

# The Service Improvement Network Project (SINP)

A facilitated programme to support the development of the  
ACT\* integrated children's palliative care pathway

## FINAL REPORT



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## Introduction

This is the Final Report of the Service Improvement Network Project; a facilitated service improvement programme to support the development, and integration into practice, of a multi-agency care pathway for children with life-threatening and life-limiting conditions (Association for Children's Palliative Care, 2004<sup>1</sup>).

## Background

The Children's Palliative Care Partnership Group (hence referred to as The Partnership Group) was formed in 2003 and covers the 'old Avon' geographical area which now includes Bath & North East Somerset, Bristol, North Somerset, and South Gloucestershire. It comprises Commissioners of children's palliative care services across the PCTs and Senior Managers of both statutory and voluntary sector services.

When the period of national lottery funding of local palliative care services came to an end, in December 2006, the group took on a new role to plan and develop services for families of children with palliative care needs. At this time it also expanded its membership to include representatives from 'acute' child health services, community children's services, Children's Hospices South West and the Association for Children's Palliative Care (ACT).

As part of its remit to develop services, The Partnership Group commissioned a project to improve the delivery of children's palliative care across community and hospital settings and between different agencies in the 'old Avon' area. The ACT pathway was chosen a) for its value as a 'benchmark' against which services could be measured and b) to provide a structure, based on its five key standards, to the project work.

## The ACT palliative care pathway

The pathway identifies 5 key standards against which services can be measured and assessed.

The 5 key standards are

- i. Breaking the News
- ii. Planning for going home
- iii. Multi-agency Assessment

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<sup>1</sup> ACT (2004) A framework for the development of integrated multi-agency care pathways for children with life-threatening and life-limiting conditions. Available at <http://www.act.org.uk>

- iv. Multi-agency Care Plan
- v. End of Life Plan

The ACT pathway standards provide consistency and allows comparisons to be drawn between local palliative care services and those in other parts of the UK.

## Approach

The project approach was based on the RAID improvement model, recommended by the Care Services Improvement Partnership, by which staff are actively involved in:

**Reviewing** current shortfalls,  
**Agreeing** goals,  
**Implementing** changes in working practices, and  
**Demonstrating** their effects.

The success of this approach depends on the involvement of staff and their willingness and ability to engage with the process. This was promoted by ongoing facilitation of the project groups to offer direct support and encouragement to see the process through each of these stages. The approach also built sustainability into the project process by actively coaching staff to learn change management and facilitation skills as they themselves took part in the project groups.

## Aims

- **Improvement** in at least 3 aspects of children's palliative care service delivery where gaps have been identified by parents
- **Raised awareness** of the 5 key ACT standards and the underpinning care pathway among those involved in delivering children's palliative care services
- **Improved joint working** between agencies in implementing the ACT care pathway

## The Project Process

### *Steering group*

A steering group was convened to oversee the project process and to offer guidance and support to the project facilitator. Members represented a range of different services and provided a range of perspectives. (Appendix 1. Steering Group members)

### **Launch event**

In September 2007 a launch event was held in Bristol Council House to introduce the project to providers of children's palliative care services and invite them to become directly involved in a project group.



*Bristol Council House, venue of the SINP project launch, October 2007.*

Over 50 people, representing health, social care and education services and voluntary sector organisations, attended for an afternoon of presentations and guided group discussions. Participants were asked to describe current service provision ( see Appendix 2; launch mapping exercise) and to recommend priorities for improvement. Opportunities for exchanging ideas and networking between service providers were maximised by arranging groups with a mix of locations and specialties. The afternoon concluded by asking the participants to sign up to work in one of five project groups, each focusing on one of the key standards of the ACT palliative care pathway.

During the launch event a picture postcard was given to each participant upon which they were invited to write one aspect of children's palliative care that they intended to work on over the coming weeks. These self-addressed postcards were collected in and kept in a safe place for 6 months. They were then posted out – their arrival acting as a reminder to the participants of the aim they identified and wrote down during the launch of the Service Improvement Network Project. Anecdotal feedback confirmed that this purpose was met.

After the launch event, project groups for each key standard were identified from the sign-up sheets. The most popular group, as indicated by the number of people who had signed the sheet, was that looking at 'End of Life' plans. Over-subscription to this group meant that some people were asked to join another group. Few people signed up to work on the fourth key standard, care planning, so it was decided to merge this with the third standard, multi-agency assessment. The groups formed were:

**Group 1: Breaking News**

**Group 2: Planning for going home**

**Group 3/4: Multi-agency Assessment and Care Planning**

## Group 5: End of Life Planning

Potential group members were contacted by email and arrangements made to start a rolling programme of project meetings. These are described further in the section on Project Groups.

### ***Audit of parents' assessment of services***

Soon after the launch, an audit of parent's views was carried out to establish a baseline level of how parents perceived services were being delivered across the five key standard areas.

The ACT Integrated Palliative Care Pathways Standards: Parents' Service Assessment Tool was adapted and used to gather the views of parents within the project area (available at [www.act.org.uk](http://www.act.org.uk).)

Parents of children receiving inpatient and/or community based palliative care services from both voluntary sector organisations and statutory agencies were invited, by letter, to participate in the audit. Twenty five completed questionnaires were returned and the results were entered onto Excel spreadsheets to assist analysis (the raw data are presented in Appendix 3).

The assessment tool asked parents to indicate 'yes', 'no', 'not applicable' or 'don't know' to 64 questions relating to each of the ACT pathway key standards. There were questions about the circumstances of breaking news to the family, how discharge home was arranged, how the child's needs were assessed, the plan of care delivered and, finally, about plans for the end of life. Parents answered 'yes' to almost half the questions (46%), and 'no' to just over a fifth of the questions (22%). The responses 'not applicable' and 'don't know' accounted for the remaining 18% and 14% respectively (see Chart 1.).

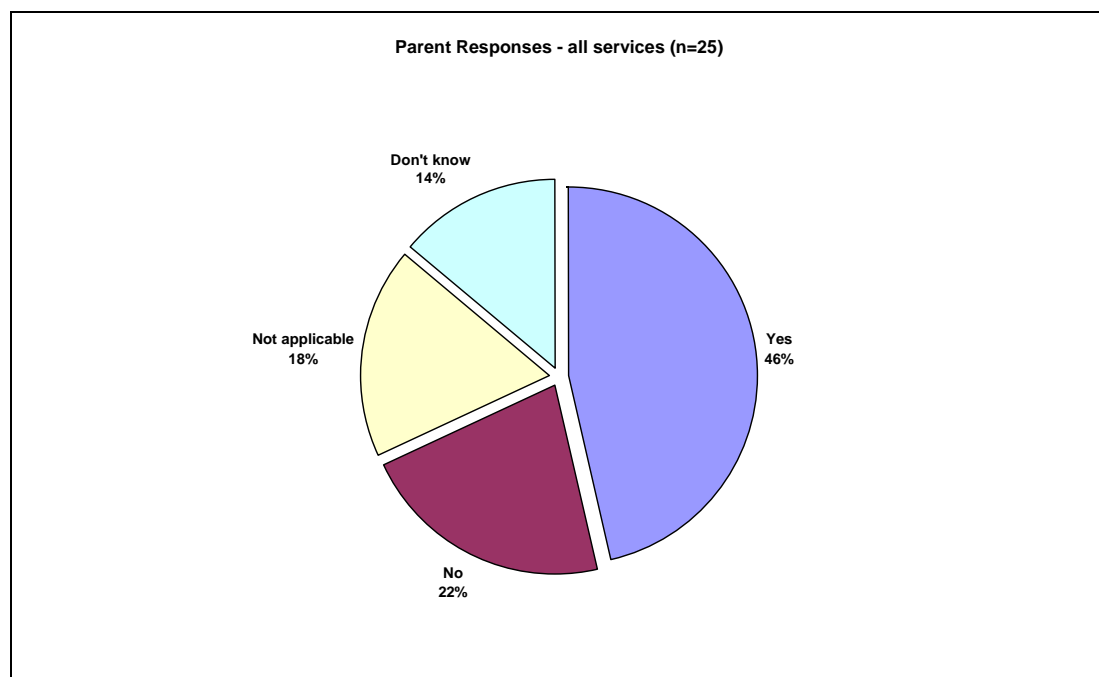


Chart 1: Collated responses to achievement of all key standard questions.

When the responses to the questions relating to each key standard were grouped, the results depicted in Chart 2 were revealed.

