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Service Evaluation of an Advance Care Plan Tool

Jenny Billings
Laura Holdsworth

Centre for Health Services Studies
University of Kent

June 2013

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Service Evaluation of an Advance Care Plan Tool

June 2013

Jenny Billings, Reader in Applied Health Research
Laura Holdsworth, Research Associate
Centre for Health Service Studies
University of Kent

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Diane Arthurs
Administrator
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent CT2 7NF

Tel: 01227 824057
E-mail: d.arthurs@kent.ac.uk
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1 Introduction

Following the successful bid for a Department of Health grant in October 2010, the Kent and Medway Children and Young People's (KMCYP) Palliative Care Network ran a six month project to raise the awareness of children's palliative care. One of the key outcomes of the project was to agree a standard Advance Care Plan (ACP) tool to be used across the network. Advance care planning involves the process of discussing life-sustaining treatments and establishing long-term care goals with families. It requires effective communication to clarify the goals of care and to enable families to agree care at the end of life, including resuscitation decisions (Henry and Seymour 2008). This work was based on that undertaken by the South Central Strategic Health Authority. With their approval the tool was adapted for local use.

KMCYP Palliative Care Network worked closely with the Evelina Children's Hospital at St Thomas's, who modified the same tool to suit local needs. Early agreement was reached that all tools would be printed on the same lilac paper so as to be quickly identifiable and recognisable in an emergency. The project has also been rolled out to East Kent Specialist Community Nurses. A major part of the success of the tool was recognised to be education and training of its use among professionals to ensure a standard approach as far as possible, and this has been accomplished. The tool was launched during the autumn of 2011and the initial aim was to run it as standard practice initially through the chYps (Children and Young Peoples' Services) from EllenorLions Hospice, the Evelina Children's Hospital, and within the East Kent Community as used by specialist community nurses.

This report gives an account of a service evaluation of the ACP. Conducted by researchers at the Centre for Health Services at the University of Kent, it was undertaken between October 2011 and April 2013. The initial intention was for the evaluation to be conducted over a year; however this was extended due to the need to accommodate training in each area before evaluation, and to allow for time to recruit families to the study.

1.2 Aim

The aim of the evaluation of the Advance Care Plan tool with families and staff was to:

- Investigate how accurately the documentation was being completed;
- Ascertain the appropriateness of the tool from the family and staff perspective;
- Discover the extent to which families were able to agree care at the end of life, including resuscitation decisions;
- Identify staff perceptions of training received regarding application of the tool;
- Identify and build on the strengths, and make recommendation for improvement

1.3 Locations

The initial intention was to conduct the evaluation in all three sites. However Evelina Children's Hospital at St Thomas's had to withdraw, therefore the primary sites were The chYps team at EllenorLions Hospice and East Kent Community Trust. Towards the end of the evaluation, the ACP was being rolled out from Demelza Hospice Care for Children in Kent, and therefore some data was obtained from this source.

1.4 Method

The project took place over 20 months and consisted of a combination of qualitative and quantitative approaches. The evaluation design consisted of three main data collection areas: Document audit of the Advance Care Plans; Interviews with families about the process and outcome; and Focus groups with professionals undertaking the ACP. Multi-methods approaches to evaluation are the preferred approach in order to capture and assess all aspects of the process (Robson 2002). Each data set was analysed separately and then the data as a whole was subjected to a thematic pattern-matching to identify common threads throughout (Yin 2003). This enabled a clear direction to emerge for establishing the benefits and challenges of the project and making recommendations for practice.

1.4.1 Document Audit of the Advance Care Plans

This consisted of an assessment of all plans with regard to completeness and accuracy that had been completed and signed off for the first time (i.e. before any follow-up reviews) over the locations. An audit framework was constructed to collect and analyse data – this was done quantitatively and qualitatively as information recorded on the plan consisted of both types of data.

Sample: During the study period, ACP documents were returned from three sites. A total of 18 documents were received for analysis: 13 from the chYps team, 4 from EKCT, and 1 from Demelza Hospice Care for Children. Forms were submitted to the researchers by fax or post. A flowchart was constructed for the lead nurses to ensure consistency of approach (appendix 1). Teams were asked to anonymise the forms prior to sending them, however this was not done in all cases and so some forms were anonymised by the researchers. Most forms were copies of the original, though some were anonymised in their electronic state which meant that some data was missing and could not be analysed. The quality of the faxed forms was poor in some cases. Follow-up ACP forms were excluded from analysis.

Analysis: A descriptive content analysis was carried out on the documents (Sarantakos, 2005). ACP documents were analysed section by section; in most cases each page contained multiple sections which were determined by headings or the type of information recorded. The sections were entered as headings into an electronic spreadsheet and a numeric coding system for rating completeness was developed from the ACP documents. Each section was analysed for completeness in relation to the heading and information requested.

Sections could be marked as one of three options: complete (2), partially complete (1), and incomplete/blank (0). For partially complete sections, the missing data was recorded in the framework for further analysis. Any data which was judged as not relevant to the section or in the incorrect part of the document was noted with a 9, followed by the erroneous data. Sections of the ACP document which relied more heavily on open-ended narratives were coded in terms of themes present as they emerged from the documents rather than for completeness (Bailey, 1994). Additional notes about how the document was completed were also included in the framework. The framework was then analysed looking for patterns in missing data and themes.

1.4.2 Interviews with Families about the Process and Outcome

Semi-structured interviews with families were conducted using questions that developed with the project evaluation steering group, and took place with the primary carer. Questions related to the ACP and considered aspects such as how the ACP was introduced, how it was completed, how the sections were perceived, the context of its collection, the appropriateness of the tool for the intended purpose, the extent to which agreement was reached about plans made, and the professional's approach to the family (appendix 2 for interview schedule).

Sample: The aim was to recruit five families from each of the locations (n=10) which was thought be sufficient to achieve data saturation as the subject matter was focused (Richie & Lewis 2003). The intention was to attain some diversity of background and strive for purposeful sampling to reflect this, but it was recognised that the sample would inevitably be one of convenience, given the small population group. In the event, only four parents were interviewed. Possible reasons for this are reflected upon in the 'Limitations' section at the end of the report. The interviews took place within three to four weeks of completing the Advance Care Plan to maximise memory recall. Interviews were conducted at a time and in a location of the participant's choice, were recorded, and took no longer than 45 minutes.

Analysis: This focused on Flick's (1998) approach using the development of pre-determined themes connected to the interview schedule and a content analysis of the data. Interviews were transcribed verbatim and data were sifted into the pre-determined themes. Data that lay outside of the themes was organised into 'blank' categories and analysed separately to generate new themes. Care was taken to ensure that valid representation of data was made and monitoring between researchers checked for any artificiality.

1.4.3 Training

Two focus groups with professionals and lead nurses took place. Focus groups are becoming a method of choice in the health care setting, important to explore ideas but also gain consensus about issues discussed (Fern 2001). Questions were again developed with the project steering group and included how the form was introduced and completed, perceptions of the process of gaining information and consensus about the Advance Care Plan, appropriateness of the tool, and perceptions of training received (see appendix 3 for focus group schedule). Focus groups took place six to nine months after commencement of the pilot project. This was to ensure that sufficient exposure to plan completion with families had taken place and professionals were able to fully inform on the process and any training received.

Sample: A total of 17 members of staff took part in the focus groups. One group represented the chYps team based at EllenorLions Hospice, who are Children's Palliative Specialists (n=8), comprising two consultants and six nurses; the other group were Specialist Community Nurses covering the East Kent region (n=9) and described themselves as mainly dealing with general community nursing.

Data collection: Focus groups took place at EllenorLions Hospice, and the Kent and Canterbury Hospital, where the East Kent Community Nursing team are based. Good facilitation were a necessary prerequisite to obtaining a range of responses and to permit full participation by all focus group attendees (Pope & Mays 2006) and information was recorded with participants' permission. Both focus groups were an hour and half duration.

Analysis: Data was analysed as described for family interviews.

1.5 User Involvement

It was important to involve service users during the research process in whatever capacity they are able. The research team linked with parent forum at Demelza Hospice Care for Children and enlisted the support of carers. In the form of a single workshop, their advice was sought on the research plan, access to and recruitment of participants, instrument design, ethical issues and dissemination of research.

1.6 Research Governance

Ethics approval was obtained through the University of Kent's ethics committee. Researchers updated research passports and ensured they were compliant with clinical governance procedures in each location. Permission to proceed was granted by the respective governance groups in each location. As the research dealt with a sensitive situation and with groups who could be considered vulnerable, full ethical procedures were put in place.

For the families, in the first instance, on completion of the ACP, lead nurses introduced the project to families and ascertained permission for completed ACPs to be anonymised and sent to the research team for analysis. They then introduced the notion of participation in an interview and disseminated an information sheet to families (appendix 4). Researchers liaised closely with professionals to ensure that it was non-coercive process. Contact details of the research team were also provided at this time so that potential recruits could discuss issues about participation with them. For those wishing to take part, a prepaid reply slip attached to the information sheet was completed either with support from the lead nurse at the time of introducing participation in an interview, or by the family themselves. Once received by the research team, arrangements for the interview were made by contacting the families directly. Consent for the interview took place at the time of the interview (appendix 5) to ensure that families were aware of what would be asked and had the chance to question the researcher. It was stressed that families were under no obligation to take part and that they could withdraw participation at any time with no effects on any future care they may receive.

Researchers telephoned families on the day of the interview to verify that they were still able to participate in case anything untoward had happened to the child between completing the ACP and the interview. A support mechanism was arranged between researchers and professionals in the event of families becoming upset during the interview.

With reference to professional involvement, a researcher was present at training events and was able to introduce the evaluation to professionals verbally and provide an information sheet (appendix 6) and flow chart of the procedure (appendix 1). Focus groups in each location were arranged with lead nurses and consent obtained from each participant to ensure full understanding of what was being discussed (appendix 7).

Care was taken to ensure that information received from all participants was rendered confidential. Plans had identifiable details that were coded. Personal details were kept on a password protected computer and known by two researchers. All other data from families and professionals was rendered anonymous during analysis to avoid identification.

1.7 Development of Recommendations

An important outcome of the project was concerned with suggestions for improvement, so dissemination to professionals for comment and application was important. A workshop with four professionals representing the chYps team, the specialist community nurses and Demelza Hospice Care for Children convened at the University of Kent in June 2013 to develop recommendations emanating from the evaluation.

2 Findings

This section reports firstly on the results of the document audit, and secondly on the qualitative results.

2.1 Quantitative Findings: Documentary Audit of Advanced Care Plans

Presented here is a detailed account of how 18 forms were completed, without consideration as to whether sections are more or less important compared to others.

All forms were generally complete. All sections had some information recorded and there seemed to be a consistent use of concise writing. In the sections for additional comments/communications there were some variations in the type of information recorded (e.g. medication, family relationships, death review panel, etc), but this most likely reflected the personal nature of an open discussion on advance care planning rather than tick-boxing. Most of the information recorded seemed to be of reasonable quality and reflected the general aim of the advance care planning process.

However, there were some apparent issues with the structure and electronic formatting of the form which made key pieces of information difficult to interpret. The remainder of the analysis will focus on areas of the form judged as problematic, first presenting general observations followed by a page by page analysis. Recommendations for improving the form are given at the end.

Firstly, the ACP forms are meant to be printed on lavender paper, but most forms received were on white paper or faxed. While this was acceptable for the research, in practice forms cannot be copied or faxed and still retain the signature lavender colour which is used for easy recognition. Three copies of lavender forms were received, of which one was pink rather than purple.

