Recommendations for the child and young person's advance care plan (CYPACP) collaborative.

Listening to families and professionals

EVALUATING ADVANCE CARE PLANS
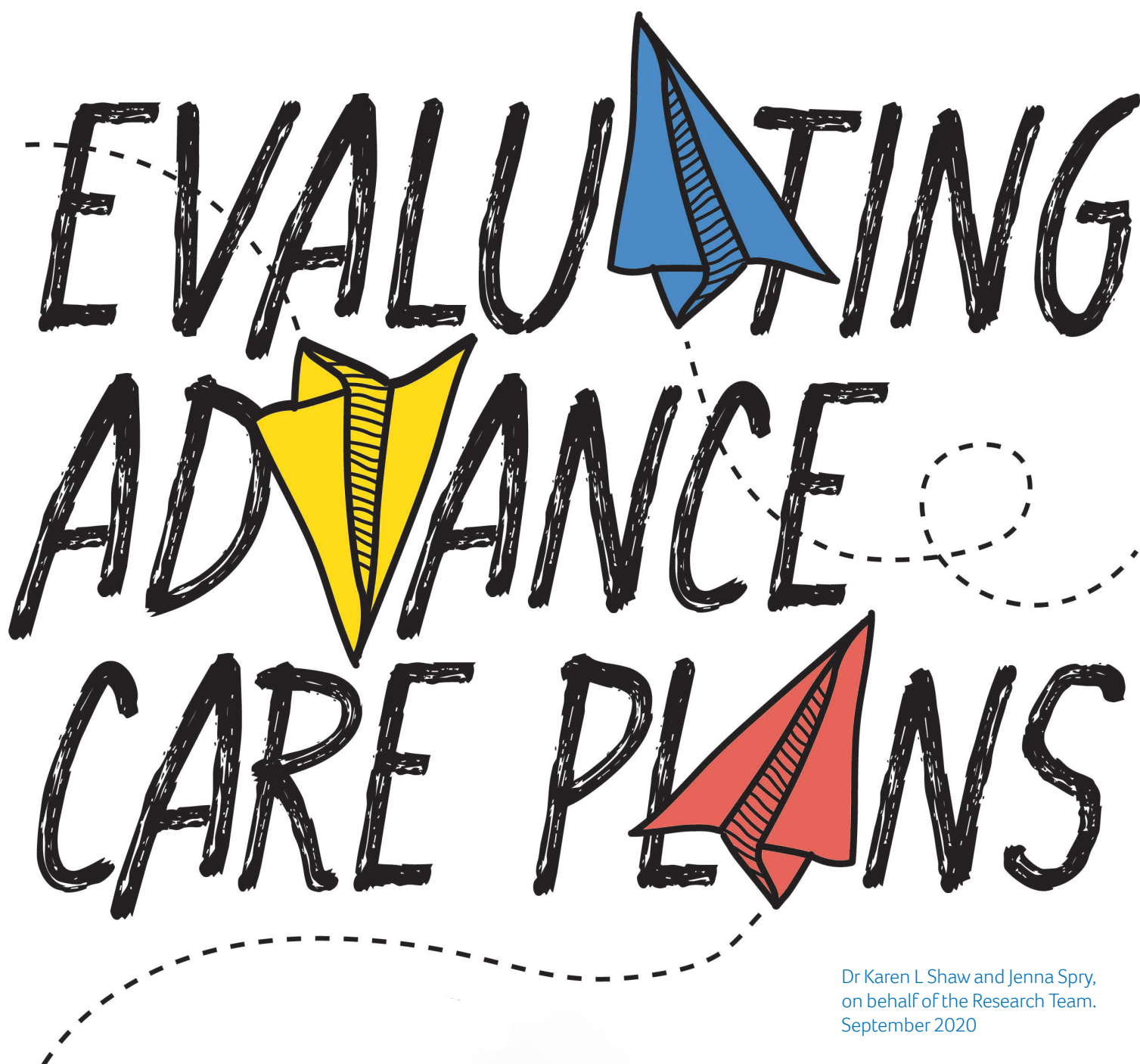
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Introduction

This report has been written following analysis of, and in response to, the findings from the research study *Evaluating advance care plans: Listening to families and professionals*. This study was the first in-depth examination of the implementation of the Child and Young Person's Advance Care Plan (CYPACP, available at **cypacp.uk**). Its aim was to understand the perceptions, experiences and impact of the CYPACP on children, young people, parents and healthcare professionals, in order to inform improvements in supportive and palliative care.

The study found that the CYPACP was a valuable component of high quality care. However, it also highlighted aspects of the CYPACP that could be improved for the benefit of children and their families, and are amenable to change. It is organised into four broad sections that reflect different levels of impact: family support, support for professionals, CYPACP process and documents, and wider changes. In each section we explain the main findings of the study, and then make a series of recommendations based on them. These recommendations come primarily from the research findings, but also incorporate examples of good practice identified at the end-of-project events, including a study day for professionals and a family day.

While participants' views may not be representative of all families and professionals caring for children with serious health conditions, a number of recurrent themes were identified that were relevant across participants, settings and contexts.