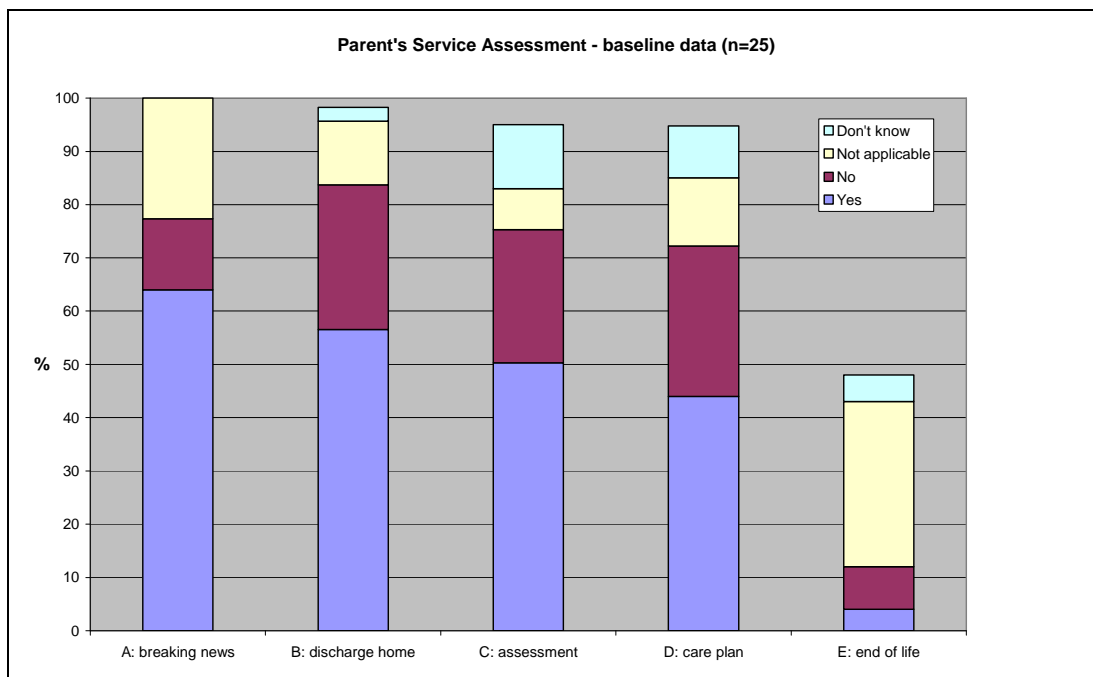


Chart 2: Summary of parents' responses to performance of five key standard areas.

This chart shows that the proportion of 'yes' answers (indicated by the blue shaded area) was different for each of the key standards and that the percentage decreased sequentially with each standard, falling from a high of over 60% for 'Breaking News' to fewer than 10% for 'End of Life' planning. The proportion of 'no' answers was lower for the first and last standards and higher for 'discharge home', 'assessment' and 'care planning' which were all within two percentage points (see table 1).

Key Standard question area	%Yes	%No	%Not applicable	%Don't know
A: breaking news	64.00	13.33	22.67	36.00
B: discharge home	56.57	27.14	12.00	2.57
C: assessment	50.33	25.00	7.67	12.00
D: care plan	44.00	28.25	12.75	9.75
E: end of life	4.00	8.00	31.00	5.00

Table 1: responses to key standard questions expressed as percentages

The 'don't know' responses, particularly relating the assessment standard, may indicate that the questions in the section sought information that was not always available to parents.

The 'not applicable' responses suggest that although all the respondents were parents of children who were receiving palliative care services they did not feel that the questions were relevant to them. This was of particular note in



relation to the 'end of life' questions which are those to which most parents gave the 'not applicable' answer.

The results presented here are those collated from all the responses received. During the project, separate analyses were conducted on the responses from parents of each service involved in the audit. Individual reports, based on their own data, were compiled for each service to provide feedback for their staff and service users.

The parents' audit results, together with the results of the mapping exercises undertaken at the launch event, meant that the project groups were furnished with a range of local and recent information about the level of achievement of each key standard that would prove useful in helping the project groups to decide where should focus their attention.

## **Project groups**

### ***a) The overall process***

The majority of project group meetings were held at the university research centre where the project facilitator was based. This enabled staff from a range of posts within different services and agencies to meet on 'neutral' ground and to be able to distance themselves physically from their day-to-day work environments. Where staff were not able to meet at the university, due to clinical or other work commitments, alternative arrangements were made with either face-to-face meetings being convened at a different venue or virtual meetings being held by conference call.

Over the course of the project each group met eight or nine times with a total of x sessions being held. Notes and action points of the sessions were written and circulated and contact with group members between sessions was maintained my email and telephone. Contact was also maintained by the compilation of a newsletter during December 2007 which was circulated to all group members and launch attendees (see Appendix 3) . Attendance at the group meetings was variable during the course of the project reflecting changes in membership of the groups as they became established and fluctuating levels of involvement at different stages of the RAID process.

At the first meeting of each project group the information that had been gathered at the launch event together with the evidence from the parents service assessment audit was discussed and from this decisions were taken about the scope and nature of the intended project work.

### ***b) Detail of each groups' work***

This section describes the project work undertaken by each group.

### **Project Group 1: Breaking News**

Using the feedback from the launch event (Box 1) and the parents' audit (Appendix 4) the Breaking News project group chose to focus on how news relating to scan results was given to parents.

#### **Standard 1: Breaking news**

"Every family should receive the disclosure of their child's prognosis or other significant information in a face-to-face discussion in privacy & should be treated with respect, honesty & sensitivity. Information should be provided both for the child & family in language that they can understand."

#### *Comments on standard:*

- Not always the case that child and family told together – maybe family told first to enable them to acquire skills/time to share information with their child in a more planned way
- Family may tell child – professional may tell child/GP without family present
- What about the "looked after child" and legal guardian status?
- This standard is about the whole process of disclosure – from diagnosis and beyond and is a continuum
- Documentation vital to this continuum when whole team involved

#### *Gaps in standard:*

Examples of good practice and advice

e.g. turn off phone/bleep

assemble right people etc

tea after ½ hour when time to reflect

time later to re-iterate important information

- Do not assume all breaking of bad news always happens in an acute situation
- Collusion – professionals with parents or child, maybe denial by one or more family members i.e. responsibility for knowledge resting with the young person

Box 1. 'Breaking news' gaps & recommendations from the launch event group work

The project group had two work streams and involved nursing and medical staff from two acute and one community based service.

#### Workstream A:

Children's Neurology Department at Frenchay Hospital.

This group wanted to improve how news relating to neurological scans was broken to parents. This was currently done at the nurses station on the ward as this is where scan results could be viewed on a computer monitor. The staff wanted to change practice so that news was broken in a more appropriate and private space where parents could be supported as the results and their implications were discussed.

The staff designed an audit form to gather a range of quantitative and qualitative data about their current practice to use as a baseline against which to measure the effect of changes they implemented.

The changes they made were; to create a designated room in which breaking news could take place; to have computer equipment on which scans could be viewed installed in the room, and to reinforce best practice by encouraging medical staff to plan breaking news discussions to enable nursing and other appropriate staff to be present.

A post audit was then performed which demonstrated that local practice had improved in that the designated room and computer equipment therein was now being used routinely and medical staff were requesting a nurse to be present during breaking news discussions.

#### Workstream B:

Royal Hospitals Bath CLIC staff and Consultant Oncology staff at Bristol Children's Hospital.

This group recognised that breaking news was not a 'one off' event but an ongoing activity for their patients, many of whom had been in their care for a number of years. They described how check up scans and blood tests, although being a routine part of the treatment process, were nonetheless stressful events for these families - reminding them of their initial diagnoses and raising the possibility of recurrent disease. They were also aware that parents themselves often informed staff of the dates and times of their scan appointments.

Conscious of these shortfalls, the staff in this group wanted to make the process for planning, reviewing and passing on results of scans to parents as smooth and predictable as possible. They did this by reviewing the current process for scan review and making sure each member of staff knew what part they played in this. A gap was identified in the passing of information about the outcome of scan reviews to shared care centres.

A Coordinator was appointed whose role included providing liaison between the hospital and shared care centres. What this meant in practice was that the coordinator shared notes from the meetings at which individual patients scans were discussed directly with shared care staff, enabling them to contact families at a planned time.

The gap in information about booking scans was filled by liaising with the staff member who arranged the scans and asking them to inform staff of dates and times so they might then pass this on to parents. This improved

communication process also gave staff the opportunity to negotiate with families how they would prefer results to be given – some choosing by telephone, others during a face to face meeting.

## ***Project Group 2: Planning for going home***

Again, using feedback from the project launch (Box 2) and the parents audit (Appendix 4), this multi-disciplinary group chose to focus on two aspects of planning for going home, a) communication about admission to hospital, and b) multi-disciplinary discharge planning meetings.

### **Standard 2: Discharge home**

“Every child & family diagnosed in the hospital setting, should have an agreed transfer plan involving the hospital, community services & the family, and should be provided with the resources they require before leaving hospital.”

#### *Recommendations for service improvement:*

1. Develop a new model for multi-agency transition from hospital – community care which:

> plan for discharge from admission

shared paperwork develop key roles hospital outreach/community in reach to facilitate this

use equipment (e.g. telemedicine)

different than traditional ‘discharge meetings’

includes a 24 hour contact agreement

has lead Dr/keyworker

2. Develop parent/family held assessment/planning/review documents (shared across agencies) that start here and are added to along the Pathway

Box 2. ‘Discharge planning’ gaps & recommendations from the launch event group work

### Workstream A:

Recognising that the most effective planning for going home starts as soon as possible after admission to hospital, the group were keen to explore the potential for computer based system to improve communication between staff across the hospital/community boundary. A staff member of the information technology department of the local hospital trust advised the group that a Clinical Alert System - which automatically generates an email which is sent to nominated care providers when a child is admitted to hospital – might facilitate this. The system would hold ‘lists’, provided by service providers outside the Trust, of patients on their caseload about whom an email would be sent out when that patient was admitted. This automatic message would mean that external services would not rely on hospital staff, or parents, to inform them of admissions.

Setting up the lists involved overcoming many hurdles. Clinical Governance requirement had to be satisfied, with written permission being sought from parents to have their child included on a list. Managerial responsibility for keeping the list up to date and acting on the email alerts had to be decided within the services. Access to the NHS computer email system (NHS.net) for voluntary sector agencies had to be negotiated and a staff member with access to the system identified. Despite these hurdles, the system has been warmly welcomed as a way of improving communication between the many different staff involved in the care of children with palliative care needs.