Many of the sections come with instructions for the person filling in the form. For example:

Table 1

page 3	(**Clearly delete all options NOT required**. Add comments to clarify wishes):
page 4	(*Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).*

On some of the forms these instructions were deleted when data was entered. This is likely to be a problem when the time comes for an annual/biannual review of the ACP because the instructions to the clinician are missing, so a new form would be needed rather than reviewing the existing form. Also, as seen above, there are different sizes and styles of font and capitalisation used seemingly randomly throughout the forms. This made it particularly difficult to differentiate between instructions to the author and information for the user of the ACP. Also, different font styles used for instructions or information entered may be perceived as indicating that some information is more important than other pieces, but again, there was no consistency even within forms. In some places on the form information was requested in boxes or on lines, and in others there was just free text. This lack of consistency added to the confusion between instruction and information.

The remaining analysis is presented on a page by page basis in table form for easy understanding. Each point is labelled with a number corresponding to a section of the ACP form which is indicated by a red circled number (appendix 8). The points are focussed on inconsistencies in the use of the forms, or for narrative sections themes are presented.

Table 2

Page 1 – Contact details and background	
1	For some patients, 'other emergency contact' details were left blank, though this may be because they did not have a contact person. However, for some patients 'N/A' was recorded to indicate why the form was left blank,
2	Two of the forms had the review date box at the bottom filled in when only the 'date plan initiated' line should have been completed,

Table 3

Page 2 – Management of cardio-respiratory arrest	
3	The box for resuscitation was inconsistently used. The structure of the columns in the box seems to indicate that one of three options should be used; sometimes only text was deleted, but more often entire sections of the box were deleted. However, in 5 of the forms two boxes were left which took some consideration as to whether CPR should be attempted "as per standard guidelines" or "with modifications" listed on the form as both boxes were present. In one of the forms with two boxes, one box said "For full resuscitation" and the other was "DNACPR", giving contradictory instructions,
4	Contact details were missing on 7 of the forms,

Table 4

Page 3 – Intercurrent illness / acute deterioration	
5	One form referred back to the first page for the diagnosis rather than filling it in again.
6	It was unclear how these two paragraphs were meant to be used given that the wording of the first paragraph seems to indicate that the author should fill something in, but most were left blank. Six forms had added text to the list of problems to be treated actively. On one form the paragraphs were altered, with sentences removed.
7	The font of some of the text was altered on some of the forms (e.g. bold italics), which might be interpreted as certain issues being more important than others. This might in fact have been the author's intention, but it makes the document appear messy and inconsistent when styles for headings, instructions, and text are used interchangeably. On one of the forms the author elected to cross out some actions rather than delete them.

Table 5

Page 4 – Intercurrent illness / acute deterioration	
8	For patients who do not suffer from seizures, some of the forms had this written: “NO CURRENT SEIZURE PROBLEM” with the box deleted. Three forms had deleted the entire section on seizures rather than indicate no seizure problem.
9	On one of the forms the boxes had moved out of alignment with ‘yes’ or ‘no’ so it was not readily apparent which box was ticked, indicating a formatting issue with the form.
10	The sections on ‘Management of infection’ and ‘Instructions for emergency care’ were at times deleted entirely, or left blank.
11	The ‘Additional comments’ were completed on 8 of 18 forms. The comments included the following types of information: current medications and treatment plan; status of illness; place of care in case of deterioration; and existence of additional care plan.

Table 6

Page 5 – Wishes	
12	"Child's wishes", complete on 14 forms. This section contained the following type of information: preferences for place of care; personal information about the child such as likes, dislikes and hobbies; child's information needs or capacity for understanding; family relationships and carers; care packages; spirituality; and language,
13	"Family wishes", complete on all forms. This section contained the following type of information: preferences for place of care; who is involved in child's care; living arrangements; who can make decisions about care; location of family members; sibling information needs; hopes/wishes for child and family; spirituality of family; and school matters,
14	"Others wishes". This section was interpreted ambiguously by authors, either interpreting "others" as other 'people' or as other 'wishes', such as for quality of life. The example given in the instructions indicates that it should be read as the former, i.e. siblings' or friends' wishes, in which case 7 forms miscoded information which would have been more appropriate under 'child's wishes', 'family wishes' or elsewhere. Therefore information was only completed correctly on 7 forms and the remaining 4 left blank. This section contained the following types of information, regardless of whether it was appropriately recorded: school matters; information about grandparents; siblings, friends and other family; personal information about the child such as likes, dislikes and hobbies; decision making by others; and wishes for care and quality of life,
15	"Wishes around end of life" were complete for the sections on "preferred place of care", "funeral", and "spiritual" wishes. The last two sections on "other wishes" and "organ donation" were left blank on 12 and 3 forms, respectively.
16	Job title was not filled in on 7 forms and 2 forms did not state which family member was involved in the discussion.

Table 7

Page 6 – Decision making	
17	The following topics were covered in the "Communications and discussions" section, with the frequency of the theme in brackets: parent and sibling awareness of child's condition (13), child's capacity to understand their condition (8), progression of the child's illness and condition (5), care and treatment preferences (4), role of the death review panel (4), child's prognosis (3), who is involved in decision making for the child (3), sibling and family relationships (2), role of professionals, sibling support needs, safeguarding, symptom control, school and quality of life.

Table 8

Page 7 – Who has agreed and supports this plan?	
18	GMC numbers were missing on 2 forms.
19	Only 1 form had something recorded in the "Communications and discussions" section. The comment was about the parents' awareness of the purpose and use of the plan.

Table 9

Page 8 – Signatures	
20	Some authors used √ or X to indicate a box was ticked; others used √ to indicate a box was ticked and X to indicate that it did not apply, and some did not tick any boxes but gave contact details anyway.
21	There was inconsistency in the contact details given: most gave names, addresses and telephone numbers; others gave either address or telephone. Some had ticked boxes but did not given any contact details.

2.1.2 Commentary

Overall, the forms appeared to consistently capture the same type of ACP relevant information for each child, albeit sometimes the information was recorded in different places. However, the main issue with the form is that some of its structure and format details appear inconsistent and this can lead to some confusion in finding and interpreting information quickly. Boxes for recording information are used in some sections and others use dotted lines. This, along with different font formatting means it can be difficult to distinguish between text which is for headings, guidance for the author, or information to the user of the ACP. Inconsistent font use is made worse as the form is available as an MS Word document and is therefore open to editing by the author. This has meant that some sections of the forms have been altered leading to a variety of differences between the forms which may make finding information difficult if it is not recorded where expected.

2.1.3 Limitations

The reviewer who carried out the analysis has no medical training so was not able to assess the quality of the medical notes recorded, but only whether they seemed to reflect what was being asked. Additionally she was not in a position to judge whether a section of the form was important or trivial, so all sections of the forms have been analysed in a common sense approach.

2.1.4 Suggestions for Improvements to the Process

Based on the results and discussion, the following suggestions for improvement have been made:

a) Consistent font formatting should be used for headings and instructions to the author so that this can be clearly differentiated from text that is meant to be entered or altered by the author.
b) There should be consistent use of boxes/lines for capturing important information.
c) The form should be 'locked' from use by the author so that they can only enter or alter certain pieces of information and not alter the structure of the form.
d) In the section on 'Wishes during life', the section on 'others wishes' should be clarified or redesigned to indicate more clearly what the section is intending to capture.
e) Minor errors in completion, such as not recording author information or not stating a diagnosis on page 3 might be reduced by having a second person review the form to ensure it is complete prior to dissemination.
f) The lavender colour of the forms means that they are easily recognisable, but not easily faxed or copied for dissemination. Consideration should be given to the importance of the colour of the form, or whether there is another way to mark the forms so they are easily recognised if not on coloured paper.

2.2 Qualitative Findings: Parent Interviews and Staff focus Groups

This section reports the findings of the parent interviews and the staff focus groups. The analysis of both parent and staff qualitative information was conducted separately, but the themes emerging from the data were largely similar, so a blending of perceptions was made. This enabled comparison between the comments, highlighting differences between participants and where consensus of opinion was reached.

Participant quotes are used liberally throughout the section. Efforts have been made to ensure confidentially by removing names, but the small samples inevitably mean that some identification may be possible. This is particularly so for the teams involved, as important differences between them were evident in the discussions, so they have been named by role. Efforts however have been made at all times to secure the confidentiality of individual staff members. Participants were made aware of this potential before agreeing to participate. Each quote is attached by a code, using either S1 (the chYps team of children's palliative specialists), S2 (the Specialist Community Nurses) or P1-4 (the four parents), followed by the page number of the original transcript where the quote can be located.

Below is a table indicating the themes and sub-themes. Some of the sub-themes are uniquely from either parents or staff and are labelled as such.

Table 10

Theme	Sub-theme
Introducing the Advanced Care Plan	*Making the Introductions (P)* *Following a Crisis* *A State of Readiness* *'Selling' the ACP (S)* *Tensions with Oncology Patients (S)*
Completing the Form	*Timing the Meetings* *Completing the Sections* *The Issue of Resuscitation* *Family Involvement in Completion*
General Views about the Form	*Positive experiences and perceptions* *Professional training and the ACP (S)* *Co-ordinating the ACP use across professional groups* *Improvements to the process*

2.2.1 Introducing the Advance Care Plan

On discussion, a number of predominant and contrasting themes emerged regarding the introduction of the plan. The first theme is from the parent's perspective and describes who was involved in *making the introductions*, and the appropriateness of this. The following two themes relate to 'trigger points' for families when introduction seemed most appropriate, namely *following a crisis*, and being at *a state of readiness.* A fourth theme emanated from focus group discussion with professionals and was concerned with how staff were sensitively *selling the ACP* as a tool that would support decision-making for parents. A final theme in this section concerned the experiences relating to *tensions with oncology patients,* again from a professional perspective.

Making the Introductions

All participants revealed that there were a number of routes through which the ACP was introduced, usually through the nurses, a community consultant, a paediatrician or a combination of these. The parents below describe their experiences, highlighting the importance of the child being known by the member of staff introducing the plan to them, as well as being knowledgeable about the plan:

> [Child's] doctor.... she started talking about it and thought it would be a good idea to put one in place and then I think she got in contact with our community nurse and then she come

> out and talked to me about it and I think a few weeks later she brought one out with her... (P3:2)
>
> [The nurse] was very familiar with it and how it worked and she could explain how it had worked for patients of hers before which it… it just all sounded very good. (P1:3)
>
> [community consultant] was definitely the right person to do it. She knows [child] very well. (P2:9)

Following a Crisis

This usually concerned an emergency situation where the child's condition became critical and where experiences and circumstances surrounding the incident were not optimal, but nevertheless prompted the need for an introduction to the ACP. Staff described the following situations:

> …it's after an event's happened and a situation where a child's been rushed in and things haven't gone all the way that the parents would like and it's usually that they've had not a positive experience… that they felt that their voice wasn't heard and they actually had wishes and views about their child and actually that's quite a good opportunity to say, "Well actually we've got a format that …we can capture some of that in now." So that's one way of introducing it. (S1:4)
>
> ...he was a birth asphyxia and ...and then he actually hit a crisis point and I know it's not a great time to talk about it but actually for mum that was the right time to bring it up and that's when she understood why I was talking about it. (S2:9)

From the parent's viewpoint, this participant understood the need for an ACP following repeated crises:

> It was our community consultant.... [child] ..... had quite a lot of intensive care admissions and his seizures weren't very well controlled, she wanted something to be put in place so that we… so we all understood, you know, what we wanted; what we wanted as a family, what our wishes were and so that we didn't have to keep explaining yourself. (P2:6)

However, a discussion about the ACP was prompted when this parent experienced an acute incident herself, indicating that for the family, the ACP is an important tool if the primary carer is compromised:

> I had a detached retina, which is an emergency procedure and it was a Sunday morning and my husband was away... A few weeks after … my operation… [child] had a check-up with her consultant and she was fine, but I think he was worried about me … he put things into motion....and through that I was visited by a … head of sort of local community paediatric nursing. (P1:1)

