

Use of formal advance care planning documents: a national survey of UK Paediatric Intensive Care Units

Sarah Mitchell,¹ Adrian Plunkett,¹ Jeremy Dale²

¹Paediatric Intensive Care Unit, Birmingham Children's Hospital, Birmingham, UK
²Division of Health Sciences, Warwick Medical School, Gibbet Hill Campus, University of Warwick, Coventry, UK

Correspondence to

Dr Sarah Mitchell, Paediatric Intensive Care Unit, Birmingham Children's Hospital, Steelhouse Lane, Birmingham, B4 6NH, UK; S.Mitchell6@nhs.net

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ABSTRACT

Objective Advance Care Planning (ACP) is nationally a core element of adult and paediatric palliative care strategies. It is defined as a process of discussion between an individual, their care providers and those close to them, about future care. Formal procedures and processes can help with some of the most difficult elements of communication related to ACP. The majority of children who die do so in a Paediatric Intensive Care Unit (PICU). This survey aimed to identify and compare paediatric ACP documents that are in use within UK hospitals with a PICU.

Design Email survey of lead clinicians from UK PICUs (n=28).

Results 24 (86%) questionnaires were returned. 14 (58%) responded that formal ACP documents were currently in use within their hospital trust. Of the remainder, 2 (8%) detailed plans to launch local ACP documents in the near future, 1 (4%) had a 'Children and Young Persons Deterioration Management (CAYPDM) Document' and 3 (12%) listed rapid discharge and extubation pathways. 6 (25%) provided details of the document in use. They varied widely in terms of their presentation, content and intended use with some having been developed locally and others having been adopted across regions.

Conclusions There is variation around the UK in the existence of formal ACP documents for paediatric patients with palliative care needs, as well as variation in the type of document that is used. Consideration of a national policy should be informed by further review and evaluation of these documents, as well as current practice in ACP.

INTRODUCTION

The 2008 Confidential Enquiry into Child and Maternal Health report 'Why Children Die', and Department of Health statistics suggest that the majority of children who die have complex, life-limiting conditions and that 73% to 75% of deaths occur in hospital,^{1,2} despite patient and family preferences for end-of-life care at home.³⁻⁵ Around 86% of childhood deaths in hospital occur in the Paediatric Intensive Care Unit (PICU),⁶ and the mortality rate in children following discharge from PICU is 10 times higher than the normal child population mortality.⁷ Paediatric intensive care staff inevitably become involved in the management of end-of-life care once intensive life-supporting therapies have been exhausted.⁸ The death of a child is a tragic event, beyond cultural norms. For PICU staff, there are associated complex and emotive ethical dilemmas, particularly around the delivery

What is already known

- ▶ The majority of children who die have complex life-limiting diagnoses. Most children who die do so in hospital, most frequently in the Paediatric Intensive Care Unit.
- ▶ Formal Advance Care Planning documents are being advocated to improve and standardise care for paediatric patients with life-limiting illness.

What this study adds

- ▶ This survey suggests that there currently exists wide variation in the availability and nature of formal paediatric Advance Care Planning (ACP) documents in the UK.
- ▶ The findings inform future review of paediatric ACP documents and contribute to the debate around the value of a universal framework or national standard.

of invasive intensive care interventions to patients in the terminal stage of their illness and the subsequent withdrawal of this intensive therapy, which remains the most common mode of death on PICU.⁹ This delivery of end-of-life care for children with life-limiting illness on PICU presents challenges for families and healthcare professionals and for the wider National Health Service (NHS) in terms of commissioning and resources.

Advance Care Planning (ACP) is a process of discussion between an individual, their care providers and those close to them, about their future care.¹⁰ ACP for paediatric patients is gaining increasing attention, but is a difficult and controversial area of practice. Currently in the UK, formal ACP documents are being developed, but their nature, uptake and how they are referred to vary region by region. Recently devised quality care standards in one UK region, for example, recommend that every child and young person with palliative care needs should have the opportunity to discuss and agree their future care, which should be written in a 'Personal Care Record' and communicated to all services involved in their care.¹¹ However, this is not a view shared by all, and some controversy around the use of formal documents for recording an ACP exists.