#### Workstream B:

the second workstream focused on multi-disciplinary discharge planning meetings, a crucial bridge between hospital and community services when planning discharge for children with palliative care needs, and the role of the Clinical Nurse Specialist (CNS) in these. CNSs were chosen as they, more than any other staff group, were thought to be likely to be involved in multi-disciplinary discharge planning meetings and would be in a position to give a comprehensive and multi-specialty view of current practice. A questionnaire designed to investigate the scope of current practice was devised by the group and approved for use by the hospital questionnaire committee.

Results from the questionnaire (Appendix 7) revealed wide diversity in practice, with most challenges being faced by specialists caring for children with a range of complex palliative care needs. Respondents usefully identified factors that facilitated multi-disciplinary meetings. These were:

- effective communication/open discussion
- appropriate staff present and good chairing
- taking the lead/initiative then maintaining momentum
- good planning/organisation – including space to hold the meetings.

And those that hindered multi-disciplinary meetings. These were:

- availability / getting everyone together
- identifying who is responsible
- process takes a long time

A notable finding was the lack of use, reported by these staff, of either the hospital Trust discharge policy or the ACT palliative care pathway. Reasons given for this included a lack of awareness, particularly of the ACT pathway, and a perception that the existing Trust discharge policy documents were not relevant to child patients. This perception may change as a Trust-wide discharge policy specifically for children is developed, a process which ran in parallel to the SINP group work with some members being active in both groups.

## **Project Group 3/4: Multi-agency Assessment and Care Planning**

Members of this group were presented with two sets of information from the project launch ( Box 3 & Box 4) and parents audit (Appendix 4) from which to select the focus of their work.

### **Standard 3: Assessment**

"Every family should receive a multi-agency assessment of their needs ASAP after diagnosis or recognition, and should have their needs reviewed at appropriate intervals."

#### *Gaps in standards:*

1. Education Assessment & Psychology
2. Embed in early years/extended schools assessment (vision + gap)
3. Agreement about 'multi-agency assessment'
4. Individual agency assessments – not joined up especially in acute hospital
5. Acute care 'deaths' – no opportunity for multi-agency assessment (except where Lifetime/Jessie May Trust in community – then multi-agency)
6. No single framework being used meeting process

#### *Recommendations for improvement*

1. Define multi-agency assessment:  
who involved, who leads this contact details  
timescales for assessment (urgent, medium, other)  
frequency of review documented at first assessment
2. Develop a shared template to cover all the elements of standard 3 – shared document (based on CAF but locally 'owned')

Box 3. 'Assessment' gaps & recommendations from the launch event group work

### **Standard 4: Care Plan**

"Every child & family should have a multi-agency care plan agree with them for the delivery of co-ordinated care & support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family."

- Need examples of multi-disciplinary Care Plans to identify good/best practice to take forward in this area
- Process care planning must involve carers/parents and if appropriate children
- Keyworking is a specific role which needs skills and resources including financial resources
- All children referred through CYPS should have multi-agency plans & services which are reviewed every 6months.

*Gaps:*

- Multi-agency – Care Plans
- Should we have one comprehensive Care Plan?
- When? Always necessary?
- Parents as keyworkers
- Care assessment – information shared
- Executive summary of Care Plan. Headlines – review dates etc.

*How to improve keyworkers role:*

- Common understanding needed
- Keyworkers vs. lead professional
- Multi-agency planning meeting

Box 4. 'Care plan' gaps & recommendations from the launch event group work

Again, two main workstreams emerged, the first to build on an existing scheme to promote parents self-assessment of their child's needs, the second to explore the keyworker role in planning care.

Workstream A:

During early discussion about current practice and members of this group presented examples of existing good practice from their services. One example was an assessment tool, developed by a voluntary sector children's palliative care service, in response to the need for a transparent system of allocating care. The 'FRIPP'<sup>2</sup> document provides a framework which parents use to assess their own child's needs. The framework allows this qualitative assessment to be translated into a quantifiable score. The score is used as a measure for which hours of support are allocated. A benefit of the assessment framework and that the hours of support related to particular scores can be tailored to accommodate fluctuations in the resources available to the service, whilst retaining the relative intrinsic fairness of the hours allocated to each family.

The FRIPP document was recognised by the group as fulfilling the key standards for assessment, as described by the ACT pathway, in terms of user involvement and empowerment. It had also been found to be popular with both staff and families of the who had used the document since it's introduction in 2003. Group members representing the service were aware that the FRIPP had the potential to be a useful resource for other home palliative care services in the UK, indeed some had already expressed

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<sup>2</sup> FRIPP - The Framework For Respite In Partnership with Parents and Carers, further information available from [www.jessiemytrust.org.uk](http://www.jessiemytrust.org.uk)

interest in using it. However, the service was conscious that the document had not been formally evaluated and recognised that this was an important step in establishing its' value. Through encouragement by the group, an application for funding to evaluate the FRIPP document was submitted. This was granted and an evaluation project is about to commence. This will provide evidence about the perceived value of the document and allow the service to promote its use across other areas of the UK.

#### Workstream B:

Early discussions amongst this multi-agency group revealed a range of views about the meaning of the term 'keyworker' and, related to this, the scope of their role. It was also noted that in the parents service assessment results (Appendix 4) over half the respondents had indicated they didn't have a keyworker, even though these families were receiving palliative care services. It was felt that this might indicate a lack of clarity about the term keyworker, even though the coordination and liaison functions associated with such posts were being fulfilled.

The group decided to explore professionals own views about the meaning of the term keyworker and compare this with their understanding of other title used to describe related roles. A brief questionnaire was designed, using the 'gold standard' of keyworker role descriptions offered by Every Child Matters national framework ([www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)). This was piloted with School Nurses and Health Visitors. Responses were reviewed and a revised questionnaire devised and distributed to community nurses, social workers and bereavement support staff. A report presenting the findings appears in Appendix 8.

One notable finding is that five respondents indicated that the term 'coordinator' best represented their role, whereas only two chose 'keyworker' or 'lead professional'. The survey also revealed diversity in usage and understanding of the terms keyworker and lead professional, even within this small sample. The survey has provided local evidence of the need for clarity roles and functions relating to the coordination of care for children with palliative care needs.

### ***Project Group 5: End of Life Planning***

#### **Standard 5: End of Life**

"Every child & family should be helped to decide on an end of life plan and should be provided with care & support to achieve this as closely as possible."

Gaps in Standard:

- Early introduction of end of life planning discussions with families.
- *Suggestion*
- develop guidance for end of life planning that follows on from continuing care planning



- Staff support
- *Suggestion*
- Stock-take / mapping support resources, develop education/shared practice and structured debriefs

Box 5. 'End of life plan' gaps & recommendations from the launch event group work

This was the largest group in terms of numbers of members, with active representation from 12 medical, nursing and allied health care professionals working in a range of settings providing palliative care for children, including hospital, hospice and home. The group met eight times over a 12 month period during which documentation for an End of Life Plan was developed.

The process began by reviewing existing documents used to support end of life planning and critically assessing what aspects of them were valuable and should be retained. To this core of information, further pages were added to provide guidance for professionals working in a different services. The most notable additions were pages to record plans for when a child becomes more unwell or experiences an acute life-threatening event. The document was continually refined through a process of facilitated discussion and debate.

The document was piloted by staff in a range of settings (Appendices 7 & 8) and amendments made in response to feedback received. Advice was sought from experts in the legal aspects of end of life documentation and approval sought for the resulting document to be available on the hospital trust intranet for staff to access and use. This permission was granted in October 2008. It has also now been adopted by the Association for Children's Palliative Care and is available to download from their website, <http://www.act.org.uk/index.php/act/south-west-england.html>

The document is reproduced in full in Appendix 9 of this report.

## Outcomes summary

### *a) Outcomes of the project groups:*

<b>Group 1</b>	Demonstrable improvement in breaking news relating to scan results in a range of clinical settings and declared intention to formally review spring 2009.
<b>Group 2</b>	Establishment of email alert system triggered by admission to hospital of children nominated by services involved in care of nominated. An understanding of current practice in multi-disciplinary discharge planning meetings from the view of clinical nurse specialists to use as a baseline for development.

<b>Group 3/4</b>	An understanding of the current understanding of what the terms keyworker and lead professional mean to staff in a range of different services. Funding identified to support a formal evaluation of a needs assessment framework used by families.
<b>Group 5</b>	Audits of current end of life planning practice in a range of settings. Production and introduction to practice of a document to support health care professionals in discussing plans for the end of life.

### ***b) Outcomes of overall project process:***

In addition to the specific outcomes listed above, the overall project generated a number of outcomes which were related to the process and the way it was implemented. The **RAID** (Review, agree, implement and demonstrate) **process** was useful in that it offered a sequence of stages to work through so groups could monitor their progress. The process also promoted the identification of shared challenges and seeking of mutually useful solutions.

Having a **facilitator** with dedicated time to manage the groups was found valuable in helping to maintain momentum, to steer members towards consensus and to keep activity focused. The facilitator drew on a combined clinical and research background to understand the contexts from which the project work was derived and the perspectives represented by group members from a diverse range of professional groups.

Making contact with others involved in the care of children with palliative care needs and their families was one of the most beneficial aspects of the project process. This **networking** produced opportunities for sharing of knowledge, insights and perspectives and also produced tangible collaborative links between group members. Examples of this include a declared intention to set up a joint ward round between hospital and hospice based medical staff and the establishment of the email clinical alert system by services outside the hospital.

**Skills** were also developed by group members through the various stages of the project work. These included the interpretation of data such as that generated by the parent's service assessment, the design of questionnaires and the presentation of project results. An opportunity to share findings with a wide audience of those involved in delivering children's palliative care was presented by the 'Aiming Higher' Conference held in Bristol in October 2008.

The value of having a national organisation, in the case ACT, to both inform the project and allow wide **dissemination of** findings to those working in similar settings in other parts of the UK, cannot be emphasised strongly enough.