A State of Readiness

Related to the above, and from a largely professional perspective, there was recognition of the need to be at a certain stage of awareness. Teams felt that introducing the ACP may help parents along the journey of acceptance, as well as give them control over making decisions about their children. Sometimes this was following an event as above, and for others it was more a growing realisation that could take place over considerable time:

> It's almost an acceptance as well of where their child is on their journey…. they're not looking for the wonder cure… they've been told probably by a consultant somewhere that actually their child unrealistically isn't going to survive into adulthood but they've actually acknowledged that. (S1:6)

> some parents make [the decision to go forward with the ACP] very quickly and some parents are going to take years over it but I think it's… it shouldn't not be done because they're not ready to say, "Let's stop now." (S1:7)

> I think there's an overwhelming relief that they can make a decision. There's been some parents that *so* know what they want and their experience is nobody will listen to them but it's, "Oh thank god, I can do something official about what I want." (S1:14)

One parent explains how she appeared to reach this stage:

> ...it was quite a good time. We'd sort of just started to sort out [child's] epilepsy and yeah, [child] was… was doing quite well and yeah, it was discussed that maybe it might be something that we should think about. We were given a blank copy of the Advanced Care Plan just to have a look through and to think about the answers … (P2:6)

This state of readiness also included a practical dimension, with or without acceptance, as this professional illustrates:

> …some families, they don't want to believe it and… but there's also the very practical side of well, we still need to look even if it doesn't happen. (S1:6)

However, professionals acknowledged that achieving this state was seen to be variable between families according to where they are along the continuum of readiness and acceptance, often connected to issues of uncertainty, denial and the unsettling situation of shifting prognoses:

> And you may, say, see two children exactly disabled for exactly the same reason or exactly the same condition but one family will not accept it whereas one family… not that they *will* but they're in a different place with it. (S2:9)

> In fact he's lived longer than they thought that he would do, they'd given him like a couple of months to live but even at the Consultant's appointment, "I don't want to talk about him dying … Like can we not just talk about him as he is and what we're dealing with now," rather than wanting to, say, think about funerals... (S2:7)

In addition, the process of introducing the ACP highlighted the skills needed in terms of assessing reactions and adapting to family responses to determine when to proceed and when to withdraw. The following quote provides an example of the importance of sensitivity when considering how ready families were:

> ...it's... it's either been, "I can't talk about this right now," burst into tears and we leave it, even with all the persuasion in the world or it's perhaps a few tears, "Let me think about it. Yes. I think that... that is a good idea," and then you get to the starting blocks... (S1:7)

Leading on from this, there were other instances when there were tensions between the readiness of the family and professional impetus to move forward with a plan, as indicated by this quote:

> .....she's just not at a point where she really wants to talk about that but actually, from a professional point of view, it's something that we do need because this little girl is very poorly. (S1:13)

There were also differences between the teams in this respect, with the chYps team seemingly moving gently forward when the need was seen as acute, and the community specialist nurses more inclined to wait:

> I think sometimes you need to push before the family's ready because of just where the child is, isn't it?... I'd been saying mum's not ready and I thought I'd got to a point where she was and actually as soon as we arrived she said, "I don't want to talk about this..." and actually, we just talked about some other stuff and she opened up and we managed to get bare bones of an ACP completed... (S1:13)

> ... the doctors want it in place, we want it in place but the parents have to get to that crisis point... It's just not something they want to be talking about at that… They're not ready. (S2:12)

Connected to this, some strong views were also expressed, raising the question of in whose best interests the ACP was there to serve:

> What, are we pushing for it because *we* feel better to write it down on a bit of paper and there it is? Well actually if that doesn't make the families feel better then don't... don't push it. (S2:23)

However, there was one illustration of a particular set of circumstances in the care of the child where pressure had been put on the family to have the ACP introduced and completed, and this did not sit comfortably with the team involved. So for both teams, there was clearly a tension between proceeding with a plan, and simultaneously avoiding any distress:

> There are occasions when we've *had* to do it when families aren't ready, mainly about care-givers. So the child's coming home from hospital and there's going to be a package of care, the agency or whoever's managing the package of care saying, "My carers can't go in if they

> don't know what to do with that child," so you have a... there is a pressure point there and you can explain to the family, "Look, I know this is really difficult and I know you really don't want to do it *but* if you want any respite carers coming into your home, unless they know what to do they won't do what you want." (S1:13)

Professionals also recognised that there were situations where the ACP would not be acceptable under any circumstances, such as having strong religious convictions, and at these times family decisions would be respected:

> With some families, no matter *how* much you talk about it… *no* way it *would* have been used....One of them had a *really, really* strong faith and even talking about putting it on paper... They wouldn't have even entertained the conversation. (S2:10)

> No matter how good your form is, there's *always* going to be a group of families that won't... it's not going to work... And I think actually as professionals we just have to accept that that's fine, that's their decision... (S2:22/3)

In addition, there were particular difficulties experienced by the community specialist nurses, due to the length of time the family had been known to them in a non-palliative or 'curative' capacity:

> It's been a bit difficult to introduce some care plans to family, especially when you've known them for so long on a case load and it's never been addressed or recognised. (S2:3)

There were other related challenges for this team with respect to their dual 'curative' and 'palliative' roles with the families that will be explored later.

'Selling' the ACP

From a professional perspective, given the sensitivities surrounding the ACP, team members from the chYps team had recognised a number of ways that the ACP could be promoted to parents. This was largely in response to countering the perception of it as predominantly a resuscitation tool, an aspect elaborated on more fully later. With the first quote, the main 'selling' point was seen to be related to identifying wishes:

> I think the key to selling any of [the plans] to the family whatever time you do it is about parental wishes and if we sell it as a tool for the parents to document their wishes.... it's usually okay to sell it. It's when you try and come in and say, "You must have this 'do not resuscitate plan'" that you get that stone wall… (S1:10)

Further to this, some team members described the ACP as a pro-active integrated document that could facilitate control over decision-making, which in their experience engendered a positive response by parents:

> ... if you come in and say, "Actually this can be an active plan – it doesn't have to be a 'do not resuscitate plan'" you get them used to the idea that they've got some choices and they can make some decisions and they can document what they want... (S1:7)

> …for me, I think it gives for some of our families that sense of control over what's happening with their children and I'm just thinking recently to… [a child] that recently died as well and actually for that family, it really was about the control of what was going to happen to their child, and this is how I introduce it. (S1:7/8)

> ...quite often these… children have got specific little plans in place already and is a bit bitty. They might have an epilepsy plan, they might have a metabolic plan rescue plan, they might have something else and I say to parents, "Well it's about bringing them all together in one place and in one documentation that can go around to everybody in notes and ambulance," and so again, using that as a positive active plan (S1:10)

From the family point of view, the latter quote from a professional is clearly corroborated by this parent to good effect:

> .... everywhere you go with a child like [name] you have to fill in endless, endless forms and you're repeating yourself and there's a danger that you're going to forget something because there's… there's a lot to put down for [child] and the older she gets, the more history there is and you are going to forget something. [Nurse] said what… what we should do is we should do a form that does everything. I thought it was a really good idea. (P1:2)

Tensions with Oncology Patients

This was again a particular theme identified within the chYps team. The team highlighted some particular dilemmas associated with children who had cancer, pointing out the tensions between medical treatment, expectations, engendering hope, and the need for a plan to be in place:

> ... there's that difficult *are they palliative or not* and we're all sensing this child's going to die and we know the family wants to stay at home but we know also that the oncologists are being still quite aggressive with management ... (S1:5)

> I find the oncology ones are the hardest to introduce because the families are still looking for a hope, the doctors are still looking for cures, there's always trial medicines and then actually they then come out for end-of-life care still with a hope because that's what the hospital are giving them and that's really, really hard. (S1:15)

> ...there hasn't been those early conversations with some of these families as to what their treatment is. You know ... it is about treatment - a plan - and very often the oncologists just won't go down that line. (S1:15)

Summary

This section indicated the importance of the child being known by the member of staff introducing the plan to them, as well as them having knowledge about the plan. An emergency situation often prompted the need for an introduction to the ACP such as following a crisis, and there was recognition by professionals and parents of the need to be at a certain stage of awareness or readiness for the plan to be introduced to them. This degree of readiness varied between families due to unstable nature of child, but professionals highlighted the importance of continually assessing the emotional status of families. Tensions existed between the teams regarding when it was felt necessary to gently push for a plan, or to wait, but there were occasions when it was recognised that the ACP would not be acceptable under any circumstances.

Professionals from the chYps team revealed how they promoted the plan to parents, describing it as a proactive integrated document to facilitate control and decision-making, and highlighted tensions with oncology patients regarding the need for a plan to be in place in the face of continuing hope.

2.2.2 Completing the Form

This section reveals a number of practical issues and challenges to ACP form completion, highlighting the ease or difficulty associated with this. While themes emerged included practical issues of *timing and organising the meeting* and *completing the sections*, much of the discussion centred around *the issue of resuscitation.* In addition, there was consideration of *family involvement in completion,* regarding who was interacting with the plan, and whether the child was involved.

Timing the Meetings

Parents and teams recognised that timing was paramount, in terms of the amount of time to allow for completion, but also that completion was an on-going process. This was seen as important to allow for reflection and the sensitivities surrounding the form. The following parent participants elaborated on this:

> ...some of the things are hard to talk about and [nurse] knows that and, you know, she would give you the option to talk about things later or, “Do you want to think about that and we’ll talk about it next time?” So she gave space... (P1:13)

> We went through it and she was always saying, you know, “are you okay to talk about it? Are you all right to carry on?” and I was just like, “Yeah,” you know, you’ve got to just sort of get it done in one go and then you haven’t really got to think about it. (P4:8)

> ...she gave me enough time to… to think about it and then came out and we discussed it. (P3:4)

These professionals added to this consensus view:

> ...the important thing though is that you need to ensure that you've got enough time. These things can't be rushed. You can't do it in a half an hour slot. (S1:17)

> ...you start to complete it about the bits that they are ready to complete and that's when you do as much as you can and then you revisit and you revisit and you revisit. (S1:14)

> I think with our experience we can work gently through that and we can get them there and we can, you know, do it step-by-step and recognise that maybe it will be a year or two down the line before we get the end result. (S1:19)

But importantly, parents emphasised the importance of not completing the form when the child is in crisis to avoid added trauma and misjudgements. It was preferable to wait for conditions to stabilise and have the opportunity to reflect on the choices:

> I was really pleased to be able to talk about it in a… in a calm manner because it's not something you *want* to think about and I have twice had those talks in intensive care, "Well what do you want us to do?" and it's very hard at the time because you don't quite know what's the right thing to say and you're in shock and it's not the right time. But… but to be able to do it… when you're calm and think about it and have the option to say, "Yeah, we'd like to do everything, but keep us posted…" ... if it had been, you know, in a stressful situation you might have put things down that you might have regretted or want to put differently. (P1:12/13)

> ...that's why we do it at a good time; the Advanced Care Plan because that… that's actually my true wishes but, you know, get me in that situation and I'd probably be "Resuscitate him!" (P2:11)

This parent however was not sure that any time was right, highlighting the emotional dilemmas and conflicts involved in the procedure:

> ...it doesn't feel like the right time because he is generally quite healthy but then thinking about it, if anything was to happen and I wasn't there or anything did happen and like when he had his fit – you just go into a state of panic and at least they have got something to go on if anything that bad did happen but it doesn't… I suppose at any time it doesn't feel the right time to think about stuff like that. (P3:3)

With regard to the location for the meeting, all agreed that home was preferable, as these parents explain:

> ...the family visit at home was lovely. You know, if she's in hospital it's stressful regardless of how calm you might be. It's much better to do it at home at a time when the child is well. I believe so. (P1:7/8)

> It was more comfortable, you know. (P4:9)

Completing the Sections

This section considers some practical issues about completing the form. A key feature of the parent interviews concerned the importance of explaining and guiding them through each section of the form in detail and having a discussion. This was needed to overcome problems with understanding, but also helped mitigate any fear and anxiety associated with completion. The fact that difficult decisions could be deferred also appeared to be reassuring:

> [The nurse] explained in detail about what was required, what bits might sound frightening, but they just *had* to be covered for certain reasons, a bit about coroner and things like that which it's lovely to have it in there and know that it's something that I, should it happen, I won't have to worry about. (P1:3)

> We kind of talked through each bit because there was a lot of things on there that I don't understand, like the different forms of resuscitation – it's written obviously in medical terms so I didn't understand them so we just talked through everything and the bits I wasn't sure of she said like, you know, "We'll put it down as *mum's not sure at the moment* and then we can always come back to it and if you ever want to change your mind…" (P3:4)

Parents were keen to point out the sensitivity with which completion was handled and high level of interpersonal skills required. They were able to perceive the nurse who completed it with them as a 'friend' that they could trust. This seemed to be at the route of ensuring parental engagement with and acceptance of the ACP, and in reducing the potential for stress:

> ...she helped explain everything as well but yeah, she was… I felt like I could talk to her. She was absolutely wonderful...she was really sympathetic...she knew that it wasn't… it wasn't a nice form to fill out but she was really, really nice about it. Really supportive as well. (P3:3)

> They've all been really sensitive and understanding and… and yeah, just… just, you know, listening to… to what we want and they've all been very professional about it. (P2:15)

> I suppose where we got on so well, it was just like talking to a friend and, you know, she was quite sensitive about it. (P4:7)

Regarding the format of the form, discussions within the teams considered where on the form completion should start, and the issue of resuscitation was central to these debates. These first professional responses from the chYps team followed an approach given during the training:

> Always start at the back... Because there's CPR pages on the front...and it's the wrong place to start. (S1:22)

> ... start at the back and start with the wishes.... if you start with that page then ... you work to the resuscitation. The reason it has to be presented that way around is because of course if a crisis happened, you don't want to be wading through nine pages trying to find the

> page.... And reinforced by A&E departments and by Intensive Care Departments; they want that page. (S1:22)

There were differences between the professional teams however about the order of the information. The community team highlighted the need for the plan to be led by the families, with particular reference to the point at which they are at:

> I mean I had the training and I can remember the training; *start at the back and work your way…* I found I ended up going to different questions. It wasn't a simple case of starting at the back in practice. It made sense when they were teaching it but then in practice with a family it didn't make sense. (S2:13)

> I tend to fill it in or try to fill them in just by whichever part of the conversation I'm having at the time so, you know...that family was talking to me about the fact that they don't want to prolong anything ... I start at *that* point, you know, and … some bits of the form I would leave completely blank.. (S2:14)

Conversely, the experiences of other professional across the teams suggested that families were ready from the onset to discuss what were perceived as highly emotional aspects like resuscitation, and there were other sections that families found more upsetting:

> ....for some families actually the resuscitation is the reason they want to do the plan so you might start with that. (S1:23)

> .... they were all ready to be talking about resus and then when I actually talked about funerals and after death that… that was more upsetting. So you never quite know what's going to be the thing that makes them feel the worse. (S2:6)

> They're quite happy to do the active resuscitation.....but actually coming to talk about their wishes to do with funerals and even things like organ and tissue donation, I've put... quite often I've put *parents don't want to discuss this at this moment* because that's the point where they find that they can go so far .... (S1:13)

The above quotes demonstrate the family-centric nature of the interactions teams have with the parents. From the parent's perspective, there were some examples of what information needed to have prominence and where it needed to go on the form, and the guidance given by team members was central to their decisions. Quotes from these two parents intimate that there was agreement about where information should go:

> ...she in the past has had cardiac arrest under anaesthetic and I said, "We've got to have that on. That needs to go somewhere where it should…" and she said, "Yes, that should be on the front," (P1:6)

> what she's put in to sleep.... it's obviously not important enough for the front page so it was a question of finding the place where it was going to go on ...and she helped me find the right place for that. (P1:6)

Some professionals however questioned the necessity of some parts of the form, and the quote below provides an example of this:

> ...do we really need to know what they're going to have funeral-wise? .... Unless there's a particular religion or, you know, you've got to do specific things.... it's probably something that we would have very little understanding of anyway. (S2:14)

To some extent, this quote from a parent parallels the above concerns. It shows the emotive difficulties in completing this section, relating to the issue of detail:

> And like the funeral. They say about if you want to talk about the funeral, planning it and like what we want him to wear.. I did cry because obviously it's something you've *got* to think about but you don't want to because you don't want anything... I don't want anything to happen to him but it's got to be like spoke about. It's got to be sorted and organised. But yeah, it was quite emotional. (P4:7/8)

Leading on from this, this level of detail did seem to be problematic for parents in that there was a requirement to think about and address every eventuality. Parents were being asked to contemplate scenarios that may previously have been the domain of professionals. The importance of guidance was clear:

> I would say the hardest thing that I… that I found about doing it was talking about the different circumstances that we… that we may have … if [child] was to die at home, what would our wishes be then? Would we want him to go to the hospital? Would we want him to go to Demelza House? Or if… if he was to deteriorate in hospital, what… what would we want? It was…. to me, that was… that was quite difficult for me to get my head around and think about all those things... It is the attention to detail. It's the… it's the… the *small* things... (P2:6/8)

> … there is a bit on there where it talks about stopping feeds and I think IV and stuff like that and what else was there? Something about after death as well. I think they were the most… the worst bits to do. But again, [nurse] was …really good. She was really sympathetic and she didn't like doing it either so it was quite nice. (P3:4)

The Issue of Resuscitation

This particular area occupied a large part of the discussions due to its highly challenging and emotional nature. A recurrent theme concerned how the uncertainties around decision-making for resuscitation could be translated into written instructions to satisfy both the families themselves and the requirements of professionals dealing with families, and there was clearly a tension between the two.

These quotes from parents emphasise some of these dilemmas, highlighting how some decisions cannot be planned for due to the uncertainty of the child's condition. There was a tendency for concrete decisions to be postponed in favour of discussions later, or if the situation arose:

> I must say when I was left the form I was rather dreading that [resuscitation] bit because I, you know, I thought *Oooh, this is going to be tricky. What are we going to do about… about that?....* I mean some of the things we just left blank or said we'd discuss it another time. (P1:12)

> It's horrible to talk about it and obviously now because I'm calm and he's healthy, but put me in that [crisis] situation I'd probably say a different answer. (P2:11)

The quote below from a parent, touches again on the level of detail required for the form and the dilemmas with decision-making associated with this. It also raises issues concerned with quality of life:

> I suppose the thing that I found difficult was talking about how long… like how long to resuscitate....so if [child's] heart was to stop and they were to resuscitate for twenty/thirty minutes and they felt like that actually it wasn't going to help.....for us as a family to have [child] more disabled than what he is…it… it just… it wouldn't be worth him being here because I think… because he can still, you know, he smiles and I think he's got some sort of understanding of what's going on, but I think to take that away from him, he would have nothing. So that was quite difficult to discuss. (P2:11)

From a professional perspective, the examples below highlight that staff were aware of the magnitude and difficulty of decisions in this area for families and compensated by weaving in medical involvement to support them at the point it would be needed:

> ...to ask a parent to make the decision that their child's going to die – which is effectively what you're saying – I think it's completely inappropriate so I don't… expect the parent to make that decision..... I mean we know this child's very sick and we want the doctors at the time to assess whether the ventilation or whatever's right. (S1:18)

> ..... as a parent, they shouldn't be shouldering that responsibility and ... often in the first review or first time you write it it's, "They have a full CPR but it's dependent on medical appropriateness at the time." (S1:18)

> I say to ninety percent of the ones I've got is to call an ambulance crew to go to A&E but that's when they need support to make the decisions so it's for initial resuscitation. Regards ventilation and intervention, that's when we put *to be discussed at the time as appropriate* and things like that because a lot of parents said, "How will I know whether this is the end or a chest infection that can be reversed?" (S1:18)

So while teams work with a clear ethos of encouraging family control and decision-making, there is at the same time a virtual continuum along which at some point the professionals need to assume some sort of control. Again, there is no clear juncture, but it is dependent upon context and on-going assessment of the family in these critical situations. This parent agreed with the medical profession taking the final decision:

> ...we discussed that if… if… if the doctors at the time feel that, you know, enough's enough then we would… then we would take their word for it. (P2:11)

Even if parents are able to make a concrete decision at the time of completing the ACP, professionals noted that this could change in an acute situation. It was also of interest that parents linked a written decision about resuscitation to a premature and unwanted sense of 'finality', in that committing to paper made the situation 'real':

> ....parents, they're up for the, you know, saying no resus status but when it actually comes to putting it down on paper… two of my families have backtracked and then not wanted to actually have that care plan go through at all and got a little bit angry about it after it had all be done; "But actually I don't… I don't… I don't want that put on paper." (S2:3)

> ....the mum was like, "Well if I can change my mind at any time, why do we have to do it because I just want to make the decision at that time for their resus. Why… What is the point in writing it down because I'm always going to be there. (S2:3)

In addition, the constant acute episodes in the child's condition added an extra layer of difficulty:

> ....and where that child might be at that stage when you start that and then they are better afterwards and then they're thinking *what if they get better and then I've signed…* It's… They've sort of described it as signing their life away...(S2:3)

> I think with a lot of families, when [the children are] that disabled or they're that chronically ill that I'm not sure they're going to rush around for a piece of paper. They're just going to say, "Do everything." (S2:4)

In the context of completing the plan, the importance of reviewing the situation with families to gauge changes and new decisions was emphasised. The quotes from both a professional and a parent endorse this view:

> I've found that when you come back and you re-address it, they will often have changed their mind or they will be more comfortable with me saying, "Look…" you know, "they've got sicker and resuscitation isn't going to work and…" you know, "you could keep your child at home if you say no to this," and then they will change… you know, we'll go with that. (S1:19)

> ....the fact that it's reviewed every six months, I think, is important with a child like [name] who can… you know, things change all the time. (P1:7)

Family Involvement in Completion

Family involvement in completing the forms was seem as paramount by the teams and wholly appreciated by the parents in the study. One parent suggested that families needed to have an openness to discuss their child and consequently engage in the plan:

> There are some families, but to be honest a lot of families don't want to talk about it where I'm… I'm... quite open and I'm quite honest about my feelings and I always have been and I… and I think that's what's helped me cope over the years is by talking about it. Dealing it with it as, you know, as a family. (P2:13)

The importance of the families having ownership of and control over the decision-making within the ACP has been mentioned before and was a predominant undercurrent throughout the team discussions. These quotes from a professional and a parent illustrate this feature:

> I always give them the first draft and say, "Please write over it. If I haven't captured what you want to say please write over it. It's not my document, it's your document," and I always give it to *them* before it goes to the consultant... because that's what they feel anxious about, is actually them having a voice and them saying what they want so it's... it... it's important that it's their words, not my words that are down there. (S1:17)

> ...she left me the blank form then we scribbled down together some things and she left it with me again and typed up what she… what we'd scribbled and sent it to me as a draft and then reading it I could see that there were some holes... it was quite a long process. (P1:5)

From the parent's perspective, the joint approach used for completion seemed to be a vital part of the process, enabling there to be a trusted information flow from the professional that included sound guidance. From these quotes it is clear that parents needed and valued the support:

> She came and helped me fill it in … I really valued her information about what was best to put in ... the big boxes. There were some things that I might think were important that she would know from her nursing background that weren't so valuable, but might be valuable later on in the form so what to put where. I… I really thought the guidance was quite important there (P1:4)

> ...when we had the blank form we sort of wrote a few things down – our wishes – and then we were able to sit down and then discuss that and while we were discussing that the community nurse was writing things down of what we all agreed on.... we got a copy for us to check and go through and she left that with us for a few days. (P2:10)

Regarding who was actually engaging with staff in the plan, discussion revealed that the form was completed with the mothers in each family on most occasions, although this varied between members of staff. This was due in part to the practicalities of mothers being the main carers, and where there was a two parent family, with fathers in paid employment.