Many recommendations are general principles for advance care planning. These show a high degree of consistency with the NICE guidelines for advance care planning

for children and young people (available at **nice.org.uk/guidance/ng61**) and can 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. The majority of recommendations can be made into SMART goals (specific, measurable, assignable, realistic, time-related) and used to plan future development strategies.

Evaluating advance care plans: Listening to families and professionals

The CYPACP is a complex planning document that involves dialogue over extended periods and input from many people, and takes account of varied settings and changes over time. This study therefore used qualitative design to provide a multi-layered understanding of this complex intervention. Data from 146 individuals was integrated from the following sources:

1. **In-depth qualitative interviews with families** (17 interviews with 12 families, five interviewed on two separate occasions) to provide a detailed understanding of how families experience and understand the CYPACP and whether it responds adequately to their evolving needs.

2. **Case-based interviews with professionals named in these families' CYPACPs** (37 professionals across varied care settings) to develop a better understanding of how families and staff work together to implement the CYPACP and how organisations and working practices influence this implementation.

3. Online qualitative questionnaires (a further 7 parents and 90 professionals) to 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 research was undertaken in the West Midlands, with recruitment facilitated by ACP co-ordinators. Eligibility criteria for families included having experience of the CYPACP, contact was confirmed appropriate, and the ability to participate with the provisions that were available to the research team (eg interpreters). Professionals were invited to participate if they were named in a child's CYPACP.

A range of approaches were used to analyse data – including interpretative phenomenological analysis, thematic analysis, linguistic analysis and framework approach – 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 implemented and sustained in practice.

Overall, the CYPACP was valued by the families and professionals who participated in this study. They felt that it improved practice in advance care planing compared to previous ways of working. This is outlined further in the final report available at: **birmingham.ac.uk/acp-study**

However, we also identified areas of the CYPACP that could be strengthened. Our recommendations to address these issues are listed here, in this companion document.

Contents

1.0 Family support

The findings and recommendations derived from this study are detailed in the following sections. However, many are encapsulated in this artwork created with families. This shows what matters to them, in their own words, and incorporates some of the many pledges made by professionals who attended a study day.

1.1 Supporting families when introducing the CYPACP

Many parents are understandably resistant to making a CYPACP. Making a CYPACP has significant emotional implications for parents, forcing them to contemplate and articulate their greatest concerns and fears. It is therefore understandable that parents may want to avoid or postpone making a CYPACP in an attempt to avoid distress and maintain hope.

Parents were more open to making a CYPACP when:

- it was perceived as a plan for life, rather than a plan for the end of life
- it was introduced by someone they knew well
- it felt like a choice – not a service requirement
- they could see how it related to important priorities for their child. These could be clinical (such as seizure management) or non-clinical (such as improving school attendance)
- they could see how it might support them personally (by reducing anxiety or increasing control)
- they could see how it related to core parenting functions (protecting children from harm, supporting child development, helping parents advocate for their children's rights and needs)
- it felt like a personalised document that reflected their unique family needs, not a 'tick-box' exercise.

Recommendations

Identify the best person to introduce the CYPACP to the family. This person does not have to be the person who will complete the CYPACP with the family. Anyone close to the family can begin the conversation.

Where possible or appropriate, introduce the CYPACP as a plan for life. This may be easier if introduced early and when the child is relatively stable. Parents may not want to make a plan at this time, but may be more receptive if the CYPACP is discussed again at a later, and perhaps more critical, time.

Show how the CYPACP relates to the family personally. This includes relating it to their history (such as how it might have helped in relation to previous events), current priorities (for instance, are their main concerns about managing seizures at school, making choices about places of care, avoiding unwanted treatments at end of life?) and important future goals (such as a family holiday, death at home).

Explain how the CYPACP can grow and change to fit children's needs including current and future needs. Explain that parents have a choice about what sections they want to complete and explain how information can be added, amended or removed to reflect new circumstances. Where appropriate, emphasise that the CYPACP is part of a parallel planning approach where all foreseeable scenarios have a plan.

Talk about what might stop families wanting to have a plan and ask what would make it easier for them to be involved. Also consider pre-existing factors that may make it more difficult (such as communication needs, mental health needs or personal context). For example, it may be difficult for parents to consider the CYPACP if they are pre-occupied with providing basic protections, such as a safe place to live or adequate food.

Discuss the range of options for completion and agree next steps. This could include making a start now or imminently, deferring until an agreed time or set of circumstances (for example, next month, before the child starts school), or declining whilst keeping the door open to revisit the CYPACP should things change. This should be recorded in the child's notes or wider care plans to ensure that opportunities are not missed.

Reinforce their right to change their minds about the CYPACP at any time.

Declining a CYPACP should not be seen as poor choice or detrimental to care, if based on informed decision-making. Respecting family decisions is important. Instead, options should be explored about the best alternative ways to have and record important conversations/decisions.