This is especially the case for locally based projects such as this for whom sharing process and outcome experience is challenging.

## **Recommendations**

This report has described a number of valuable steps that have been made towards improving the implementation of the ACT palliative care pathway in the 'Avon' area. However, those involved in delivering services for children with palliative care needs will know that the task of improving them is never complete. Our recommendations reflect the view that service improvement projects share some features of a relay race; in which the baton is carried by a team who share in its delivery to those following. The messages, delivered on the momentum generated from this project, leads us make the following recommendations to The Children's Palliative Care Partnership Group.

1. Project groups are contacted in 6 months time to provide a snapshot of how the work has developed.
2. The ACT parents' service assessment audit should be repeated by participating services with further annual audits recommended.
3. End of Life planning should be re-audited by September 2009 to inform the review of the Child & Family wishes document.
4. The FRIPP evaluation should be disseminated via ACT and local networks to extend use of this family self assessment tool.
5. Further multidisciplinary service improvement work should build on the positive experience of adopting the RAID approach and having an identified facilitator to carry the project along.
6. Publication through professional journals should be supported and encouraged as a means of sharing good practice.

## ***Acknowledgements***

I should like to acknowledge the support of The Children's Palliative Care Partnership Group whose allocation of funds from the BIG lottery grant made this project possible. Thanks also to the members of the Steering Group for their helpful guidance and advice at all stages of the project process.

The project benefited from generous practical help from administrative staff in many of the services involved in the project, in particular the distribution of questionnaires to parents of the Lifetime Service and the Jessie May Trust. Finally, a particular thank you is due to all the project group members who found time in their busy days to come to the group meetings and bring their

knowledge and enthusiasm to the task in hand. It has been a pleasure working with you.

*Antonia Beringer*  
*December 2008*

## **Appendices**

1. Steering Group members
2. Launch event mapping exercise
3. Newsletter
4. ACT parents' assessment tool
5. Steering Group Meeting notes (example)
6. Multi-disciplinary discharge planning meetings questionnaire
7. Keyworking questionnaire and report
8. End of life planning audits; a) Community Paediatrics, b) PICU
9. Child & Family Wishes for End of life

## **Appendix 1: Steering Group members**

*(Alphabetical order)*

<b>Antonia Beringer (Project facilitator)</b>	Research Fellow, University of the West of England, Bristol  antonia.beringer@uwe.ac.uk
<b>Sue Dolby</b>	Consultant Clinical Psychologist, University Hospitals Bristol NHS Trust.  sue.dolby@UHBristol.nhs.uk
<b>Nicky Harris</b>	Medical Director, Children's Hospice South West.  nicky.harris@chsw.org.uk
<b>Jonathan Hughes</b>	Resources Manager, Disabled Children, Bristol City Council  jonathan.hughes@bristol.gov.uk
<b>Mary Lewis</b>	Executive Lead Nurse and Assistant Director of Clinical Effectiveness, Bath & NE Somerset PCT  mary.lewis@banes-pct.nhs.uk
<b>Katrina McNamara- Goodger</b>	Head of Policy & Practice, Association for Children's Palliative Care.  katrina@act.org.uk
<b>Chris Roys (Chair)</b>	Chief Executive, The Jessie May Trust.  chris.roys@jessiemaytrust.org.uk

## Appendix 2: ACT Pathway Standards



### ACT PATHWAY STANDARDS: Launch event group work

#### MAPPING

##### **Standard 1: Breaking news**

Every family should receive the disclosure of their child's prognosis or other significant information in a face-to-face discussion in privacy & should be treated with respect, honesty & sensitivity. Information should be provided both for the child & family in language that they can understand.

##### **Bath and North East Somerset**

- Training breaking bad news courses
- Limited availability for alternative forms e.g. audio, pictorial, other languages
- Generally children spoken to - often following private conversation with parents
- Lots of written information available – child appropriate is available
- Staged approach to what is going to happen next
- Depends on diagnosis 'how' it is delivered
- Depends on circumstances of interaction e.g. if results arrive unexpectedly
- Private rooms available
- Translation services available but depend on timing and availability. A telephone link and hospital staff
- Parents spoken to away from child. Child not always spoken to
- Link to universal
  - phoned GP to give diagnosis
  - GP may give diagnosis if knows family well

##### **Avonwide:**

- Focus on diagnosis
- Current 'Bombshell' e.g. news breaking
- Not good at 'picking up the pieces'
- Meet families where they are
- Missing ones
- Education issues – lack of preparation for professionals
- Language used – not always appropriate, literacy
- Led by a 'senior' person
- Assumption of equality of service position – actually depends on condition
- Location/setting – where best?

##### **South Gloucestershire:**

- Room in Frenchay
- Outpatients privacy varies
- GPs follow on
- Lack of information
- Neonatologists
- Community Paediatricians in family home
- Time
- No translation
- Always in health setting
- Family huddle around x-ray
- All trained
- Out of community centres
- Not just an event

#### North Somerset:

- DGI & paediatrics rotating to BCH
- Bristol CH specialist services
- Lifetime – 0.5 CCN
- Policies re: respect, dignity, etc
- Health visitors
- Prenatal diagnosis midwives
- Face-to-face mostly
- Community child health team
- Diagnosis and prognosis may become clear are a series of meetings/investigators - so will be gradual process

#### Bristol:

- Variation and needs:
  - Communication (documentation to others, language, jargon)
  - Funding private space
  - Confidence in community
  - Availability paediatricians training on communication
  - Multi-media information
- Variation in ability to meet communication needs for families
- More likely to have better integrated approach to breaking bad news after initial diagnostic bad news
- Some written information given but linked to key languages
- In some situations good support & coordination of people at meeting to break news e.g. follow up by nurses need more coordination
- In some situations good follow up with information but not always

#### **Standard 2: Discharge home**

Every child & family diagnosed in the hospital setting, should have an agreed transfer plan involving the hospital, community services & the family, and should be provided with the resources they require before leaving hospital.

#### Bath and North East Somerset:

- Home visits arranged pre-discharge
- 24 hour ward contact number
- Community and acute paediatricians work closely together



- Equipment and resources need organising so cannot always be arranged
- Good planning in some cases but dependent on condition and pressures
- Joint community equipment is limited and complicated
- If an inpatient more likely to happen
- Transfer plans under time pressures to get people
- Not written agreed transfer plan
- Lifetime community services & CLIC Sargent nurses provide liaison and transfer

#### **Avonwide:**

- 24 hour contact not always clear
- Unrealistic standard
- Condition changes – new assessment
- Resource directory – not covering all areas
- Patchy
- Do not know what is available
- Depends on mainly individual contacts
- Health/social care interface
- Assessment better than delivery
- Equipment at home delays discharge

#### **South Gloucestershire:**

- Complexity of care
- Consultant
- Social services OT
- Frezenius
- Lack of notice
- Who is responsible
- Nursing staff?
- Depends on time
- Lifetime
- Training?
- Equipment?
- Distance
- Ward provides 24 hours Southmead
- Hard to set up
- Who is budgeting PCT

#### **North Somerset:**

- Home visits prior to discharge for neonates
- Transport needs sorted via social care
- No local i/p service – commissioned to BCH
- Discharge planning meetings at BCH
- CCN team
- Lifetime
- Jessie May Trust
- NHS direct and GP services for 24 hours on call
- Occupational Therapy via social care – very good (not as easy via paediatricians)
- No 24 hour cover in North Somerset – via BCH

### **Bristol:**

- Some specialities at BCH will have a discharge meeting e.g. respiratory
  - Community Paediatricians
  - Lifetime
  - Hospital SW
  - Hospital education

Good examples are when this is multi-agency in thinking – not always multi-agencies

- CLIC Sargent services for paed oncology – outreach nurses from discharge – follow up 24 hour ward based cover
- Works well when equipment and carers trained ready to receive child/young person home at the time of discharge – rapid discharge planning can be challenging
- Lack of general paed nursing currently re 24 hour and low key equipment household adaptation
- Would be helpful to develop guidelines to help discharge planning or care planning to involve all agencies

### **Standard 3: Assessment**

Every family should receive a multi-agency assessment of their needs ASAP after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.

### **Bath and North East Somerset:**

- CAF – not used universally and gap as just being developed
- Disabled children's Team Schooling – home, special ed. provision
- Voluntary agencies – Rainbow Trust
- Education services accommodate children quite well, but some limitations e.g. amount hours allocated
- No uniform way of who takes lead for planning assessment
- Children in need framework used
- Disease specific processes – multi-disciplinary negotiate multi-agency needs
- Education involved if require educational assessment
- Oncology – social worker part of team in hospital, not get statutory involvement unless concerns
- Families involved

### **Avonwide:**

- Multi-agency missing whole groups of professionals
- Down to individual level of engagement
- Poor links to schools
- Under-using school nurse skills and resources
- Sharing assessments to same resources
- Gaps in home provision of equipment/services by social services
- Need for a 'listening ear', general skills
- Common assessment framework has deficiencies – common aspects left out
- Systems cannot cope with changing needs

### **South Gloucestershire:**

- Multi-discipline not multi-agency
- Health OT
- Social services OT
- Team around life limited child – Health Disability Team
- For young child
- Includes families
- Deficit parenting model
- Is it needed?
- Separate assessment
- Who is responsible?
- Barrier. IT and notes
- Oncology. MDT then Int. Care Pathway

#### North Somerset:

- Multi-agency assessments – often repeated not efficient
- Assessments via JMT or Lifetime or Social Services
- Family included in health assessment (not always education)
- Very limited home visits prior to discharge for older children
- No process for identifying lead professional/keyworker
- Paucity of 24 in support
- Lack of paediatric trained nurses for 24 hour care
- Poor translation of assessment into action plan
- Paeds therapies lacking, e.g. OT/physio, etc
- Bereavement services – need more access, coverage, range
- How to identify one lead person for common assessment
- ? Training for communications abilities for staff
- How to get family feedback
- Parents, GP informed? Delay?