> I mean sometimes [dads] go out to work and mum's not at work to look after the child so they're the ones that are accessible... And the mums generally know more about the child than the dad does. (S2:18)

> on the whole the dads have been in and there's been some dads that have actually been the most active. (S1:12)

This parent gave an example of the practical help a professional gave to enable her husband to attend an appointment:

> ...we did discuss all those sort of finer things like the… the details in… in clinic and we had the community nurses there and we had the consultant. My husband had to come along as well so we were both doing it together and she made sure that we had child minders so we didn't have no distractions…(P2:7)

Teams recognised however some reluctance for fathers to be involved, but endeavoured for them to be included:

> Dad's don't always want to be part of… they… they don't necessarily want to be part of the discussion but I *always* leave the rough draft for them for like a week even to… to make their comments if dad doesn't want to be involved. (S1:11)

> ...often it is the mum that takes on the... the whole thing. The dads find it too stressful. They don't know how to handle it so they take themselves away and let the mums... But not always but it's... it's... it's more common, isn't it? (S2:18)

> There's been some [ACP completion] when dad's been booked and then he's backed out and mum's said, "It's fine, we've talked about it but he doesn't want to be here," ... on the whole the dads have been in and there's been some dads that have actually been the most active. (S1:12)

This parent's experience was congruent with staff perceptions:

> He gets quite… quite angry about it because he thinks why should we be filling something like that out and… but yeah, he's… he's still pretty in denial about [child's] problems anyway so filling something like that in is I think… it freaks him out a little bit. (P3:7)

Other times the logistics of organising meetings at home for both parents to be present was difficult, as this professional points out:

> ..... sometimes it's just not as easy as kind of saying, "Right, we'll have it next week. I really want both parents," and the parents work shift work and that, it does take them quite a while with different things have been cancelled.... it can be quite frustrating. (S1:6)

Difficulties arose when there were differences of opinion due to altered family structures and responsibilities:

> ... the parents [were] separated but both involved in his care.... the paediatrician ....spoke to dad, signed the hospital do not resuscitate form ...and then mum didn't want it so then we were sort of battling with mum and dad and then...then dad changed his mind. (S1:15)

> I think sometimes when you know that there's going to be a lot of difference in opinion, it helps the actual parents if they know they can put it down on paper in advance to avoid arguments and things after the event. (S1:17)

There was some discussion about the extent to which the child could be involved in completing the ACP. Professionals could only think of three incidences when this had happened, as mostly they were deemed not to have the mental and physical capacity. However, when children have the capacity, parents and children can work together well as indicated by these quotes:

> ...the little girl was eleven or twelve and ... her mum was one of these .... salt of the earth type - everything was talked about - so this little girl knew everything all the way through and she was sat there with us filling out the form and she was like… even did the funeral plan. She said, "I want to have a white coffin. I want to be buried with my nanny. I want to have a horse and carriage" and it all happened.... But it was only because mum had been so open all along and wanted a plan and involved her in it. (S1:20)

> I think some of the teenage oncology children can do it and I think that's partly because they have peer discussions that we don't know about and they, you know; what music do you want at your funeral ..... we give them the opportunity then they'll tell us but often we lose it so actually this tool is quite good for that group… (S1:21)

Summary

Timing issues around completion of the ACP needed to be considered to allow for sensitivities and to reflect on choices, and it was agreed by all that it was not something to be rushed or to be completed at a time of crisis. The home environment was considered the best location. Important factors relating to completion included the skills of professional in explaining, enabling reflection, relieving anxieties, and being sensitive to knowing when deferred decisions were needed. Trust was also an important attribute in engagement with the ACP.

There were differences between the teams regarding where on the form completion should start, highlighting training needs, but all agreed that it should be family driven. There was some discussion about the level of detail required from all participants, and families found this particularly difficult when making decisions. The issue of resuscitation was considered at length by parents and professionals alike, with parents often not able to be decisive or postponing the decision, and professionals recognising that sometimes medical involvement to support a decision when needed was required. All agreed that on-going assessment of resuscitation decisions was needed due to the instability of the child's condition, and that maintaining quality of life was key.

Children themselves were mostly unable to be involved in completing the ACP, but professionals gave ownership of the plan to the families at all times and this was valued by parents. Mothers were mostly engaged with this process for practical purposes. There was recognition that fathers were not often able to be present either through work or because they had difficulties accepting the situation. Professional highlighted added tensions within families where there were altered family structures.

2.2.3 General Views about the Form

This section considers some general views expressed by the participants regarding the usefulness of the tool for staff and families. Themes in this section give examples of *positive experiences and perceptions*, and from a professional perspective, highlight some interesting comparisons between the teams with respect to their *professional training and the ACP*. In addition, this section explores experiences from all participants around *co-ordinating the ACP use across professional groups,* and highlights suggestions for *improvements to the process.*

Positive Experiences and Perceptions

From a family perspective, it was seen as a helpful document, acting as an important resource and reassurance that care will be co-ordinated and given as chosen by the family:

> You know, the fact that it's there is a comfort .....and [child's] not going to get better so I think something like this will… it'll be part of her luggage, as it were, that goes with her and if people are accepting it then I think its strengths will come into… into play as people realise what… what a valuable document it is, actually. (P1:12)

> if anything was to happen, at least I know they have got that so they're not going to do anything I don't want them to do or they can take the steps to help him if need be. But yeah, when he goes to nursery, at least again I know they've got that so I suppose it's a comfort thing for me knowing they know what to do. (P3:4)

> ...the whole thing, you know, it is quite emotional because at the end of the day you're sitting down talking about something that you wish would never happen, but it is… it is going to happen at one day, but yeah, I think it's quite a positive thing and, you know, to have in place. (P2:16)

> I'm quite happy with it...because obviously you have a choice.. ... how far you want them to go. I mean I've ticked everything at the moment but I know that we've got the choice if they have to use it and if they have to resuscitate him, you know, we can say no. (P4:15)

As previously intimated parents also valued the input given by the staff involved in their care and were keen to voice their experiences in this respect:

> She was *very* supportive and she had great empathy about the whole thing. Clearly she's very experienced at what she does...even my husband said ..... she's fantastic, this nurse, you know, and the local community nurse. The service that they've given and they've *really* supported us. (P1:13/14)

> All the people that we have I get on really well with and I can't fault them, really.... if I've needed something or advice they've always helped me out. (P4:7)

From the staff perceptive, there was the view that when a plan was completed to the satisfaction of all, the families had a positive outcome, and that it enabled a focus to be made on the quality of life of the child and eased the complexities of decision-making:

> ...just the best experience that that family could have had and it wouldn't have happened without the Advanced Care Plan. (S1:10)

> For them it's helped because mum doesn't want resus but she also doesn't want any intervention. .... for instance if it meant him going on a ventilator she doesn't want it so that's all documented so she's happy....If ... he came home worse off than he went in she doesn't want it… want any of it. So for them, it's… helped them....she wants him to have a very good quality of life as much as he can have.... (S2:8)

As a professional tool, there was agreement within the chYps team that it can facilitate professional practice:

> I think for us particularly with the 24/7 on-call service that… we deliver, to have something there on paper so that we know what we're doing if there's an acute episode ... for end-of-life...I think it makes our life easier. (S1:27)

At the same time however there was recognition of the skills involved and the confidence needed to work with families in the best possible way, perhaps reflecting the need for on-going training and peer support:

> ...it is something that you want to get so, so right ..... It's something I certainly need to work on and the more I do, the better I will get at it and I kind of almost once you kind of sort of do… do one, it does kind of increase your confidence and your confidence in completing the forms. (S1:16)

Professional Training and the ACP

Some interesting comparisons emerged relating to the relative ease or difficulty staff had with the forms in relation to their professional training and experience, and this has been evident within some previous themes. The chYps team for example felt a natural affinity with the ACP and the client group:

> ...this team is specialist palliative care team so it's actually bread and butter stuff and some of it depends on your case load and your experience and what-have-you but at least everyone in this team has got children in that field (S1:16)

> ...being part of the palliative care service it comes more naturally to us than when you go to paediatricians and the oncologists (S1:18)

However, the specialist community nurses experienced tensions within their roles. They were experiencing difficulties with having to change the dynamic from curative or symptom improvement to palliative, thus having a competing 'dual' role with the same families. This proved challenging, given that they had not undertaken specialised palliative training with children. Before the introduction of the ACP, the team used a more simplified form, but this one places more emphasis on end-of-life details that seemed to create those difficulties:

> we're specialist community nurses but we are mainly general community nursing, we're not… we're not specially for palliative end-of-life care so the kids that come into our caseload it's more symptom management which, you know, we're trying to...treat things and improve things and then we also on the one hand come in later on saying…'end of life'... (S2:6)

This role had repercussions of the way the ACP was being introduced and the consequent effects on families, with added uncertainty regarding the right time:

> I think we as a team, we're anxious about upsetting families ... because we're not palliative care specialist nurses so it's really difficult, we've got to work with these families but also there's a group of families that maybe want it but we... because we don't ask it across the board we're also missing out families that might want it.. (S2:22)

> It's meant to be there at the beginning. It's not meant to be chucked in at the end... but it's so difficult for us to put it there in the middle. (S2:22)

There was also the perception that the curative/palliative 'divide' was also responsible for tensions with ACP interpretation and usefulness according to different settings of care, especially evident in hospital settings. This was felt in part to be linked to difficulties with parental decision-making with respect to treating or not treating the child. But it also implies that the ACP may be difficult to be universally understood and accepted by professionals, and may result in a certain reluctance to introduce it:

> I can see that going into like Demelza, a hospice situation, it would fit there very nicely....Because, you know, everybody associates hospice with end of life or, you know, palliative shortened life.....I can see that that is beneficial and it... feels a bit more comfortable in talking about that because everybody knows why you're there. But if you're going into an acute setting you sort of expect to get treated for that chest infection or the hospital, they're not thinking particularly "oh let's think of end-of-life palliative care" at that point, they're thinking "let's treat x, y, z symptoms". (S2:27)

Co-ordinating the ACP Use Across Professional Groups

From the discussions, staff and parents reported a range of other professionals who were using or had sight of the ACP; this included GPs, the ambulance service, the hospice, and doctors and nurses in the acute setting. With respect to how effective the ACP seemed to be in co-ordinating end-of-life care between professionals, there was a mix of responses from all participants. For some parents and professionals, there were positive experiences:

> Well it's only been up.....a little while, but the fact that the people that I've been in contact with, since it's been up, have known of its existence and asked for it I found very encouraging. (P1:10)

> I've just today booked her into Demelza for two nights and they said to me, "Oh, we'll need to go through an Advanced Care Plan," and I said, "Oh well she's got one. It should be on your system," and she checked and it was. (P1:2)

> It's nice when it works. I've had two; one where a mum said she phoned an ambulance for a child … they knew all about her because they… they had it all up on the system so that was a relief for me. And the latest one is when I rang the GP out of hours and the child had died. ... I could actually say to the family, "The on-call GP has got a copy. They've seen it." And so for them to know that it works like that is… is reassurance as well. (S1:23/4)