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Different priorities are being identified and addressed between regions, including the recognition and acceptability of documentation by ambulance services, the organisation of formal documents (such as whether resuscitation plan pages should be removable) and how the documents are circulated, updated and identified.

This survey aimed to determine the presence of formal paediatric ACP documents within UK hospitals with a PICU and to gain an overview of the documents that are currently available. Its purpose was to inform any future proposal of national guidance.

METHOD

Survey development

Relevant questions were generated following a review of existing literature regarding formal ACP documents in paediatrics. The survey was also informed by information gathered from local and national meetings in paediatric palliative medicine. The survey comprised four open questions (whether there were any formal ACP documents in use, the duration of their use, the nature and/or derivation of the documents and if there were no current ACP documents, whether there were any plans to develop and launch any) allowing respondents to reply succinctly or with more detailed comments.

Survey execution

PICU contact details were obtained from the 'Paediatric Intensive Care Audit Network (PICANet) list of unit contacts 2011',¹² which lists lead PICU consultants and nursing staff details in the UK. The survey was sent by email to the lead clinicians at the 28 PICUs identified from this list. Medical consultants and nursing leads were contacted, in order to maximise the chance of a response from each unit. Reminder emails were sent 1 month and 2 months later to units who had not responded.

For those units who had not responded after reminder emails, the PICU administrator was contacted to clarify lead clinician contact details, and personalised emails containing the survey were sent to these clinicians.

Results were collected and summarised using Microsoft Excel. Comments received were collected together and analysed for common or recurring themes.

RESULTS

Of the 28 UK PICUs contacted, 24 email responses (86%) were received; there were no notable common features to link the four non-responders. Eighteen responses were received from PICU consultants, and the other six responses were received from senior nursing staff, including PICU Advanced Nurse Practitioners, Matrons and Research and Audit Lead Nurses. The detail of responses was variable; however, each reply answered the question about whether or not ACP documents were in use in their PICU or whether there were plans to develop any.

Current use of formal ACP documents

In total, 14 (58%) of the 24 PICUs reported having ACP documents in use. They had been in use for varying periods of time, from 2 to 10 years.

The nature of ACP documents

All ACP documents in current use had been developed locally with input from PICU physicians, specialty paediatricians including oncologists and neurologists and children's hospice

and palliative care physicians. Care pathways produced by Together for Short Lives (previously the Association for Children's Palliative Care (ACT) and Children's Hospices UK)¹³ had been referred to in their development, with reference also made to existing documents from other regions (table 1, 1.1).

ACP documents were referred to as either 'Advance Care Plans', 'Emergency Care Plans' or 'End-of-Life Care Plans' (table 1, 1.2), with one unit having an 'Emergency Care Plan for Life-limiting or Life-threatening Illness' and an 'End-of-Life Care Plan' with distinct and different purposes (table 1, 1.3). Six responders detailed which documents were in use or sent copies of those documents for review. Three departments use the 'Child and Family Wishes' documents, a template for end-of-life care discussions with families.¹⁴ Other ACPs in use were the West Midlands Paediatric Palliative Care Network Advance Care Plan¹⁵ and the South Central Advance Care Plan.¹⁶

Documents varied widely in terms of their presentation and content. Some were single A4 sheets that were to be completed and maintained in medical records, alongside a separate 'Do Not Attempt Resuscitation (DNAR)' document. Others were detailed, colour-coded booklets with separate pages for different clinical scenarios including seizures and infection, resuscitation decisions and patient and family wishes around their care and end-of-life care, such as organ donation and funeral planning (table 2). Many of these had completely separate documents for communication with local ambulance services. The importance of recognising that the DNAR document was only part of the ACP process was highlighted (table 1, 1.4).