#### Bristol:

- Initial assessments undertaken:
  - Jessie May Trust
  - Lifetime
  - OT/Physio Community Child Health
  - CLIC Sargent assessment
  - Education assessment
  - Hospice assessment
  - Bristol Palliative Care Team
- If children are part of disabled children's services (CYPS) – joint agency partnership panel and will be enable coordinated assessment
- CLIC Sargent for oncology do multi-agency assessment

#### **Standard 4: Care Plan**

Every child & family should have a multi-agency care plan agree with them for the delivery of co-ordinated care & support to meet their individual needs. A keyworker to assist with this should be identified and agreed with the family.

#### Bath and North East Somerset:

- Identification of keyworker:
  - who is formally named as such and recognised by all agencies and the family

- is inconsistent and not systematic process
- Limited social services availability in who will be involved
- Complex needs care pathway in place
- Respite care services, but could be more flexible
- Services there but not coordinated into care plan that is joint
- Lifetime nurse
- CLIC nurse
- Social worker (sometimes)
- Wider multi- disciplinary team
- Robust assessment process for specific groups, e.g. complex needs, oncology

#### Avonwide:

- Keyworker role – takes too much time for an individual professional
- Lack of technical support for equipment
- Not flexible or dynamic to cope with changing situation
- Do not use parents enough as keyworkers
- Repeat attendees – coordination challenge (changing needs)

#### South Gloucestershire:

- Lifetime
- Assumes its role
- Care plan
- Children's Hospice CHSW + Acorns
- Jessie May Trust
- Social work issues Dis Child Team
- Family support meetings
- Family link
- Short breaks at home
- Short break units x2
- 6 month reviews or as necessary

#### North Somerset:

- Poor knowledge of care plan example outside JMT/Lifetime
- Lifetime care plans – updated, signed etc
- JMT care plans

#### Bristol:

- Current care plans:
  - Lifetime
  - Jessie May Trust
  - CYPS multi-agency plans in some instances
  - Bristol palliative care team
  - Hospice care plan

#### **Standard 5: End of Life**

Every child & family should be helped to decide on an end of life plan and should be provided with care & support to achieve this as closely as possible.

#### Bath and North East Somerset:

- When acknowledged by families, and it is recognised by professionals - skills, training and knowledge available to get these done and some do
- Concern professionals not acknowledging/early enough that child going to die too late – so late interventions
- Inconsistent approach – may not be giving families opportunity
- Aggressive treatment often means unexpected acute death
- Families in Bath have choices about where they die – hospital/home/hospice

### Avonwide:

- Reluctance to allow 'natural' death
- Must be introduced at appropriate times
- Acute setting – acknowledged gaps, not discussed
- Regarded as 'fixed' document
- Currently do not recognise fluctuations
- Difficulty in breaking subject – entered ventilation and 'prolongation' of life

### South Gloucestershire:

- Lifetime
- Hospice supports families
- Jessie May Trust
- Chaplaincy services
- Guidance needed
- Through relationship
- Family wishes plans
- Parental permission to allow children to talk
- When to raise the issue?
- Community paed
- Informal

### North Somerset:

- End of life care planning at hospice
- Lifetime care plans include end of life
- Bereavement services via BCH, hospice, JMT
- Hospice 24 hour care

### Bristol:

- CLIC Sargent have examples of end of life plans but variable

## Appendix 3: Newsletter



SERVICE IMPROVEMENT NETWORK PROJECT

### Newsletter

Winter 2008



#### Project Launch

Many of you will remember the Project Launch which was held at the **Bristol Council House** last September. The event, chaired by Mike Bowden, Asst. Director Bath & NE Somerset (BANES) PCT, was attended by almost 50 delegates representing **Health, Social Care and Education** services in the old 'Avon' area which now includes Bristol, Bath, South Gloucestershire and NE Somerset.



Bristol Council House

After a buffet lunch, **Katrina McNamara-Goodger** from ACT (Association for Children's Palliative Care) introduced the Palliative Care Pathway which sets goals around **5 key standards** for children with palliative care needs. Group work sessions then followed, in which delegates mapped current service provision and made recommendations for improvements. **Antonia Beringer**, the Project Facilitator, outlined the Service Improvement Network Project and described the RAID\* methodology that is being used to guide the work.

To round off the launch delegates were invited to write **postcard pledges** of their individual aims to improve children's palliative care and to **sign up** to work groups, each taking one of the ACT standards as their focus. These groups have now begun a rolling programme of sessions.

\*Review, Agree, Implement, Demonstrate  
As recommended by the NHS Care Services Improvement Partnership (CSIP)

#### Welcome

To the 1st Newsletter of the Service Improvement Network Project which offers you a brief update on progress so far and information about how to get involved...

**POSTCARDS**  
"Check the post for your cards!"

#### Project Groups ...

have been convened, based on the 5 key ACT standards:

1. Breaking News
2. Discharge Home
3. Assessment
4. Planning Care
5. End of Life

#### How do parents rate children's palliative care services?

The ACT Parent's Service Assessment questionnaire has been distributed to families who receive palliative care services across the region. Initial results indicate that parents perceive the standards in the earlier stages of the pathway are being met more fully than those later in the pathway.

...More results in the next newsletter...



A Project Group Meeting

#### Contact Details

**For more information on this project or to join one of the Project Groups, contact:**  
Antonia Beringer, Research Fellow, tel: 0117 310893, email [Antonia.Beringer@uwe.ac.uk](mailto:Antonia.Beringer@uwe.ac.uk);  
or Esther Heijnen, Secretary tel: 0117 3310896, email: [Esther.Heijnen@bristol.ac.uk](mailto:Esther.Heijnen@bristol.ac.uk)  
Centre for Child and Adolescent Health, Hampton House, Cotham Hill, Bristol, BS6 6JS

## **Appendix 4: ACT parents assessment tool – collated results**

	<b>Key Standard</b>	<b>Yes</b>	<b>No</b>	<b>Not applicable</b>	<b>Don't know</b>
<b><u>Breaking news</u></b>					
A1	Was your child's diagnosis shared with you during face to face discussion?	24		1	
A2	Was the news shared with you in a private setting?	25			
A3	Was the news given to you with a relative/friend to support?	21	4		
A4	Was useful written material provided to you?	14	10	1	
A5	Was an interpreter offered, if you needed one?	1	2	22	
A6	Was appropriate information available for your child/ren?	11	4	10	
<b><u>Discharge home</u></b>					
B1	Did/Do you have a key worker?	13	10		
B2	Was your GP informed?	22	2		1
B3	Were community services informed e.g. health visitor; community nurse?	19	4		2
B4	Was a community children's nursing service available.	17	7		
B6	Were you involved in your child's discharge plan?	16	3	6	
B6	Was your child's discharge planned early?	5	12	7	1
B7	Were home visits arranged pre discharge?	10	11	3	1
B8	Was shared medical care between the lead centre and your local service planned?	12	4	5	4
B9	Did you receive the equipment you needed to care for your child?	17	4	4	
B10	Were your transport needs addressed?	8	6	11	
B11	Were you/carers trained before transfer?	18	4	3	
B12	Were clear communication lines agreed with you?	17	7	1	
B13	Were you provided with a 24 hr contact number?	16	8	1	
B14	Was a Keyworker identified before discharge home?	8	13	1	
<b><u>Assessment</u></b>					
C1	Were your child & family's needs assessed ASAP following diagnosis?	16	5	1	3
C2	Were assessments coordinated across services?	12	6	1	4
C3	Were you fully involved in assessments?	17	4		4
C4	Was your Child kept central to and included in the process?	15	5	2	2
C5	Did the assessment include all of your family?	13	8		3
C6	Did the assessment recognize and respect your child's individuality?	16	3	1	2
C7	Were your transport needs considered?	6	8	10	1
C8	Was information gathered and recorded systematically?	10	5	1	7
C9	Was non-jargon language used?	11	9		3
C10	Did the process address confidentiality and consent?	16	3	2	3
C11	Were you given a copy of the assessment information?	9	12		3
C12	Was the key worker's role clear to you?	10	7	5	1
<b><u>Care Planning</u></b>					
D1	Was a Keyworker identified?	11	12		2
D2	Was the Care Plan available to you and you child?	10	8	2	5
D3	Does the Care Plans include the whole family?	8	6	1	9
D4	Was Symptom Management, Nursing Care & Personal Care planned for?	14	5	2	3
D5	Was psychological care available for your whole family?	10	12	2	
D6	Was benefits advice/financial information given to you?	18	4	2	

D7	Were flexible short breaks available for your child?	6	13	2	2
D8	Was social care and support available?	6	11	4	2
	<b>Key Standard</b>	<b>Ye s</b>	<b>No</b>	<b>Not applicable</b>	<b>Don't know</b>
D9	Were there opportunities for play/social activities?	15	6	2	1
D10	Was your child's education fully supported?	13	6	4	
D11	Did the Care Plan address your health issues?	5	13	2	2
D12	Was a Community Children's Nurse allocated to your child?	17	5	1	
D13	Were aids/equipment available for home and school?	17	2	3	1
D14	Did the Care Plan address transition to adult services?		4	18	2
D15	Were there regular updated reviews?	13	5	3	3
D16	Were you able to request reviews?	13	1	3	7
	<b><u>End of Life</u></b>				
E1	Do you have an End of Life Plan?	1	7	9	
E2	Are professionals open & honest as end of life is approaching?	3	1	7	1
E3	Are resuscitation plans agreed, written up & communicated appropriately?	2	1	7	2
E4	Do you have access to 24hr symptom control?		2	8	1
E5	Are symptom control staff suitably qualified & experienced?			9	2
E6	Is emotional/spiritual support available?	2	2	6	1
E7	Are your choices able to be supported with resources?		1	8	2
E8	Are you and your child & family given a choice in the place of care?		2	8	1



## Appendix 5: Steering Group meeting notes (example)



### Service Improvement Network Project

Steering Group Meeting  
June 24<sup>th</sup> 2008

#### Project update

Chris Roys (chair)  
Antonia Beringer (project facilitator)  
Sue Dolby  
Nicky Harris  
Jonathan Hughes  
Mary Lewis  
Katrina McNamara-Goodger

#### **1. Update on project groups**

All the groups continue to meet regularly. Notes and action points from each session are written and distributed to group members. The groups have now each met 6 or 7 times (total 26) and are at the 'Implement' stage of the RAID (Review, Agree, Implement, Demonstrate) process. The groups are being encouraged to complete their projects over the summer and then to focus on presenting their work at the October conference.