For others there were some 'sticking points' to do with the needs of teenagers, and how the ACP is disseminated, as described by the professionals below:

> where the difficulties – the biggest difficulties – arise is with those sixteen/seventeen year olds that… that go into adult services and… and, you know, and for some adult services they don't recognise the Advanced Care Plans and we need to bear in mind that they're not a… a legal document.. (S1:27)

> ...the dissemination bit I found quite difficult. We've… we've been quite good at keeping them in the notes and then maybe to the parents but also disseminating it to like the school that… and also the ambulance directly, when I tried to give them a form I don't think they recognised it.. (S2:5)

However, the biggest problems by far were experienced within a hospital context. These comments from professionals demonstrate that the ACP is seen more as a resuscitation 'licence' which has the potential to create tensions:

> Some consultants I've come across.....as soon as they've decided that they're palliative they want the 'do not resuscitate' form and they can't see a middle ground and so they'll push the parents or insist or demand that they have one which then is just a nightmare, isn't it? It's the worst thing they could do. So I think in inexperienced, untrained hands it's quite dangerous.... (S1:19)

> if they go into a hospital it's about whether the hospital trust also recognise the Advanced Care Plan as a… as a do not resuscitate document which I think has been a bit of a discrepancy. (S2:11)

Not only did some parents view the usefulness of the ACP with scepticism in this context, but professionals in the community team also recognised this. Parents could understand the value of the plan, but were experiencing problems with its integration in hospital:

> I think it will be really useful *if…* if they can use it the way it's supposed to because that's the thing with all of these things, isn't it, is that you put all these ideas in place and… but it's actually getting them to use it.... [Child] has got open access to [name] ward. The amount of times I've been up there because of his seizures and they still sit down and ask me all the questions. (P2:14)

> ...when the actual care plan was… was mooted to me, my first reaction was, "I don't think [other professionals] will accept it," because that was what I'd been given to believe..... (P1:2)

These following quotes illustrate the insight professionals had regarding the parent's experiences:

> Lots of these families with children with like chronic health problems, they've been in and out of hospital *so* many times and they never get treated very well when they're in the acute setting so I don't know, is it... do they really feel that it's going to make any difference because they're never listened to anyway. (S2:20)

> mum was totally on board with the Advanced Care Plan and then the child was admitted to hospital with a chest infection, the hospital didn't do what mum wanted and she said, "I'm not... I don't... I don't want that Advanced Care Plan to go through because they can't give basic care, let alone advanced care" (S2:20)

Suggested Improvements to the Process

There were a number of suggestions for improvement for using and understanding the ACP from all participants emanating from the discussions, mostly concerning training and improvements to the form:

a) Continuous training within the teams

> I thought [the training] was quite good.... They explained it very well actually.... I felt quite confident straight afterwards!... And then it was several months later when the reality actually hit that I had to do one and it was like, *oh I've forgotten...* (S2:30)

> ...for training, I think it's ongoing and ... we do almost need a format, maybe a nurse's meeting...like if you're working on one to… to bring it to the group and say, "Look, how can I word this? … how can I go back to the parent?" because some of them are tricky. (S1:28)

... I got feedback from [colleague] so I think sort of as a team it would be good to actually get some more feedback from each other... I feel we could maybe do that better (S1:16) .

..[we] did a walk-through of just practically how to use the form and again, it might be good to revisit that.... I'm still learning. I mean I've been using this for years now but I'm still learning. (S1:28)

with our admin staff, it was really important to include them because actually I type my own up partly because of the issues that were coming out of the admin but now I've been spending some time with them of how… which things need to be bold, what needs to be highlighted because the way it's actually… the template's set up..(S1:28)

b) *More training for staff using the ACP in the acute setting*

Some [doctors] have got more experience than others and there's some that I don't think they necessarily use it *right* at the right time or introduce it right.... (S2:11)

I think it is A&E and I think it is junior doctors and I think it is changing staff ....we've had some families that have gone in clutching their form and junior doctors have ignored it and that… that is an educational problem. (S1:25)

... we haven't had the resources to go around to train A&E departments and things. We've had to just send them with a sort of cover note or a quick phone call whereas ideally in an ideal world .... we'd have done training sessions with wards to say, "where are you going to keep it? How are you going to access it?" (S1:24)

c) *Improving access to the ACP in the hospital setting*

In the hospitals, their files go to be filed away. If a child comes in at the weekend.....I think *that* is the main issue… it needs to be on the system so that when the child comes in they can press and hopefully see if they've got an ACP.... (S1:25)

d) *Improvements to the form*

(i) Simplifying language and including a glossary

..there was a lot of things on there that I don't understand, like the different forms of resuscitation – it's written obviously in medical terms so I didn't understand them. (P3:4)

I would say for… for a professional, it's… it would be quite… it would be easy for them to read..... but the only thing I found was because my partner wasn't there when I had to try and explain to him like all of the medical terms that I just couldn't remember what they were... (P2:7)

I think it would have been nice to maybe have another sheet or something just explaining what each thing was because obviously I was trying to explain to [husband] and I was like, "I can't remember if that one's that one or that one's that one." (P3:5)

It's not user-friendly enough. It's not basic enough to... for... I mean for all our families who have different levels of understanding, that's what I find.... (S2:18)

(ii) Improving the ease of electronic completion

I think what we could do with is investment from an IT person who could make it one of those PDFs that you, you know, the boxes don't move around and, you know, all that stuff because that's why… It's… it's… it's hopeless. If you're not very IT savvy, it's really, really difficult to fill in so that's my biggest complaint with it. (1:30)

(iii) More detail on medical interventions

...apart from her epilepsy management which was on the form there was nothing... no medical... you know, there was no *what to do if she has respiratory distress, use a, b, c or*, you know, *this medication if she goes into retention use a, b...* That's what I would have found useful on the form. (S2:19)

(iv) Reducing funeral details

...maybe there should just be a bit of a block, you know, *Is there any specifics for after death* as opposed to recording all those funeral details (S2:17)

e) Speeding up form completion

If it had come sooner it would have been lovely, but obviously it's a new thing.. (P1:4)

I would actually say it's taken too long to sort out…. it's taken over six months, I think, to do... And I just think… partly it's to do with the consultant because [consultant's] obviously got a lot of children to look after and then there's getting it all signed by these certain professionals. (P2:8)

...we've been talking about it a long time and been reading about it for a long time, but it's not actually in place. (P2:14)

Summary

Parents interviewed were positive about the ACP, recognising it as a valuable document that gave choice, and emphasised the importance of the quality support given by the teams. Professionals themselves understood the value of it as a tool and the high level of skills needed to administer it.

There were differences between the teams regarding the degree of affinity they had with the ACP, with the chYps team feeling more comfortable with it than the community specialist nurses. This was largely due to background training, and the fact that there were tensions with having to change from curative or symptom improvement to a palliative role

with the same families. This also led to difference with how teams viewed its usefulness and hence its application.

Despite differences in experiences, the ACP did seem to be well-co-ordinated across a range of professional groups, but there were less positive experiences about its acceptance in the acute setting, highlighting again a training need. Suggestions for improvements focused on training and improvements to the form itself.

2.2.4 Commentary

From the qualitative aspect of this study, it can be seem that there are distinct areas of success with the ACP that should be continued. It is clear that according to the participants here, the ACP is being introduced at the right time, in the right way and in the right place for parents. Professionals are going at the pace of the family, and using a high level of skill in ensuring choice and flexibility in decision-making. For example, the difficulties parents have in making decisions about the detail is mitigated by the manner through which professionals seem to be sensitive to how difficult this is and enable families to concede areas where it should be left to the professionals, or at least made jointly at that point in time when needed. Also, professionals are proficient at handling uncertainty especially around resuscitation, and support a postponement of decisions as a way of coping.

There is a clear focus on the family needs, and the quality of the child is paramount when completing the ACP. The empathetic and professional skills of the teams in this study are highly evident, highly appreciated and highly regarded, with the result that the ACP appeared valued by the participants. When it comes to co-ordination of the plans between different professionals, progress is being made.

Aside from these indicators of success, an interesting finding relates to **the** difference between the approaches of the teams, with one dealing with palliative and end-of-life care as a matter of course, and the other working more with clients in symptom management and improvement, yet having to face end-of-life issues with the same families. This has the potential to create a dynamic tension in the professional relationship with the family and role conflict.

It was not surprising therefore that there were more positive experiences expressed by the chYps team, articulating a different approach and attitude towards the plan, its application and completion, alongside the benefits that were perceived to be associated with it. Of interest was the way for example the plan was described as an active plan, and that persuasive techniques were being employed on some occasions to complete the ACP that did not sit so well with the other team. With the other team, there were more challenges, perhaps due to the dual role previously described, or perhaps due to the fact that its use was relatively new compared to the chYps team. In addition, the community specialist team may have felt some discomfort introducing it as clients were known in a curative capacity

and their role in palliative care was less pronounced. Either way, these implications point towards a need for greater support and an assessment of training needs.

2.2.5 Limitations

The major methodological difficulty with the qualitative aspect of this project was the recruitment of parents. Four participants from an anticipated total of 10 represent a poor response rate and data saturation cannot be said to have been achieved.

Reasons for the low response rate could be attributable to a number of issues. For example, children with very high levels of need and unstable medical conditions create priorities that transcend participation in a research project, and daily agendas can become easily disrupted. Also, the option for the key nurse to help complete the expression of interest form to pass to the research team on their behalf was seemingly not taken up, and this may have increased response rate somewhat. In addition, there were not significant amounts of ACPs completed within the Specialist Community team, possibly due to role conflict or lack of identification of them as expressed by the team themselves, so therefore there was not a pool of potential participants to recruit from.

Added to this, the perspectives offered by the respondents were overwhelmingly positive and complimentary giving their opinions a positive bias to the study findings. This is unsurprising, given that they were heavily dependent upon the teams for support and still in receipt of services. This does mean however that those unhappy or critical of the ACP were not given a voice in this study and this is a shortcoming. Despite this, professional perspectives on their families' experiences contributed significantly to wider insight of those parents experiencing tensions. Professionals often paraphrased family reactions and this serves to illustrate the intensity of the situation, as well as reveal the empathy of the staff.

3 Recommendations

As reported in the methods section, recommendations for improvements were developed with practitioners and the research team, and were based on the sections highlighting suggestions for improvement from both the ACP document analysis and the qualitative explorations with parents and staff using the tool. There are two sections to this, firstly recommendations will consider *improvements to the form*, and secondly there will a focus on *training requirements*.

3.1 Improvements to the form

3.1.1 The formatting of the document and ease of electronic completion should be improved. There should be clearly marked differences between instructions to form fillers and those to users. Important information should stand out more.

3.1.2 The form needs to be able to be electronically locked so that there is more control over its completion and the way information is recorded.

3.1.3 In order to ensure understanding, consistency and accuracy, a second reviewer should scan the document prior to dissemination.

3.1.4 The language on the document should be simplified to facilitate full understanding for clients. A glossary of terms should be included.

3.1.5 Consideration should be given to introducing and completing the form earlier in the family's journey.

3.2 Training requirements

3.2.1 There should be continuous training within the teams using the ACP to update and 'refresh' knowledge. This should include not only formal sources, but informal mechanisms such as peer support from those with experience within the teams, feedback and reflection on cases, and use of the palliative care network.