Table 1 The development of local Advance Care Planning (ACP) documents

1.1	'The document is derived from previous versions of the document and more recently the ACT document' 'We derived them ourselves in conjunction with the above disciplines. We note that others have since also produced similar ...' 'An emergency care plan—this was developed several years ago by paediatric intensivists, general paediatrics, paediatric oncology, community paediatrics for neurodisability and children's community nursing staff' 'Documents drawn up by the long-term ventilation team and neurology with input from our local palliative care consultant and hospice'
1.2	'Currently, the unit has a rapid discharge pathway. This document is intended to be used for children discharged from the unit to hospice/home/ referring hospital for end-of-life care' 'We have used ECPs [Emergency Care Plans] for many years ... This applies to a child wherever they are cared for, be it at home, in school or in respite/hospice. Copies are made available to parents, community nursing staff, schools, general practitioners, ambulance staff, hospice staff and so on'
1.3	'... an Emergency Care Plan for Life-Limiting or Life-Threatening Illness ... agreed by our Trust Clinical Governance Board and used by community paediatricians (eg, in severe neurodisability), by paediatric oncology and in paediatric intensive care; ... or an End-of-Life Plan, more relevant to, for example, oncology, where it is recognised there is already a dying process and where plans are made for pre-mortem and post-mortem care, for example, burial plans'
1.4	'In our hospital, paediatrics has always resisted the practice that is used with adult patients over use of Do Not Resuscitate (DNR) orders. DNR sounds to me like a last minute decision to not jump on the ill and elderly—it is not even transferrable to the out-of-hospital community. But if you are ill with a serious chronic condition or elderly and acutely ill, you need a discussion of all potential treatment options, of which cardiopulmonary resuscitation (CPR) is only one. Hence, our development of this plan' 'As an intensivist, I developed an "Agreed Limitation to Treatment" form with my colleagues and with the Trust's legal and ethics services. The objective of this form is to address only the problem of decision-making in an acute situation and not to address palliation care plans'

Table 2 Comparison of six regional formal Advance Care Planning (ACP) documents

ACP	1	2	3	4	5	6
Locations where ACP to be kept	Y	N	Y	Y	N	Y
Review dates	Y	Y	Y	Y	Y	Y
Seizure management	Y	Y	Y	N	Y	N
Management of infection	Y	Y	Y	N	Y	N
Other acute deterioration plan	Y	Y	Y	N	Y	Y
Resuscitation plan	Y	Y	Y	N	Y	Y
Preferred place of care	Y	Y	Y	N	N	N
Family wishes	Y	Y	Y	N	Y	N
End-of-life wishes (eg, funeral plans)	Y	Y	Y	N	Y	N
Organ donation	Y	Y	Y	N	Y	N
Clinician contacts	Y	Y	Y	N	N	N
Patient/parent leaflet available	Y	Y	Y	N	Y	N
Ambulance crew instructions	N	N	N	N	N	Y

Units with no formal ACP documents

Of the 10 units who do not currently have documents formally described as ACP documents, two detailed plans to launch local ACP documents in the near future (table 3, 3.1), one has a 'Children and Young Persons Deterioration Management (CAYPDM) Document' and three listed rapid discharge and extubation pathways that are currently in use. These were not considered to be formal ACP documents in their entirety since other ACP documents encompassed what was included in CAYPDM document or existed alongside a rapid discharge pathway.

Reasons for not having formal documents included the complexity of individual patient and family situations, such that it was felt impossible to develop documents and guidance that are all inclusive (table 3, 3.2). PICUs without formal documents tended still to develop care plans, which were documented within the patient's hospital notes (table 3, 3.3). It was recognised that ACP is an important area of practice (table 3, 3.4).

DISCUSSION

This survey suggests that there currently exists wide variation in the content and availability of local paediatric ACP guidance and formal documents in the UK, with a lack of national standard or agreed universal framework. Work in this area is being

carried out simultaneously in different regions of the UK. These variations may be explained by the emerging nature of paediatric palliative care as a speciality and the need for care planning; and local and personal preferences regarding how these documents are designed and used. The majority of formal paediatric ACP documents that are available have been developed locally, usually with relevant local clinicians including paediatric intensivists, specialty paediatricians and palliative care physicians.