Feedback on the work of each group follows.

#### **Group 1: Breaking News**

Two work streams involving staff from 3 centres are active under this key standard. Having met with these two groups separately for 6 months a joint meeting was convened on 19<sup>th</sup> June.

- a) Children's Neurology Department at Frenchay Hospital. The pre-post audit of breaking news practice in the Barbara Russell Unit of Frenchay Hospital has been completed. New IT facilities and space available for sharing results of scans are in place and supporting improved practice. Demonstrated by medical staff using the private space/IT facilities therein and requesting a nurse to be present during breaking news discussions.
- b) Royal Hospitals Bath CLIC staff and Consultant Oncology staff at Bristol Children's Hospital. Breaking news of results of scans the focus of this group of staff. Group is reviewing information given to parents about process of scan review and result sharing.

#### **Group 2: Planning for going home**

Two main activities. First, reactivating/initiating the Clinical Alert System - which automatically generates an email which is sent to nominated care providers when a child is admitted to hospital. Lifetime service reactivating dormant list.

Currently seeking ways to resolve access to NHS computer system for non-NHS services as this is a requirement to receive the 'alert' emails. Nick Harvey (IT manager for UHB) co-opted to help with this.

Second activity focuses on the role of Clinical Nurse Specialists in multi-disciplinary discharge planning meetings (crucial bridge between hospital and community services when planning discharge for children with palliative care needs.) Questionnaire to investigate scope of current practice devised and being authorized for use.

UHB have recently launched Trust-wide discharge policy. AB invited to advise planning committee on auditing impact.

#### **Group 3/4: Multi-agency assessment and care plan**

Again to main work streams. First, clarification of what the terms keyworker and lead professional mean to staff working in different agencies. A brief questionnaire was piloted with School Nurses and Health Visitors. Responses were reviewed, a revised questionnaire devised and distributed to community nursing and support staff. Responses currently being analysed by Clin. Psychologist for BANES.

Second work stream involves supporting the evaluation of the parents self-assessment for respite care (FRIPP) document which was developed by the Jessie May Trust.

Links made between this and the Disabled Children's Strategy Group.

#### **Group 5: End of Life planning**

This, the largest of the groups, have, through extensive negotiation, developed a pilot version of a document to support End of Life planning. Clinical Governance approvals have been sought to pilot the document in a range of acute and community-based services. Permissions have been given for the pilot to proceed at the Charlton Farm Hospice, with staff at the Lifetime service and the Jessie May Trust and with staff and families in Bristol Royal Children's Hospital (verbal decision awaiting conformation).

#### **2. Parents Service Assessment feedback**

Feedback about the assessment tool has been received which may be useful in developing and applying future versions.

#### **3. Bristol Children's Palliative Care Conference**

Project group members are being encouraged to prepare short presentations on their work for the October conference, These will provide feedback about the process and outcomes of the SINP groups.

#### **4. Date of next meeting**

Tuesday September 23<sup>rd</sup> 2008,  
2pm,  
Charlton Farm Children's Hospice.

*Antonia Beringer  
23rd June 2008*

## Appendix 6: Discharge planning meetings questionnaire

### Multi-disciplinary discharge planning meetings: the CNS view SUMMARY OF RESPONSES

13 responses received from the following specialties:

immunology x 2	metabolic
CCN generic	respiratory
gastro investigations	rheumatology
CAMHS	dermatology
home ventilation	paediatric diabetes
gastroenterology	neurology

1. Do you attend multi-disciplinary meetings where discharge planning is discussed?
  - Yes: 8 No: 5
  - a) If yes, what is/are the meeting/s called?
    - Multi-disciplinary meeting x 2
    - Discharge planning meeting x4
    - Multi-disciplinary discharge planning meeting x 2
    - No response x 5
  - b) How often do they take place?
    - When needed (depending on case) x 7
    - Weekly x 1
    - No response x 5
2. Who organises / sets up the meetings?
  - CNS x 4
  - Community CAMHS x1
  - Ward nurses x 1
  - Depends on meeting x 1
  - No response x 7
3. Who chairs / leads these meetings?
  - Consultant: 4
  - CNS x 1
  - Consultant or CNS x 2
  - Depends on consultant/CNS x 1
  - No response x 5
4. Are minutes / notes documented? Yes: 7 No: 1
  - a) If yes, where are they documented?
    - In the patient's notes x 7, with 3 respondents adding that copies were sent to all present

b) Do you use the Trust Discharge Policy?

Always x 0 / sometimes x 2 / never x 6, with one comment that existing policy is adult orientated

c) Do you use the ACT Integrated Multi-agency Care Pathway for Children with life-threatening / limiting conditions?

Always x 0 / sometimes x 0 / never x 7, plus 2 N/A's.

5. Who ensures actions decided at the meeting are carried out?

CNS x 6, not clear x 1, group of staff including ward nurses and medical staff x 3

6. Who usually attends the multi-disciplinary discharge planning meeting?

7 responses, naming range of staff involved, from minimum 4 (immunology) up to 15 different staff groups (neurology).

7. Do any disciplines / staff groups not attend who you think should / could?

No x 4, Yes x 1 (Health Visitors and GPs named as absentees by home ventilation team)

8. What makes multi-disciplinary meetings work well in your specialty?

7 responses, range of suggestions, most common being:

- Effective communication/open discussion
- Appropriate staff present and good chairing
- Taking the lead/initiative then maintaining momentum
- Good planning/organisation – including space to hold the meetings.

9. What hinders multi-disciplinary meetings in your specialty?

5 responses, including:

- Availability / getting everyone together
- Identifying who is responsible
- Process takes a long time

10. Do you have any other comments about multi-disciplinary meetings?

5 responses, including:

- MDT focuses mainly on patients whilst in community – rarely inpatients and aim to maintain this
- (immunology, rheumatology, dermatology)
- Recognise need to join in MDT meetings which currently do not (CCN team).
- Advocate MDT meetings as useful in reducing time in hospital (neurology)



## **Appendix 7: Keyworking report**

### **KEY WORKING: WHAT DOES IT MEAN TO YOU?**

A questionnaire survey was undertaken as part of the Service Improvement Network Project looking at the ACT\* standards for assessment and care planning in the 'Avon' area. The aim was to find out more about what terms such as 'Key Worker' and 'Lead Professional' mean and how these roles are understood. Questions were based on guidelines for Lead Professional working within 'Every Child Matters'.

Eleven people from the Disabled Children's Team, the Lifetime Service and the Jessie May Trust responded.

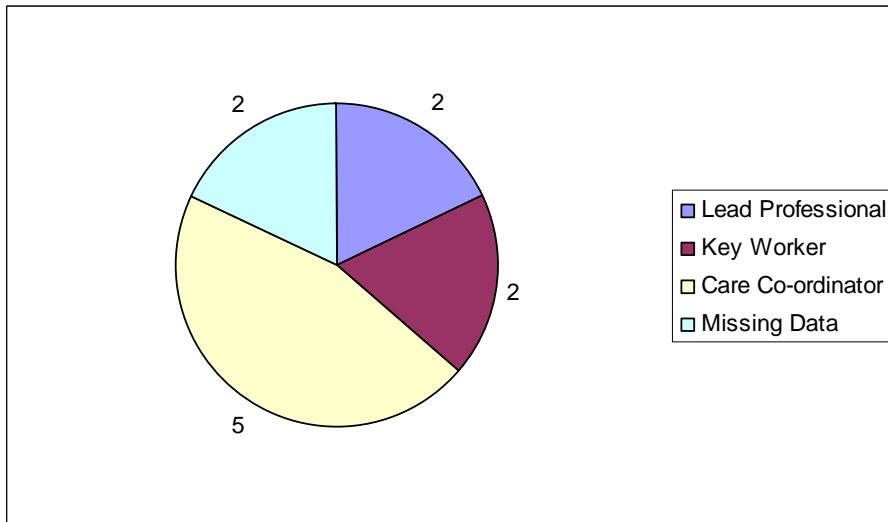
#### **1. WHICH OF THE FOLLOWING ACTIVITIES DO YOU UNDERTAKE IN YOUR CURRENT POST?**

<b>Activity</b>	<b>Number of responses</b>	
	<b>Yes</b>	<b>No</b>
Co-ordinate the provision of care of a child and family	11	0
Act as a single point of contact when a range of services are involved with a child and family	9	2
Support children and families in making choices and navigating their way through the system	11	0
Ensure children and families receive appropriate interventions when needed	10	1
Organise reviews	11	0
Provide day to day support for children and families	10	1

---

\* Association for Children's Palliative Care

## 2. WHICH TITLE BEST REPRESENTS YOUR ROLE?



### **Lead Professionals:**

The two Lead Professionals were a CCN and Bereavement Support Worker. Both felt they undertook all activities apart from one. One LP felt it was not part of their role to act as a single point of contact when a range of services are involved with a child and family, and the other felt it was not part of their role to ensure children and families received appropriate interventions when needed.