3.2.2 Administrative staff should be included in the training.

3.2.3 In order to improve multi-disciplinary knowledge and use, and wider co-ordination of the ACP, the following is recommended:

a) Construction of a flowchart for completing the ACP that identifies joint working needs;

b) Assessment of training needs for all groups in contact with families. This should include (i) medical training, targeting community paediatricians and GPs in order to understand their needs to enable them to support teams and (ii) within student nurse placement;

c) There should specifically be more on-site training for staff using the ACP in the acute setting, particularly targeting A&E staff and junior doctors. This training should be developed to accommodate rapid changes in staff;

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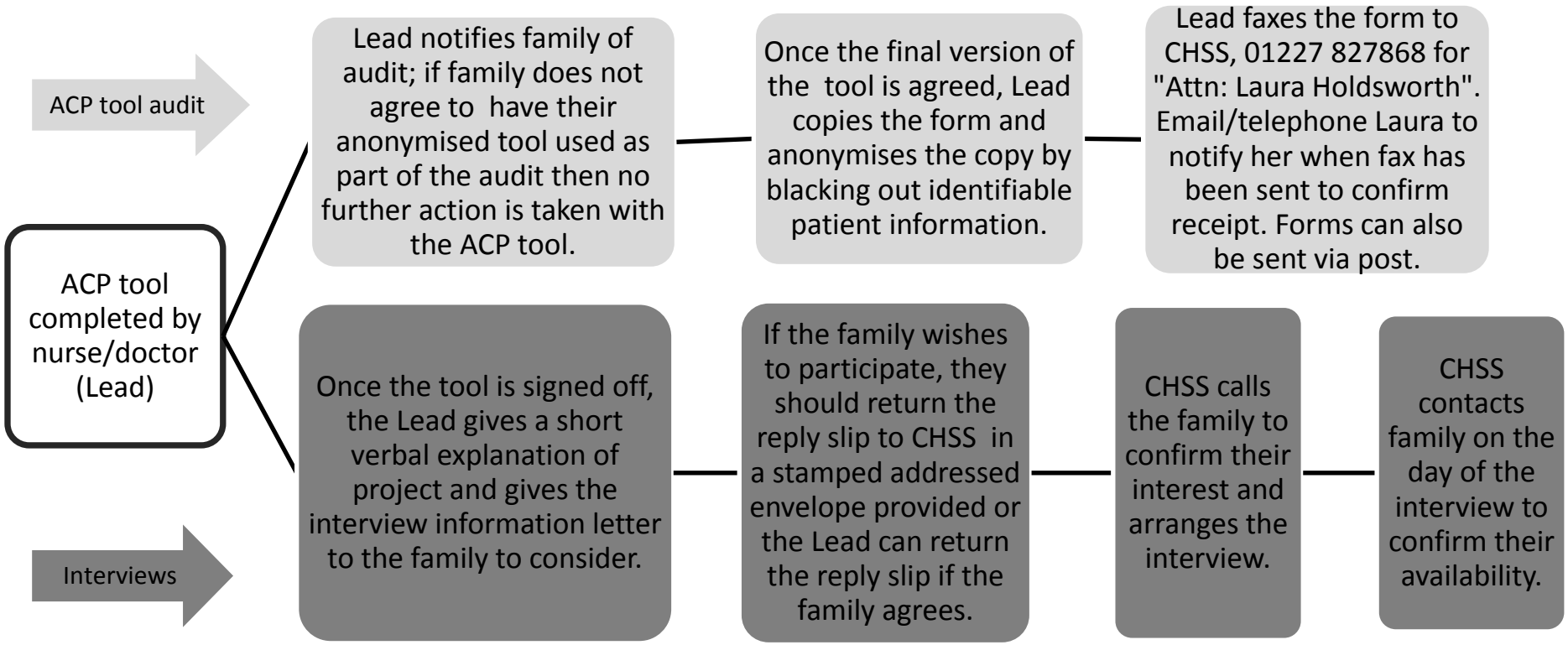
Appendix 1: What to do when an Advance Care Plan is completed (flowchart)



For all evaluation queries contact:

Laura Holdsworth (CHSS), 01227 824928, L.M.Holdsworth@kent.ac.uk /Jenny Billings (CHSS), 01227 823876, J.R.Billings@kent.ac.uk

CHSS, George Allen Wing, Cornwallis Building, University of Kent, Canterbury CT2 7NF

Appendix 2: Family Interview Schedule

Service Evaluation of an Advance Care Plan Tool

1 Contextual information

These first questions are to get a bit of background information about you and your child.

a) When were you referred to Evelina / EllenorLions chYps / East Kent Community Children's nursing team?

b) Who would you say is in charge of planning and organising your child's care? (professional)

2 Introducing the Advance Care Plan

These questions are about how the plan first came to your attention and how it was introduced to you:

a) How did you get to know about the Advance Care Plan?
(*prompts: friends/family/professionals/media/other*)

b) How did the nurse/doctor introduce the plan and the assessment process to you?
(*prompts: (i) appropriate and convenient time and location;*
(ii) manner of introduction: sensitivity of staff, nature and appropriateness of information, feelings and readiness about the doing the plan, dealing with questions;
(iii) did you see a blank copy of the form first? How useful was that
(iv) did you complete it yourself
(v) involvement of child – possible/appropriate or not

c) Could anything have been done better?

3 Completing the form

Now we come to some questions about how the form was filled out:

a) Describe to me how you and the team went about completing the form
(*prompts:*
(i) appropriate and convenient time and location;
(ii) accuracy of how information was filled in;
(iii) how far you got in completing the form – feel any pressure to complete it;
(iv) were any sections harder to complete than others – DNACPR;
(v) getting agreement about wishes – ease/difficulty of this;
(vi) paying attention to feelings and sensitivities

b) Could anything have been done better?

4 General views about the form

These last questions are about your overall views of the Advance Care Plan and its use in the future:

a) How would you describe your general feelings about the process?
(*prompts:*
(i) feelings about the outcomes – do they meet the needs?
(ii) helpful/not helpful to the child and family –why helpful/not helpful?
(iii) usefulness in the future – why useful or not useful?
(iv) use by other staff – pros and cons, how this will work for the family)

b) What were your overall thoughts about the team who completed the form with you?

c) Do you have any more suggestions for improvement?

Appendix 3: Staff Focus Group Schedule

Service Evaluation of an Advance Care Plan Tool

1 Introducing the Advance Care Plan

These first questions are about how the plan was first introduced to families:

d) How did you come to be aware of the need for an Advanced Care Plan?
(*prompts: (i) who was involved beforehand*)

e) Describe your experiences of how the plans were introduced to families
(*prompts: (i) different family reactions, reasons for differences, readiness about doing the plan, getting the timing right;*
(ii) understanding of what the plan was for, any previous knowledge, types of questions.)

f) Could anything have been done better?

2 Completing the form

Now we come to some questions about how the form was filled out:

c) Describe to me how you went about completing the form with families
(*prompts: (i) how appropriate and convenient time and location was secured;*
(ii) accuracy of information;
(iii) focus on different sections – ease or difficulty of completing them;
(iv) getting agreement about wishes – ease/difficulty of this;
(v) paying attention to feelings and sensitivities
(vi) involvement of child – possible/appropriate or not)

d) Could anything have been done better?

3 General views about the form

These questions are about your overall views of the Advance Care Plan and its uses:

d) How would you describe your general feelings about the process and the plan as a family and professional tool?
(*prompts:* *(i)* *feelings about the outcomes – do they/did they meet the needs?*
(ii) *helpful/not helpful to the child and family –why helpful/not helpful?*
(iii) *usefulness as a professional tool – eg for identifying wishes, for co-ordinating care across professional groups, why useful or not useful? Any practical difficulties?*
(iv) *use by other staff – pros and cons, how this worked for you and the family*)

e) Do you have any more comments or suggestions for improvement?

4 Training for the planning process

These questions are concerned with getting your perceptions of the training you received for using the Advance Care Plan:

a) Describe your Advance Care Plan training to me
(*prompts:* *(i)* *how accessible, convenient and timely;*
(ii) *nature of training – skills of trainer, extent of learning and knowledge gained;*
(iii) *preparation for working with families – to what extent did you feel confident in administering the tool?*)

b) Do you have any comments or suggestions for improvement?

Appendix 4: Family Information Sheet for an Interview

Service Evaluation of an Advance Care Plan Tool

We are researchers at the University of Kent and we would like to invite you to take part in a project about children's palliative care services funded by a grant from the Department of Health. The project is taking place in these three centres - Evelina Children's Hospital, EllenorLions Hospice chYps team, and the East Kent community with the community children's nurse team. Before you decide, please read the following information about the project and feel free to chat it over with family and friends if you want to.

What is the project about?

Staff who work in the above centres are starting to use an Advance Care Plan tool together with families. You are probably aware that advance care planning is a process of discussing and recording wishes and preferences for future care, including end of life care and treatment as necessary, so that anyone dealing with your child knows what the care should be. The purpose of this study is to find out from families and staff who have filled out and used the form what they think about it. This is so that any problems can be sorted out and improvements made.

Why have I been chosen?

You have been chosen because you have recently discussed advance care planning with a nurse or doctor from one of the centres taking part in this project.

Do I have to take part?

It is entirely up to you whether or not to take part. If you decide to take part but change your mind, you are free to do so and you can withdraw from the project at any time. The results of this study will probably not be of direct benefit to you, but will hopefully benefit children with complex and palliative care needs and their families in the future.

What will happen to me if I take part?

If you decide to take part, please return the attached form to the research team at the University of Kent, who are doing this project on behalf of the children's palliative care services or you can ask your key worker to return it on your behalf. We will then call you to arrange a convenient time and place to meet you for the interview, which should last about an hour. We will call again on the day of the interview to check that it is still convenient for you to meet us.

During the interview, you will first be asked to sign a consent form. With your permission, the interview will be audio recorded. You will then be asked questions about your experience of discussing your child's advance care plan and what you think about the plan in general. We particularly want to find out how we can improve the process. Some of these questions may be sensitive and difficult, but if at any time you wish to end the interview you may do so without giving any reason. If after the interview you would like additional support you can contact [NAME] who is the counsellor at [site] on [TELEPHONE].

Will my taking part in this study be kept confidential?

I would like to reassure you that any information collected about you will be strictly confidential and we will protect your identity as far as possible. It will be stored in a password protected computer and accessed only by the research team at the University. Once the project has finished, we will destroy any data collected about you and you will not be identifiable in any written report. Things you say during the interview may be directly quoted in written reports and publications, though your name and anything else that could make you identifiable will be removed.

Will the findings be published?

A report on the evaluation will be made available online via the Centre for Health Services Studies at the University of Kent website.

Who do I contact for further information?

If you have any questions please contact the researchers Jenny Billings or Laura Holdsworth at:

Centre for Health Services Studies, George Allen Wing, Cornwallis Building, University of Kent, Canterbury, CT2 7NF

Jenny Tel: 01227 823876 e-mail: J.R.Billings@kent.ac.uk

Laura Tel: 01227 824928 e-mail: L.M.Holdsworth@kent.ac.uk

Service Evaluation of an Advance Care Plan Tool

Please complete and return this form to the University researchers in the prepaid envelope provided only if you would like to be contacted for an interview.

Name:……

Telephone: ……

Address: ……

……

……

The best times and days of the week for me to be interviewed are:

……

……

……

Appendix 5: Consent Form - Families

Title of Project: Service Evaluation of an Advance Care Plan Tool

Name of Researcher: Jenny Billings

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐

3. I agree to have the interview audio recorded and understand that anonymised quotes may be used in published reports. ☐

4. I agree to take part in the above study. ☐

_____ _____ _____

Name of Person **Date** **Signature**

Appendix 6: Professional's information sheet

Dear Team

Thank you for your support with the **Service Evaluation of an Advance Care Plan Tool** project. For the evaluation, we will ask you to contribute in three ways. Please refer to the flowchart 'What to do when an Advance Care Plan is completed' as a visual aid for the first two actions.