1.2   Supporting families when making the CYPACP

Making a CYPACP is always difficult. Parents in our study often demonstrated significant expertise in relation to their child and managing their condition. However, even the most confident parents found making a CYPACP emotionally challenging, even when it was clearly regarded as in the best interests of their child. While no parent in this study regretted making a CYPACP, the experience was often etched into their memories as a distressing and difficult event. Actively planning for a child's end of life care was often associated with feelings of guilt. The nature of the experience could also impact on therapeutic relationships. When done well, parents' relationships with professionals and healthcare teams could be strengthened, but even long-standing relationships could be undermined when the CYPACP was handled insensitively.

Things that supported parents when making a CYPACP included:

- preparation for making a CYPACP
- choice about when and how to make a CYPACP
- emotional support during and following meetings
- opportunities to reflect on the CYPACP.

Recommendations

Help families to prepare for making a CYPACP by helping them understand the range of topics that might be covered, whilst also explaining that they can choose which sections are completed. Some families may value seeing the document beforehand. It may also be helpful to discuss the full range of environments that the CYPACP can be used within and who the information could be shared with (such as the hospital, school, respite, GP, ambulance). This can help families think about the CYPACP in relation to a range of relevant scenarios.

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 and to help inform completion.

Optimise choice as much as possible.

Who: Identify who should be involved in making the plan. This may include clinical and non-clinical people (teachers, family support worker). Some parents will prefer to make plans with just one or two 'trusted' professionals. Others will want a range of multi-disciplinary or multi-agency professionals to be present to access to as much expertise as possible.

Where: Families want privacy and to be in a 'safe' environment that allows them time to make decisions and enhances feelings of control. While many felt home was the best place, others preferred to be in a clinical or neutral setting — ideally one that felt home-like, such as Magnolia House; a facility at Birmingham Children's Hospital specifically designed to be a calm and peaceful place to have important conversations in relation to palliative and end of life care, or a children's hospice.

When: CYPACPs were often made as part of routine clinic appointments or home visits. While this worked well for some families, families wanted to be able choose a time that is convenient to them — one that allows other family members to be present, or is free from distractions.

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How: Some families want to make the CYPACP in one go, whereas others want a staged approach. In both cases, this is about managing the level of distress with some people wanting to 'get it over with' as soon as possible and others feeling unable to face the whole document in one go.

Facilitate families to use their own support systems. Explain that close friends or other supportive individuals (such as carers or family support workers) can attend CYPACP meetings. Parents in this study valued the support of close friends, especially where parents were completing the CYPACP alone, by choice or necessity. Friends did not typically participate in decision-making but were trusted sounding boards who offered unconditional reassurance that parents were doing the right thing. They also provided important emotional support during and following meetings, and helped parents remember key information.

Provide aftercare by facilitating access to supportive services and organisations. Making the CYPACP may identify unmet emotional and social needs in any family member. This may require referral to formal counselling services or support to access relevant support groups and organisations.

Provide opportunities to reflect on the CYPACP and follow-up activities. Parents describe themselves as feeling 'drained' or 'exhausted' after making a CYPACP, but relieved that it is done. While some people may not want to talk about it further, other parents report that the experience evokes new thoughts, feelings and uncertainties. Parents may therefore benefit from opportunities to reflect on the CYPACP, with a follow-up call or meeting to discuss how they are feeling, ask additional questions or make changes to the CYPACP.

1.3   Supporting families to involve children and young people

Children's voices need to be more evident in the CYPACP. Although plans were demonstrably made in the best interests of children, we found that few families had involved their children in completing plans, and many children (and siblings) were not aware of the document. In many cases this related to children's capacity to understand, but not exclusively. However, parents were more comfortable with plans when they felt that they reflected children's identities, their known wishes or decisions that children would (in parents' opinions) make for themselves.

Recommendations

Explore parents' views on involving children and young people in the CYPACP. Where capacity allows, explore how parents may be supported to talk to their children about wishes, decision making, the CYPACP and preferences for involvement.

Ensure that children's views, values and preferences are incorporated in the CYPACP. This could be:

(a) direct involvement (where possible and appropriate) - where children complete the document with parents

(b) indirect involvement - where information from separate conversations with children is included in the CYPACP

(c) advocated involvement - where parents are supported to identify what matters to their children and include this information in the CYPACP.

Consider using (or developing) developmentally appropriate resources and techniques to elicit what matters to children and young people. Consider how these wishes could be incorporated into the CYPACP process and documentation in meaningful ways (eg Riley R et al. 2018. Integrated person-centred planning for children, young people and families receiving palliative care. Guidance and toolkit).

Consider the involvement of other professionals to support children's voices to be heard, for instance play workers.

1.4   Developing and using family-centred information about the CYPACP

Families are likely to have unmet information needs about the CYPACP. Given the current lack of public awareness about advance care planning (and the CYPACP), it is important to explain what the CYPACP is, what it isn't and how it differs to other related documents (eg DNR forms).

Parents said more information about the CYPACP would have been helpful. Few parents received information about the CYPACP and professionals rarely offered the CYPACP leaflets for parents and young people or directed families to the CYPACP website. Nor did they use any other tools or resources to help families understand advance care planning or complete the CYPACP. Partly, this was because professionals felt that the most sensitive way to discuss the CYPACP was through dialogue. However, at the same time, professionals often lacked confidence about how to talk to families about advance care planning and specific topics within the document (eg organ donation).