### **Key Workers:**

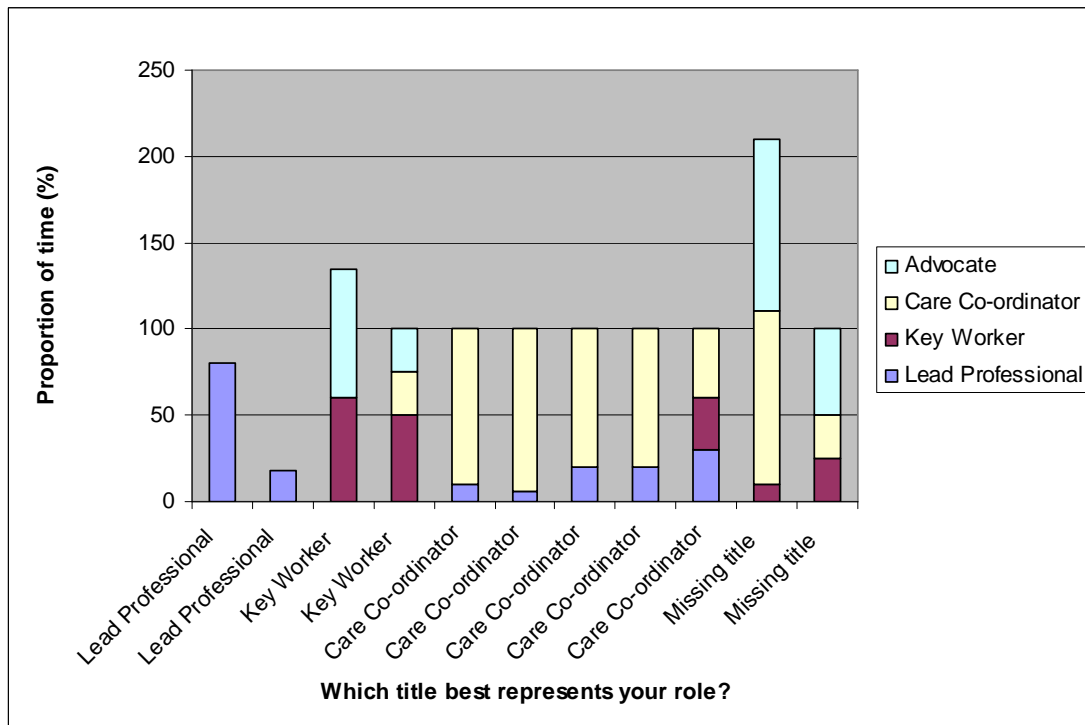
The two Key Workers were CCNs. Both felt that they undertook all activities listed as part of their role.

### **Care Co-ordinators:**

The five Care Co-ordinators were Social Workers. All felt that they undertook all activities listed as part of their role.

**The remaining two CCNs** described their roles as being Care Co-ordinator, Key Worker and Advocate (grouped as 'missing data' in figure above).

### 3.FOR WHAT PROPORTION OF YOUR CASELOAD TO YOU ACT AS...



### 4. WHAT SUPPORT, TRAINING, OR PREPARATION HAVE YOU RECEIVED TO UNDERTAKE THESE ROLES?

**Overall themes:** Most people have received formal training and supervision to undertake these roles. Others have used their previous experience to help undertake these roles.

Summarised responses are given here according to role:

#### **Lead Professional:**

**(Overall=No formal training, individual learning, supervision)**

- No formal training, done own literature searches about roles
- Counselling training, internal and external supervision

#### **Key Worker:**

**(Overall= Experience, Nurse training, & supervision)**

- Experience in acute paediatrics and management, CCN training, group and individual supervision with psychology input.
- Nurse training and experience in multi professional working

#### **Care Co-ordinator:**

**(Overall= Corporate training & supervision).**

- Supervision
- Corporate training with North Somerset, supervision.

- Supervision, training
- Corporate training with North Somerset, supervision
- Corporate training with North Somerset, supervision]

**Missing role:**

**(Overall=Training in clinical care, policies, lead professional role and CAF).**

- Jessie-Mae training about clinical care and policies
- South Gloucester training regarding Lead Professional role and CAF, past key worker training, no training in last 2 years.

**5. HOW WERE THE ABOVE ROLES DECIDED?**

**Overall themes:** Some people said it was in their job descriptions, others said their role depends on other professionals' input, family need, or decisions made at MDT meetings or in supervision.

Individual responses were:

**Lead Professional:**

**(Overall = MDT and family agreement, job description)**

- Agreed with parents and other professionals at MDT meeting
- Jessie-May Trust (development post)

**Key Worker:**

**(Overall = Dependent on other professional input and family need.)**

- Dependent on other professional input and family need.
- Evolved depending on contact with family

**Care Co-ordinator:**

**(Overall = Job description, parental**

- Within job description
- Supervision/multi-agency review decision
- Missing data
- Missing data
- Parental choice, who has the most involvement and most time to devote to role]

**Missing role:**

**(Overall = MDT designation, assumption, job description)**

- MDT meeting to designate key worker role per case, assumed by other professionals
- Within job description

**6. WHAT ADVICE WOULD YOU GIVE TO SOMEONE ABOUT TO UNDERTAKE THESE ROLES?**

**Overall themes:** Manage time and resources well, be clear about role, refer on when necessary, communicate with others, prepare for the role.

**Lead Professional:**

**(Overall = Manage time and resources, clarity of role, training)**



- Make sure you have enough time and resources to fulfil the role; make an informed decision regarding whether or not you take on the role, consider if you are the most appropriate person for the role.
- Take up training.

**Key Worker:**

**(Overall = clarity of role, prepare for the role, communication, time management)**

- Be clear about your role and know when to refer on, regular supervision, draw on previous experience, and observation of colleagues and other agencies to prepare for the role.
- Ensure you are aware of the role of others and make contact when needed; do work as you go to prevent overload.

**Care Co-ordinator:**

**(Overall = prepare for the role)**

- Be prepared
- Be prepared for more paper and less client contact
- Be prepared for more paper and less client contact
- Be prepared for more paper and less client contact

**Missing role:**

**(Overall = time and caseload management, clarity of role, communication)**

- Need more time to key work or be lead professional so don't key work your whole caseload; Consider if you are the most appropriate person for the role; Formalise the role – don't let others assume you will take the lead (communicate)
- Provide input or refer on depending on family need and wishes.

Report prepared by Kanan Pandya & Cara Davis  
Lifetime Service

## Appendix 8a: End of life planning audit Community Paediatrics

Palliative Care Audit: End of Life Plans in Community Paediatrics April 08

5 consultants responded (out of 12)

Child's initials: 11 children

DOB: ages 1-11

Diagnosis: Cerebral Palsy, Neuromuscular, Metabolic, Chromosomal disorders

1. Has there been a discussion with parents about their child having a life-limiting condition?

Yes All / No / Don't know.....

- If No: Why? No opportunity yet/ Not relevant/ Not thought to be ready yet/ Other.....
- If Yes: How was this documented? Clinic letter / Hand written in Notes / Referral to Lifetime / Other **mainly handwritten in notes and referral to Lifetime/JMT**
- If Don't Know: Why? .....

2. Has there been a discussion about parent's views re resuscitation or emergency management? Y 6 / N 5 / Don't know

- If No: Why? No opportunity yet/ Not relevant yet Not ready yet 4 / Other 'I assume full resus wanted'
- If Don't Know: Why? May have been done by another professional but I have not been informed / Other.....
- If Yes: How was this documented? Formal written plan 3 / Clinic letter 2 / Hand written in Notes / Other.....

Would this information be found easily (in < 1 min) if the child was admitted to hospital? Y 2 / N 3 / Don't know

3. If there is a formal written plan, does this include:

- Who was involved in the discussion? Y / N
- Resuscitation plan (in event of cardiopulmonary arrest or other sudden deterioration)? Y / N
- Emergency Management plan (referring to specific symptoms eg fits, chest infections, cyanotic spells)? Y / N
- Parents signatures? Y/N
- Date of agreement? Y/N

2 contained all above list

1 contained Emergency Management Plan and Date only

Who prepared this document? Comm Paed 2 / Hosp Paed 1 / Lifetime / Hospice

How was this information shared with other professionals? 7 responses

Parent held copy 1

Copied to (Hosp Notes / Lifetime / Charlton Farm / Emergency Dept) 7

Other.....

Is there is a copy of the formal written agreement in the Hospital Notes? Y 3 / N

Any other comments about this child?

A lot of professionals involved, difficult to copy everyone in

Child died as Wishes Document being introduced (had a written plan)

Mary Gainsborough Sept 2009

***Appendix 8b: End of life planning audit PICU***

**University Hospitals Bristol**   
NHS Foundation Trust

Bristol Royal Hospital for Children  
Paul O'Gorman Building  
Upper Maudlin Street  
Bristol  
BS2 8BJ

***Women's and Children's Division  
Paediatric Intensive Care Unit (PICU)***

**'End-of-Life' care planning for children with a life-limiting illness.**

**FINAL REPORT**

**October 2008**

**Audit Lead – William Booth & Danielle Taylor  
Audit Supervisor – Dr James Fraser  
Audit Facilitators – Chrissie Gardner & Trudy Gale**

***Clinical Audit Project Reference Number 2046***

## **Background and Introduction**

End-of-Life care is an integral part of working with children with life-limiting conditions. It is a fundamental right as stated in the 'Association for Children's Palliative Care' Framework. (ACT) (Appendix 1) that these children are provided with choices of what care they wish to accept and where they wish to receive it. It is the job of healthcare professionals to facilitate this by providing the information and expertise that enables them to make these choices.