1. **Evaluation of ACP forms**

We (researchers at the University of Kent) will be conducting an analysis of the Advance Care Plans to see how they are being completed and where improvements are needed. To do this, we need to see a copy of the Advance Care Plans after you have signed off the completed ACP tool with families for the first time (i.e. we do not need to see ACPs that have been reviewed). No consent is required to audit an anonymised copy of the tool, however, **you must verbally notify families that an anonymised copy of their form will be used for the audit**. It is best practice to monitor performance, but if families object to using the form in this way they can opt out of the audit.

For families who have agreed to the audit, please photocopy the form first, then using a black marker, cross out any patient information which might identify the family, i.e. names, addresses, NHS numbers. Please make sure that your organisation name is visible on the form. Once you have anonymised the form, send it to the research team at the University of Kent. Please send the form within 2 days of completing the Advance Care Plan. You can do this two ways:

- fax it to 01227 827868 with "Attn: Laura Holdsworth" written across the top. Please telephone or email Laura to let her know when you have sent it so that she can confirm that it has been received (01227 824928, L.M.Holdsworth@kent.ac.uk).
- send it via post to Laura Holdsworth, CHSS, George Allen Wing, Cornwallis Building, University of Kent, Canterbury, CT2 7NF.

2. **Interviews with families**

We have been notified that within approximately 1 week of when the advance care plan has been signed off, you will have follow-up contact with family either in person or on the phone. At this time, we ask that you introduce the family to the research. Please use the short summary on the bottom of this page to help guide you. After the brief introduction

please give them a Family Interview Information Pack. If conducting the follow-up over the phone, please post the pack to them. In the pack is a letter which further explains the purpose of the interviews and a prepaid addressed envelope with reply slip which should be sent to the research team if they are interested in participating. If agreed with the family, you may complete the reply slip and post it for them as this may be easier for the family. Once the research team receives the reply slip, they will then make contact with the family to arrange a time and date for the interview. The interview should take place within 4 weeks of first advance care planning session that you had with the family.

3. **Focus group with other children's palliative care specialists**

You will be invited to participate in a focus group discussion with other specialists from your organisation to discuss your views on the Advance Care Plan tool and the process of having these discussions. In a few months time you will be sent a letter inviting you to participate; it is entirely up to you whether you participate or not. The letter will include further details about the focus group.

Summary of the project for families

Staff in Kent who work with children and families like yourselves are starting to use an Advance Care Plan to record wishes and care at this stage of their lives. Researchers at the University of Kent have been asked to find out from families who have filled out and used the form what they think about it. This is so that any problems can be sorted out and improvements made. Researchers are inviting about 15 people for interview and they would like to interview you. Taking part in the research is entirely voluntary. Please read the letter in this Pack for more information on the study and how to take part.

Appendix 7: Consent Form - Staff

Title of Project: Service Evaluation of an Advance Care Plan Tool

Name of Researcher: Jenny Billings

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐

3. I agree to have the interview audio recorded and understand that anonymised quotes may be used in published reports. ☐

4. I agree to take part in the above study. ☐

_____ _____ _____

Name of Person **Date** **Signature**

Appendix 8: Advance Care Plan for a Child or Young Person (This form will be printed in lilac)

This document is a tool for discussing and communicating the wishes of a child / parent(s) or young person. It is particularly useful in an emergency, when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

Name:	**Date of Birth:**
Known as:	**Hospital Number:**
First Language:	**NHS Number:**
Home Address:	
	Postcode:
Telephone Number:	

NB: If the child or young person becomes unwell and needs an ambulance, inform ambulance control that the child has an Advance Care Plan. Ambulance Control will have an electronic copy of the ACP flagged under the child's *home address* and *postcode.* Don't forget to give ambulance control the child or young person's *current location* as well, if they are away from home.

Name of person/people with parental responsibility (and address if different from above):

……..

Emergency contact number for person with parental responsibility: ……1……

Other emergency contact numbers: ……

Other key people (e.g. family and friends) ……

Name……Relationship……Tel……

Name……Relationship……Tel……

Primary diagnosis and background summary: Reason for plan.

Advance care plan for use in:							
	Home		School		Hospital		Hospice
	Other please state:						

Date Plan Initiated……/……/…… **Date Review is due……/……/……**

Senior Clinician's name ……

Date reviewed/amended:	Name & title of lead reviewer	Next review due
2		

Advance Care Plan: Management of cardio-respiratory arrest

Name: …….. **Date of Birth: …../……./……**
NHS Number: …….

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: **choking, anaphylaxis, blocked tracheostomy tube, other** (*please state*):

RESUSCITATION STATUS

☐ Resuscitation status has not been discussed – **attempt full resuscitation**

☐ Resuscitation status has been discussed and the following has been agreed:

Clearly delete actions not required

For full resuscitation 3	OR **Attempt resuscitation with modifications below:**	OR **Do not attempt cardiopulmonary resuscitation DNACPR**
Attempt resuscitation as per standard RC(UK) guidelines	**Patient-specific modifications to standard resuscitation guidelines** AIRWAY: BREATHING: CIRCULATION: DRUGS: OTHER: PICU/HDU:	Patient-specific supportive care is documented on pages 3 and 4 In the event of sudden death 24 hour emergency number for doctor who knows the child: …….

Ambulance directive: (eg transfer to home/ward/Emergency Department /hospice)

……

Reason(s) for decision **(must be completed – legal requirement)** – see also page 6

Senior Clinician Signature ……Name……. GMC No…….....

Date Initiated ……/……/…. Contact Details 4 Review Date (see page 1) ……..

Advance Care Plan: Intercurrent illness / acute deterioration

Name: ……	**Date of Birth:** …../……./…… **NHS Number:** ……
Main Diagnoses: 5	**Known Allergies:**
Signs / Symptoms to expect	

In the event of a likely *reversible* cause for acute life-threatening deterioration such as choking, tracheostomy blockage or anaphylaxis please intervene and treat actively. Please also treat the following possible problems actively e.g. bleeding (please state): 6

If a cardiac or respiratory arrest is not specifically anticipated, decisions about resuscitation would normally be made on a 'best interests' basis at the time of such an event. Unless a separate resuscitation section has been completed, the presumption would normally be for attempted resuscitation initially unless this seemed futile, unlikely to be successful, not in best interests, or otherwise directed.

In the event of acute deterioration:

(**Clearly delete all options NOT required**. Add comments to clarify wishes):

- Support transfer to preferred place of care if possible *(specify):*……
……
- Maintain comfort and symptom management, and support child / young person and family
- Suction upper airway
- Face mask oxygen if available 7
- Bag and mask ventilation
- Emergency transfer to hospital if doctor considers appropriate in the specific situation
- Intravenous access or intraosseous access
- Consider nasogastric feeding tube *(insertion or removal)*
- Non-invasive ventilation
- Intubation
- Consider stopping feeds
- Consider stopping fluids
- Other; please state ……..
…….

Advance Care Plan: Intercurrent illness/acute deterioration
continued

Name: …… **Date of Birth: ……/……./……**
NHS Number: ……

Specific treatment plans if indicated

Management of seizures 8

Description of usual seizure pattern / types:……
……

Rescue medication: (drug name, dose and route)

First line	after……..mins
Second line	after further …. ….mins
Third line	after further …. ….mins

Call 999 for emergency transfer to hospital? ☐ Yes ☐ No 9 *(√)*
If yes, at what stage?……

Other instructions for seizures:……
……

Management of infection (*prompt, check for known allergies recorded p3*)

Preferred antibiotic or regime for recurrent infections – drug dose, route, duration: 10
……
……

Intravenous antibiotics will normally require transfer to hospital for investigation and initiation of treatment.

Other instructions/comments regarding infection-related symptoms e.g. nebulisers, steroids.
……
……

Instructions for emergency care in other specific circumstances:

(*Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).*

There is an additional symptom Care Plan YES / NO

Additional Comments: 11

Advance Care Plan: Wishes

Name: …….. **Date of Birth: …../……./……**
NHS Number: ……...

(Please continue on p7- free text for communications and discussions if insufficient space for responses)

WISHES DURING LIFE
Child's / Young Person's wishes e.g. Place of care, symptom management, people to be involved *(professional/non-professional), activities to be continued (spiritual and cultural*). 12
Family wishes e.g. Where you want to be as a family, who you would like to be involved *(e.g. medical, spiritual or cultural backgrounds*). 13
Others wishes *(e.g. school friends, siblings)* 14
WISHES AROUND THE END OF LIFE 15
Preferred place of care of child /young person
Funeral preferences Seek detailed information or further advice if needed
Spiritual and cultural wishes
Other child/ young person & family wishes, e.g. what happens to possessions?
Organ & tissue donation

This page discussed by: 16
Child /Young Person / Parent / Carer
Professional (full name and job title)

Date:…./…./……

Advance Care Plan: Decision making

Name: …….. **Date of Birth: …../……./……**
NHS Number: ……..

Basis of discussion / decision-making? *(Tick as appropriate) (√)*

☐ Wishes of child/young person with capacity

☐ Wishes of parent(s) for child on "best interests" basis

☐ Best interests basis *(as in Mental Capacity Act 2005)*

☐ Other *(please state)*……
……

Comments:……
……

Consider the following questions. For detailed responses use free text below

- What do you/the child/ young person know about this condition, any recent changes, and anticipated prognosis?
- What do siblings understand about the condition and anticipated prognosis?
- What involvement is appropriate / possible for the child/young person in decision-making?
- To what extent has the child/young person been involved in decision-making in this area?
- What does the child/young person know about what decisions have been taken?
- Have there been discussions about legal decisions and the Child Death Review process?
- Has the Ambulance Service/ GP/ Out of Hours Service /Coroner/ Child Death Overview Panel/ Rapid Response Team been informed that there is an Advance Care Plan written for this child/young person?
- Have these wishes been discussed elsewhere? In order to enhance continuity of care please attach documentation arising from any such discussions.

Communications and discussions

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Advance Care Plan

Who has agreed and supports the plan?

Name: ……

Date of Birth: …../……./……
NHS Number: ……..

Senior Clinician e.g. Paediatric Consultant – I support this care plan (*must be signed)*

Name: ……Signature……GMC No……..18..Date… /… /20…

It is not essential for all the following signatures to be obtained

Child / Young person – I have discussed and support this care plan (optional)

Name: ……Signature…… Date…/……/20…

Parent/Guardian – We / I have discussed and support this care plan

Name: ……Signature…… Date…/…/20…

Other e.g. CCN – I have discussed and support this care plan

Name: ……Signature…….. Date…/…/20…

Other e.g. GP – I have discussed and support this care plan

Name: ……Signature……GMC No……Date…/…/20…

Other e.g. Hospice doctor – I have discussed and support this care plan

Name: ……Signature……GMC No……Date…/…/ 20……

Other people informed: see circulation list

Clinicians have a duty to act in a patient's best interests at all times.
If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed Advance Care Plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person. The child/young person or parents /guardian can change their mind about any of the preferences on the care plan at any time.

Communications and discussions 19

Name: …… **Date of Birth:** …../……./……

Senior Clinician: …….. **NHS Number:** …….

A copy of this ACP is held by:	**Name and contact details**
Lead Reviewer – responsible for distributing this Advance Care Plan.	(as on page 1)
☐ Parents/guardians	
☐ General practitioner	
☐ Paediatrician (Community)	
☐ Paediatrician	
☐ Hospital (e.g. open access ward)	
☐ Hospice (please provide the name of the hospice)	
☐ Community Nurses (CCN)	
☐ CCN Specialist Nurses/School Nurse	
☐ GP Out of Hours Service	
☐ Ambulance Control/Rapid Response Team	
☐ Emergency Dept	
☐ School-Head Teacher (with consent to share with school staff)	
☐ Other e.g. Social Care, Short break care provider	
☐ Other e.g. CDOP, Police, Coroner	
☐ Evaluation Contact	
☐ Other	

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