Recommendations

Develop family oriented information that is co-produced with families to ensure it is meaningful and user-friendly. This could include a range of materials presenting information in simple ways (such as infographics) or more detailed ways (such as booklets, factsheets and websites with audio-visual information, and child- or developmentally friendly information such as story books).

Consider the language, communication and cultural needs of families and consider the involvement of other people or organisations who can support these needs.

Think carefully about, and communicate clearly, the messages you want to give in relation to the CYPACP. We found that the CYPACP is framed and discussed in different ways, and the language used by professionals is influential in how the CYPACP is understood and interpreted by others.

Consider providing families with an impartial contact they can get in touch with if they have general questions, concerns or complaints about the CYPACP.

1.5   Giving families more spaces to talk about the CYPACP

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 happened, the emphasis was often about updating existing information, rather than more general explorations of whether the CYPACP was helping to meet their 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 reflect new needs or include more detailed information. However, parents reported few opportunities to reflect on the CYPACP during routine care.

Recommendations

Use naturally occurring opportunities to broadly enquire about the CYPACP. For example, have they used it yet, did it work as intended, where do they keep it, have they discussed it with anyone, have they thought about anything else that needs to be included?

Check action plans to see if they are progressing as intended. For example, have any of the wishes for life been acted upon, have they been contacted by the relevant people?

Provide opportunities for families to discuss the CYPACP with other parents who have experience of making and using them.

Perhaps include some carefully selected case studies (that could be put on the CYPACP website) to show how a range of families have used their CYPACP and demonstrate a varied range of impacts.

2.0 Support for professionals

2.1 Education, support and training

Professionals found education, support and training in advance care planning generally, and the CYPACP specifically, to be beneficial, and it appears that some high-quality provision exists. However, few professionals in this study had received formal training (either undergraduate or CPD) and were often reliant on support or 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.

A number of generic support needs were identified:

- **Eligibility.** Professionals understood that the CYPACP was designed for children who are recognised to have a life-limiting or life-threatening condition. However, they were not always confident about the limits of eligibility – for example, in life-threatening conditions that appeared very stable, complex conditions where threat to life was low but children had significant care needs, or use in perinatal settings.

- **Role delineation and collaborative working.** Professionals were often unsure about the appropriate delineation and distribution of roles and responsibilities in relation to the CYPACP. This included the specific duties, expectations, authority and limits of their own role, and how roles and responsibilities should be transferred or shared at different implementation points. This could be a source of tension with individuals and 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 – for instance, those with more relevant expertise, closer relationships with families, more resources – or could assume that others were more involved than they actually were. The blurring of roles and responsibilities was particularly evident between hospital and community settings. However, without a clear understanding and agreement of roles, professionals felt it was difficult to explicitly question, challenge or reconfigure existing ways of working. Effective collaborative working often came down to key 'champions' working hard to develop good personal relationships, but this was easier for some people or teams than others. Parents were also be unsure who to contact regarding different issues in the CYPACP.

- **Processes.** Few professionals understood the entire CYPACP process and where they fit within it. They described uncertainties about national and local policy, including what was or wasn't mandatory, and were unsure if they were implementing the CYPACP appropriately. Many were also unsure about where to gain advice in relation to context-dependent queries or complex situations. Suggestions for improvement often concerned closing the theory-practice gap – ie how to apply the idealised principles of the CYPACP to real family situations in complex, busy or under-resourced care settings.

- **Compatibility with existing practice.** Many professionals have infrequent experience of the CYPACP, for example if children with life-shortening conditions are a small part of their caseload, and while a CYPACP could clarify some issues, it could also feel like a responsibility they are ill-prepared – and sometimes not supported – to deal with. Ways

of working do not always fit easily into their existing systems, or duplicate work. For example, the CYPACP provides more information than is required in an emergency, and some places have policies that require them to complete a **ReSPECT** form, even when a CYPACP is in place.

- **Using the CYPACP document.** Professionals were generally confident about the clinical aspects of the CYPACP. Other sections, however – such wishes for life, spiritual/cultural care, organ donation, bereavement care – could be more challenging. Professionals often felt they lacked expertise to complete these sections and were unsure who was responsible for 'actioning' plans.

- **Reviews and version control.** Version control was an area of concern, with many professionals saying they lacked robust systems to ensure that everyone has the most up-to-date copy of the CYPACP. Ensuring timely reviews was also an area of concern. The mandatory annual reviews were sometimes late or missed, often attributed to breakdowns in information sharing across organisational boundaries. This can be problematic. It means critical information can be out of date and CYPACPs are taken off important systems, such as ambulance control, if not reviewed within the year. We also found instances where families were left without their CYPACP while they waited for information to be updated or signed by doctors. Professionals also expressed uncertainty about how frequently to review CYPACPs with families, what the appropriate triggers for this were, and whose responsibility it was to identify, request and make changes.

- **Supporting families.** Professionals could lack confidence in key aspects of implementing the CYPACP, including:

  - Introducing the CYPACP, especially in situations where they don't know the family well, there is prognostic uncertainty or existing vulnerabilities (such as mental health needs, dissatisfaction with care) or questions about how much the family knows

  - talking about death and dying, including organ donation, bereavement and funeral care

  - spiritual/cultural issues

  - responding to distress

  - knowing when or how to involve other professionals or external organisations.