One of the strengths of this survey is the high response rate of 86%. A targeted approach to lead PICU clinicians enables confidence that the results provided around current practice in ACP accurately reflect the UK situation in terms of where formal documents are available for use in hospitals with a PICU. A wide variety of responses were provided regarding the duration of use and derivation of the documents, which is likely to reflect the emerging nature of formal ACP document use within individual departments. Common themes were identified among responses; however, the sample size limited the achievement of data saturation. Further qualitative investigation of the experiences and perceptions of PICU staff around ACP for patients with palliative care needs would allow this and the further investigation of where else formal ACP documents are available would also be of value, particularly in community settings.

Furthermore, this survey does not provide information regarding individual uptake of formal ACP documents for paediatric patients with palliative care needs, nor does it provide information regarding attitudes of healthcare professionals towards these documents. Those units who did not have formal ACP documents in use provided responses with possible reasons for this, including the difficulty in using a standardised document for all patients. Previous research suggests that professional attitudes towards the use of formal ACP documents to facilitate the process are varied and that doctors, more than any other healthcare professionals, have reservations about the applicability and validity of ACP documents.¹⁷ The benefits and perceived risks of their use for patients, families and healthcare professionals must be weighed up carefully. These are all important areas for future research.

There remains controversy and some misunderstanding around the differences between any kind of 'Advance Care Plans' and a 'DNAR' decision document, among healthcare professionals and society as a whole. ACP is a dynamic, multidisciplinary process, which can take place over time, introducing difficult concepts such as resuscitation decisions gradually, an approach which can help to avoid last minute decisions around resuscitation status in an acute situation.

The results of this survey suggest that work in this area of practice is being duplicated between regions. While there may be benefits in having regional, locally relevant policies and documents, the potential benefits of the adoption of formal ACP documents and policies should be considered nationally. Some comparison can be made here with adult palliative care and ACP, where national strategies, such as the Gold Standards Framework for community palliative care, are in existence.¹⁸ Formal evaluation of ACP strategies in adults is still emerging¹⁹ with an ongoing need for promotion of ACP as a concept and guidelines to support its implementation among healthcare professionals. In addition, the increasing numbers of young people with complex life-limiting conditions making the transition to adult palliative care services present a new challenge for the providers and commissioners of adult palliative care. The use of universal and easily identifiable ACP documents to support the care of this new and under-represented palliative care population should be considered.

Table 3 Comments from Paediatric Intensive Care Units (PICUs) without formal Advance Care Planning (ACP) documents

3.1	'We are currently looking at links between PICU and our local hospice, with reference to the ACT document' 'An ACP document which is currently being used by a hospice near here is in the process of being adapted for use in this hospital'
3.2	'We have no plans to develop them. It is not that it is unimportant, but that you have to develop such a bespoke plan for each patient that documentation and guidance would have to be so wide that it would be useless'
3.3	'The advanced care decision in this PICU is written in the medical chart, usually after minutes of a Multidisciplinary Team meeting' 'We ... do not use formal documentation for this. We have close links with the local hospice—the lead clinician attends ward rounds once a week—and a number of children now have advance care plans; we are not using any specific documentation'
3.4	'This is something we should be doing and so I would be interested to see the results of your research'

CONCLUSION

The findings of this survey provide an overview of the availability and content of formal ACP documents in UK hospitals with a PICU. Around the UK, formal ACP documents are being advocated to improve and standardise care for paediatric patients with life-limiting illness and their families. The motivations for ACP for children with life-limiting illness are numerous and include recognition that intensive therapy and invasive interventions may be inappropriate when death is near or inevitable. Guidelines, strategies and policies for ACP are being produced faster than the evidence base to support them, which may present a barrier to uptake of formal ACP documents by clinicians and warrants further research.

ACP should enable choice for patients and their families at this unique and devastating time. Valuable work in this area is being carried out simultaneously in different regions of the UK. The potential value of a national standard and the form that this should take should be debated at a national level. The publication of agreed national guidance would lead to raised awareness, sharing of knowledge and increased acceptability and use of ACP documents and would allow for international dissemination. The evaluation of ACP documentation and the development of an enhanced evidence base around their use is essential, working towards the overall aim of all children with life-limiting illness and their families having access to personalised care that is of optimum quality.

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