand the purpose of the CYPACP; work together to construct a plan; view the support they receive and use the information. Follow-up interviews will examine how decisions impact on care and whether families' wishes are fulfilled.

To support inclusion and interpretation, all eligible families (approx. n=180) and clinical staff who have experience of completing a CYPACP, but are not offered (or decline) an interview, will be invited to share their views using secure online questionnaires.

### **Proposed findings**

Analysis will use thematic and linguistic approaches to provide in-depth understanding about the 'decision-making ecology' that provides the backdrop to initiating, constructing and using the CYPACP helping us understand:

- Families' preferences for advance care planning (including communication and decision-making)
- Barriers/facilitators to co-constructing plans
- Implementation in 'real-world' settings
- How the CYPACP shapes the experience, delivery and quality of care
- What can be done to optimise the CYPACPs' capacity to reach its target population and improve outcomes

### **Outcomes**

Findings will be used to develop a theoretically informed improvement strategy, including revisions to the CYPACP resources (if indicated). The widely disseminated results will also include generalized learning for improvement beyond paediatrics.