Recommendations

Emphasise the message that the CYPACP is everyone's business. Collaborative working underpins the CYPACP and it will be important to work with the professional bodies of all stakeholders to support greater awareness and routine use of the CYPACP, especially given that the CYPACP is now included in national guidance, for example NICE guidance.

Clarify the criteria for being the 'lead' professional(s) for the CYPACP and ensure there are mechanisms to communicate this. There can be confusion about who can, or should, be responsible for a family's CYPACP, especially where numerous teams, professional groups and settings are involved. It may be helpful, therefore, to explain who can be an appropriate lead for the CYPACP, and why this may not necessarily be the lead consultant.

Develop a competencies and training framework to support advance care planning generally and are important in the implementation of the CYPAC. This should indicate what skills, knowledge and abilities are important to the implementation the CYPACP, with easy access to information, education and training to support the development of these – for example, online provision of information and signposting to relevant national, local or online training opportunities. While the general principles of advance care planning will be universal, the level of skills and knowledge required to implement the CYPACP will depend on the professional role or setting. Consideration of the different tiers of competency is therefore useful to recognise the range of roles that exist in relation to the CYPACP – for example, national or regional leads, staff who make CYPACPs with families, staff who manage or share CYPACP information as part of an administrative role, and staff who receive CYPACPs and may be required to implement them.

Clarify eligibility. Help professionals to understand who should be offered a CYPACP and why. Perhaps use examples and scenarios to help illustrate the criteria such as the **Together for Short Lives Core Care Pathway** which identifies four categories of life-threatening and life-limiting conditions.

Clarify processes. Help professionals to understand the whole CYPACP process, how it aligns to existing work and who or what might be involved at different stages. This could include information about national policy, a process map, clarity about what aspects are essential and what can vary locally.

Develop a practice-based manual for advance care plan co-ordinators and professionals who make plans with families. These should include all the information required to use the CYPACP appropriately, including best practice guidance about eligibility and key processes, information about appropriate section completion (with illustrative examples where helpful), advice about dealing with challenging scenarios and links to helpful information or organisations.

Develop quick reference guides that can be customised for use when making plans with families. Professionals often need information specific to their areas when talking to families, for example contact details of local support groups, specialist nurses for organ donation or wish-granting charities.

Develop profession-specific factsheets to support the involvement of different groups such as paramedics, teachers or GPs. When copying the CYPACP to professionals, it may be helpful to also provide a quick guide that includes key details about the CYPACP, suggested roles and responsibilities, practical strategies to manage and use the information, ways to get involved, local contacts and links to further information (such as the CYPACP website). These could also include personalised sections or cover letters to encourage professionals to get more involved in the CYPACP, with easy first steps to gain confidence, such as an invitation to talk to the ACP co-ordinator about the child's plan or attend a team meeting where the CYPACP is due to be discussed, as well as hyperlinks and signposting to useful websites like CYPACP, ReSPECT and Together for Short Lives.

Set up systems to ensure two-way information exchanges between the CYPACP working group and adoption leads or regional ACP co-ordinators to cascade national updates, identify local issues and share best practice.

Increase support for and visibility of regional ACP co-ordinators. ACP co-ordinators provide critical roles in the regional management and audit of the CYPACPs. They are also instrumental in cascading information, fielding questions, training, mentoring, networking and process development. However, these roles are not often explicitly recognised or supported, and they often depend on the special interest and goodwill of the individuals involved. Yet these people are crucial in the adoption and implementation of the CYPACP and are perfectly placed to identify gaps in uptake, support development and identify training needs – for instance, by contributing to regular audits, service evaluations and research.

Further develop the CYPACP website to provide a national repository of information and provide a central hub for CYPACP enquiries, FAQs, training and discussion.

Consider having a CYPACP training lead to identify, cascade and develop training opportunities that support advance care planning generally, and the consistent and appropriate use of the CYPACP specifically.

Develop easy practice-based tools to support local evaluation and service development – for example, self-reflection, audit, benchmarking and planning tools.

Consider national data reviews to develop a wider evidence base to support strategic development, such as mapping work, the number and characteristics of children with CYPACPs, and comparison of regional data.
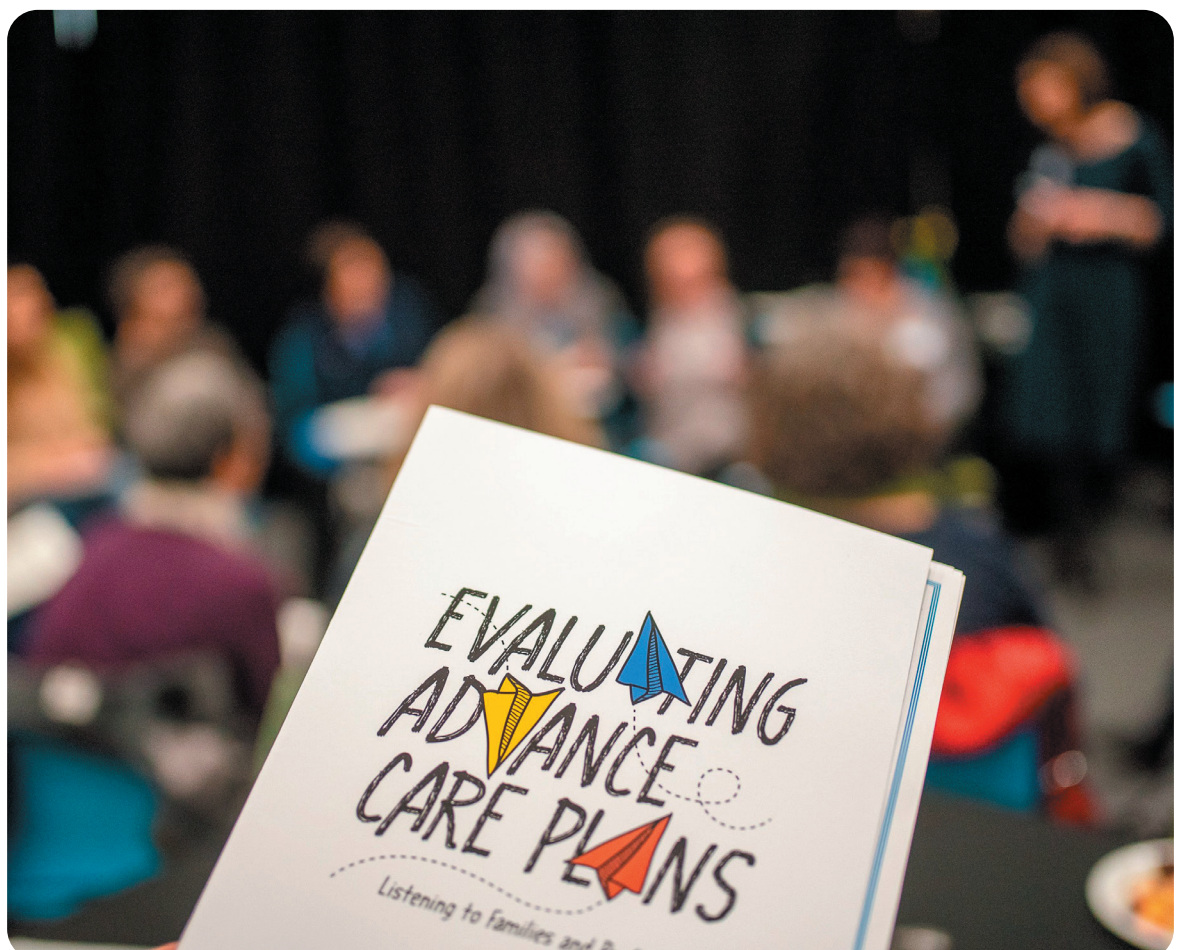
3.0   CYPACP process and documentation

3.1   Legality and ownership

We identified a number of issues related to the legal status of the CYPACP and who owns it, which may have implications on how it is understood and used in practice.

- **Legal status.** There is a misperception that the CYPACP is a legal document among many parents and some professionals. This view is often formed or reinforced by the need for signatures. Parents generally value the idea that the CYPACP is a legal document, as they feel it gives their wishes increased credibility and authority. It also provides reassurance that their wishes will be followed, if they are not present. However, it can also make the CYPACP feel more daunting to complete.

- **The right to change your mind. Most parents understand that they can change their minds at any time** – that decisions are not 'set in stone'. They understand that they can do this verbally, for instance in an emergency. However, parents are unsure about the appropriate process to make changes to the CYPACP document and questioned whether they could change the form themselves in the absence of a professional.

- **The limits of honouring wishes and preferences in the CYPACP.** There is uncertainty about the circumstances in which professionals might not follow the plan. For example, paramedics explained how they always tried to respect families' wishes, such as to be taken to a specific hospital, but felt that this was not always possible, perhaps due to the child's health status or the availability of beds. Failure to follow plans can be a source of stress for all involved and devalues the CYPACP in the eyes of parents.

- **Most professionals understand that the CYPACP is not a legally binding document**, but a 'guidance document' that informs professionals about family wishes and preferences. However, it was clear that this understanding was not always communicated sufficiently to parents and the findings did revealed a number of related uncertainties and variations in professional understanding:

  - What is the difference between the 'master copy' held by parents and the copies circulated to organisations? Can you only act on the 'master copy' or are the 'copies' equally valid? If you can act on copies, how do you ensure it is the most up-to-date version?

  - How 'valid' is the CYPACP as a directive if the parents are not able to confirm the wishes and preferences stated in the plan? This scenario was not reported as happening frequently, but there is a view that many professionals would probably act to preserve life until a parent could be contacted.

Recommendations

Clarify the legal status of the CYPACP and the role of professional duty. This needs to be understood by all professionals involved in making and implementing the CYPACP and communicated appropriately to families. This could be made explicit on the document itself, as well as in the guidance documents and discussed when the CYPACP is being introduced, made and reviewed.

Manage expectations appropriately. Explain the limits of the CYPACP, including what can or cannot be guaranteed. This includes discussing circumstances in which professionals may not be able to follow the CYPACP or honour wishes and what can and should be done in relation to this. This should be discussed when the plan is originally written so expectations are clear.

Clarify issues around ownership and what this means in practice, including who is 'allowed' to amend or add information to the CYPACP and how this should be managed and communicated.

Ensure that families understand the process to make changes to the CYPACP and ensure this is done in a timely manner. Perhaps make this clear on the CYPACP – for instance, who to contact if changes are required.

Consider including a new section in the CYPACP that enables parents to note non-urgent changes and issues that they would like to be discussed at the next opportune time or at review – whichever comes first.

3.2   Making the CYPACP child and family centred

Children and other family members should be more visible in the CYPACP. Parents and professionals understand the need for the CYPACP to include 'medical' information that is structured formally. However, the CYPACP can also feel cold and impersonal and parents made a number of suggestions to make the CYPACP more child and family centred.

Recommendations

Add space:

- **where information about the child can be given,** such as what they like or dislike, by the child or parent themselves

- **to briefly note key moments in the child's or family's journey,** such as a timeline from the family's perspective

- **for a photograph of the child (and family)**

- **where the support needs of the family can be recorded,** such as sibling support.

3.3   Section completion

We noted examples of inappropriate or insufficient completion of the CYPACP including the following:

- **Missing, out of date or illegible information**, including poor handwriting or suboptimal photocopies. While no harm was described as a consequence of these, there was potential for error and the risk that important care decisions might be informed by out of date information.
- **Inappropriate contact details**, such as locum doctors or staff no longer in post.
- **Lack of clarity in some clinical sections.** Completion of medical information was generally considered to be appropriate and sufficient, although there were occasional errors that could reduce clarity and have the potential for harm, such as a failure to tick boxes or strike through options that were not appropriate.
- **Completion of non-clinical sections was often suboptimal**, such as the wishes for life or spiritual/cultural sections. These were often given less priority than the clinical sections and included vague or tokenistic information. Examination revealed that many professional felt they lacked sufficient knowledge to complete these sections and were unsure how to 'action' these plans (including who has responsibility for non-clinical aspects of care). This is problematic, as these sections helped parents view the CYPACP as a person-centred plan for life, rather than an end of life document. Poor completion and the failure to act on plans could therefore devalue the CYPACP in the eyes of parents. For example:

  - **Wishes for life** were felt to improve the quality of family life and support lasting memories that may help after bereavement. Wishes could be big (holidays, equipment, experiences) or small (going to the park, play-date with friends) and help to achieve these was valued by families. However, professionals were not always sure what wishes were appropriate for inclusion and feasible, or how to action them.

  - **Organ donation**. Professionals making CYPACPs often feel they lack the competencies to complete these sections. However, they are important as this issue is closely related to choices about place of care and death as donation requires a specific set of criteria — for example, in PICU with many interventions remaining in place. It seems that professionals and parents are not always clear about these criteria.

  - **Spiritual/cultural issues.** Professionals recognised the importance of these issues, but felt they lacked sufficient knowledge to support these sections appropriately and were unsure how these could be honoured without linking into religious or community groups.

  - **End of life care, including funeral planning and bereavement care.** Professionals found it difficult to know how and when to discuss these issues and how to meet the needs of different family members who may have different responses, knowledge and understanding. Yet supporting families to engage with these issues could be profoundly important for families.

Recommendations

Provide more guidance about appropriate completion, especially in relation to high-risk and non-clinical sections, with examples given where appropriate.

Include prompts to promote detailed content where appropriate.

Include prompts to promote action-planning, task allocation and time-frames where appropriate.

Add hyperlinks and signposting to national organisations in the document so that parents can look at these themselves, if they wish.

Provide guidance about how services can build collaborative links with external groups that can support these sections – for example, organ donation, wish granting charities, hospital chaplaincy, local religious leaders.

3.4   Management and sharing of the CYPACP

Participants reported a number of uncertainties about the optimal ways to transfer, store and flag CYPACPs within and between organisations. It was also noted that the people responsible for managing CYPACPs administratively may have little understanding about the CYPACP.

Some professionals had undertaken significant work to develop useful systems, including local processes, to:

- identify children on caseloads who may benefit from a CYPACP
- flag-up when a child has a CYPACP
- automatically flag-up annual review dates for CYPACPs (pending, completed or outstanding)
- flag-up if a child with a CYPACP has had a hospital admission to enable professionals to consider whether a review of their plan is warranted
- ensure patients with CYPACPs are routinely discussed.

Recommendations

Develop guidelines (and process charts) for managing and sharing CYPACP data (hard-copy and electronic versions).

Develop guidelines about how patient data can be linked to the CYPACP to benefit care. For example, data systems to:
(i) identify eligible children with no advance care plan in place,
(ii) alert staff to a child's escalating care needs which may necessitate a review of their CYPACP
(iii) support regular case reviews and management.

Be aware of system risks. For instance, CYPACPs may be taken off some systems if they are considered to be out of the review date.

Consider how the CYPACP could be built into current and future data management systems, both locally and at a national level.

3.5   Use in an emergency

Not everyone was familiar with the CYPACP and its layout, making it challenging to find the right sections when time was critical.

Some professionals have found the move to ReSPECT difficult. Some felt this was attributable to their unfamiliarity. However, it was also clear that some felt the ReSPECT section is less suitable for children than previous versions and some aspects were too 'subjective' or lacked detail. Moreover, while they understand that the use of ReSPECT improves consistency between paediatric and adult care, there were uncertainties about whether the form remains valid after transfer to adult-orientated services. There were also examples of duplication, such as second ReSPECT forms completed as part of hospital admission processes.

Recommendations

Clearly mark pages and sections most relevant to those responding to an emergency, such as paramedics. The ambulance service suggested a green stripe could be placed next to the sections most relevant to those responding in an emergency (although may not be useful if grayscale photocopies used).

Provide more guidance about ReSPECT section and how completion can be optimised for children.
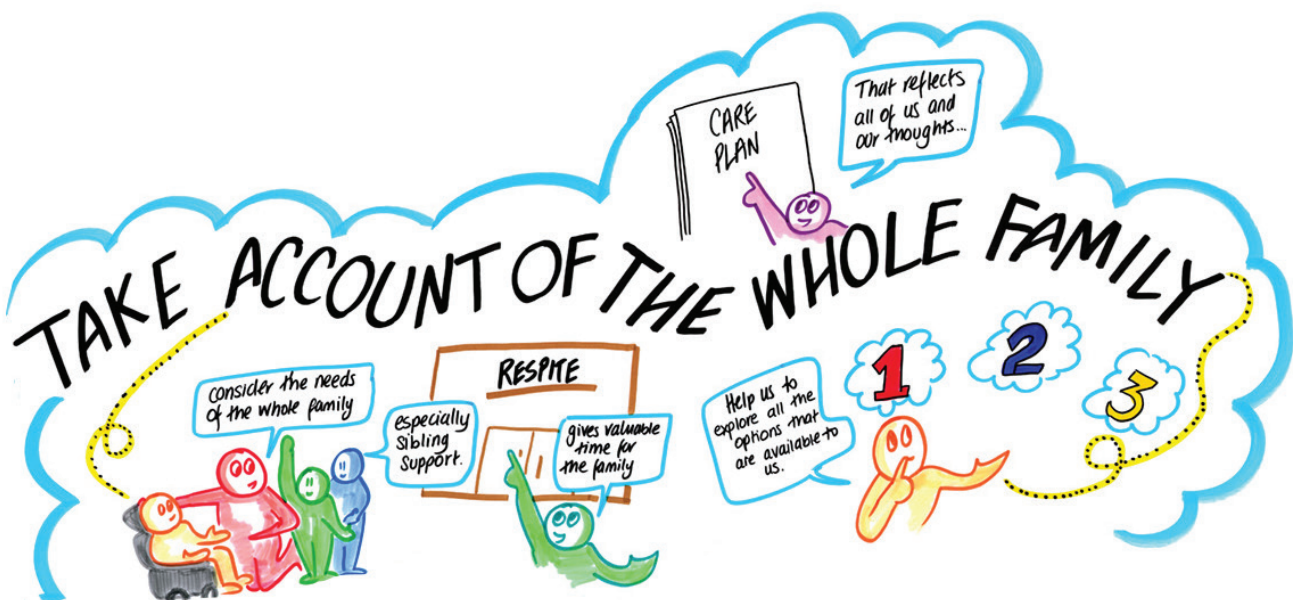
4.0 Wider changes

Parents in this study had limited knowledge about advance care planning in any context prior to introduction. They also knew few other children with an advance care plan, despite often knowing many families in similar situations.

The CYPACP is not embedded in routine care. Parents told us that many professionals involved in children's care do not typically refer to their CYPACP in consultations. It was usually up to parents to tell professionals that they had a CYPACP and professionals less orientated towards palliative care often had limited familiarity with the document and process.

The CYPACP is not used nationally. Parents often believed that the CYPACP was a universal document and having one gave some families more confidence to travel further afield from their usual care providers – for example, for a holiday. However, it was also clear that use and understanding of the CYPACP varied within and across regions, which was a source of concern for families.

The lack of visibility and routine use of the CYPACP adds to families' concerns about the CYPACP. It made families question its value and why they needed one. For instance, do professionals know something that I don't? Have they given up on my child? Why don't all professional use the CYPACP if it's so important?

Talking about advance care planning was difficult for many professionals and families. This is evidently part of a wider societal reluctance to openly talk about dying, death and bereavement, especially in relation to children. Unfortunately, this could impact on making advance care plans and the experience of having one. Professionals could avoid or delay talking about specific issues if they felt they lacked sufficient knowledge or skills to do it well. We also identified areas of tension where extended family members did not agree with parental decisions to make a CYPACP, or where family and friends were reluctant to provide childcare when the CYPACP included a 'do not resuscitate' decision.

Recommendations

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 to develop a shared vision for all professions involved in the care pathway for these children and increase understanding of collaborative working and role delineation.

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, for instance Dying Matters.

Acknowledgements

For more information:

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