In addition to the ACT standards The Department of Health's recent document 'End-of-Life Care Strategy' (DOH 2008) clearly states *'you will have access to: The opportunity to discuss your personal needs and preferences with professionals who can support you. You will have the opportunity for these to be recorded in a care plan so that every service which will be involved in supporting you will be aware of your priorities. Your preferences and choices will be taken into account and accommodated wherever possible'*. (Appendix 2).

The Department of Health has further highlighted the importance of improving service provision for End-of-Life care by publishing a report on July 16<sup>th</sup> 2008 stating that *'£286 million to improve end of life care'*. It goes on to explain that a national survey found that only 18% of patients who requested a specific place of death actually died where they had requested. (Appendix 3)

The issue of adequate initiation and documentation of End-of-Life care has been highlighted as an area which requires much improvement if ACT standards are to be met and patient care is to be given at its optimum level.

This audit examines 30 sets of patient notes of children with a life-limiting condition. These notes have been read in full and using a pre-prepared form (Appendix 4), they have been compared to the selected ACT standards of care.

## **Aims and Objectives**

As the audit proposal states, (Appendix 5) *'Professionals may be reluctant to initiate advance care planning discussions because of the fear of increasing emotional distress, loss of trust and difficulty in identifying appropriate timing'*.

There is currently no standardised protocol/framework in use for End-of-Life planning within Children's Services. There is, however, a pilot self assessment tool available for healthcare professionals (Appendix 6).

This audit will assess the need for this kind of framework and examine how it could be implemented. In addition, the issue of accountability and responsibility for producing and implementing such a framework requires discussion and debate. This audit will only take into consideration plans and discussions made outside of admissions to the PICU. The reason for this is that an effective and appropriate plan should be made before an acute admission in a controlled and less traumatic environment. A clear and decisive End-of-Life plan could effect the child's treatment immediately on admission to PICU and therefore it would need to be in place before such an admission.

This audit has been undertaken in order to evaluate current practice and identify any areas for improvement in both person practice and the service provided for children and families.

The main aims and objectives of this audit are as follows:

- To ascertain whether children with life-limiting conditions have an End-of-Life plan in place as part of the ACT pathway.
- To identify if an End-of-Life plan exists for all children deemed to have a life-limiting condition on admission to PICU.

- To assess whether prognosis was explained and given in an appropriate manner.
- To note if a multi-disciplinary team were involved and if this was documented appropriately

(Clinical audit project proposal Appendix 5)

- To identify the need for further audit and/or research into these matters
- To make preliminary recommendations for better practice
- To communicate findings with the wider multi-disciplinary team
- To ascertain if standardised paperwork would be an effective way of managing End-of-Life planning.

**Clinical Audit Standards**

Criteria	Target (%)	Exceptions	Source & Strength* of Evidence	Instructions for where to find data
<p>1</p> <p><i>'Every family should receive the disclosure of their child's prognosis in a face to face, private discussion'. (Standard 1)</i></p> <p><b>All children with an identifiable life-limiting condition should have documented discussions and evidence of 'End-of-Life' planning These to include:</b></p> <ul style="list-style-type: none"> <li>• Time should be made available for face to face discussions including opportunities to ask questions.</li> <li>• Privacy should also be provided when breaking bad news.</li> <li>• Parents should be together were appropriate when receiving the news, or at least be accompanied and supported by a friend or relative.</li> <li>• The information given should be in an appropriate language and written material given where possible.</li> </ul> <p>All of the above should be clearly documented in the patient notes.</p>	100%	None	<p>Vickers JL, Carlisle C. <i>Choices and control :Parental experiences in pediatric terminal home care.</i> <b>Journal of Pediatric Oncology Nurses 2000;17(1) 12-21</b></p> <p>A framework for the Development of integrated Multi-Agency Care Pathways for children with Life Threatening and Life Limiting Conditions. <i>The Association for Children's Palliative Care (ACT) December 2004</i></p>	Hospital Records and Patient Notes.

2	<p><i>'Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible'.</i> (Standard 5)</p> <p><b>Comments relating to 'End-of-Life' planning, which may include agreed limitation in treatment options e.g PICU admissions and resuscitation.</b></p> <ul style="list-style-type: none"> <li>• A written plan of care should be agreed including decisions about methods of resuscitation.</li> <li>• Care plans should be reviewed and altered if necessary.</li> </ul>	100%	Recent diagnosis < 1 month	<p>Hammes BJ, Klevan J, Kempf M, Williams MS. Pediatric Advanced Nursing Care Planning. <b>Journal of Palliative Medicine 2005:8 (4);766-776</b></p> <p>A Framework for the Development of Integrated Multi-Agency Care Pathways for children with life limiting conditions. <i>The Association for Children's Palliative Care (ACT) December 2004</i></p>	Hospital Records and Patient Notes
3	<p><i>'Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible'.</i> (Standard 5)</p> <p><b>Documentation of preferred place of end of life care, (e.g home, hospice or hospital).</b></p>	100%	Recent diagnosis < 1 month		Hospital Records and Patient Notes
4	<p><i>' Every family should receive a multi-agency assessment of family's needs as soon as possible after diagnosis'</i> (Standard 3)</p> <p><b>Evidence of dissemination of information to the Multi Disciplinary Team</b></p> <ul style="list-style-type: none"> <li>• Copies of letters to other relevant healthcare professional's e.g General Practitioner.</li> </ul>	100%	Recent diagnosis < 1 month	<p>A Framework for the Development of Integrated Multi-Agency Care Pathways for children with life limiting conditions. <i>The Association for Children's Palliative Care (ACT) December 2004</i></p>	Hospital Records and Patient Notes



**\*Strength of Evidence**

- A** At least one randomized controlled trial as part of a body of literature of overall good quality and consistency addressing the specific recommendation
- B** Availability of well-conducted clinical studies but no randomized clinical trials on the topic of the recommendation
- C** Expert committee reports or opinions and/or clinical experience of respected authorities. Absence of directly applicable clinical studies of good quality
- D** Recommended good practice based on clinical experience (local consensus)

## **Methodology**

A data collection form (Appendix 4) was designed based upon the selected standards (see tables on page 4 &5). The selection criteria for the children to be audited were discussed at length between the Audit Leads and Supervisor prior to the commencement of data collection.

The inclusion criteria were as follows:

- All children audited must have had at least one admission to PICU within the past four years
- Degenerative neuromuscular disorders
- Severe global cerebral palsy and developmental delay
- Life-limiting genetic and chromosomal abnormalities
- Life-limiting metabolic disorders
- Non-oncological and non-cardiac life-limiting conditions
- Life-limiting congenital neurological abnormalities

The exclusion criteria were as follows:

- Children born before 37 weeks gestation
- Children diagnosed within one month of data collection
- Children with any primary diagnosis of oncological or cardiac conditions
- End-of-Life plans made during a patient's admission on PICU
- Children with no PICU admissions with the past four years

In order to fairly evaluate the selected standards the audit team decided to only review notes of patients with Bristol postcodes. As the PICU is a regional specialist centre, many acute admissions come from areas where their core medical care would have taken place in their local District General Hospital.

As a result of this, notes held within this hospital may not include all documentation required for the audit to be accurate.

For the purposes of this audit an identifiable life-limiting condition has been defined as '*One for which there is no reasonable hope of a cure and death in childhood or young adulthood is expected*'. (Audit proposal form, Appendix 5)

A search was performed on the PICU local database to identify those patients with the above inclusion criteria admitted to PICU within the last four years. From this download, patients were highlighted based on their postcode. For this project we were only able to review notes for patients whose diagnosis was originally made at the Bristol Royal Hospital for Children.

The notes were reviewed over an eight week period from 06/08/2008 until 30/09/2008.

Notes which arrived incomplete (volumes missing), which equated to 13%, were included in the audit as these would also be the only notes available to staff on a child's admission to PICU. Therefore, any End-of-Life care would have been implemented based on the documentation available.

Consent was not required as the information being collated was routine clinical information that was part of routine management. Confidentiality was retained on data collection forms by using a study number and no identifiable patient information.

Relevant healthcare professionals who may benefit from the findings of the audit and whose notes may have been evaluated were contacted by the Audit Supervisor as a matter of courtesy.

## Results

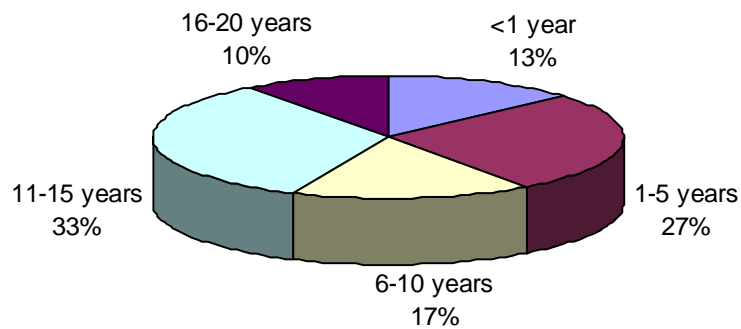
30 medical records of children who met inclusion criteria were reviewed. Their diagnoses were as follows:

### Diagnosis

<b>Diagnosis</b>	<b>Total</b>	<b>%</b>
Chromosomal abnormality	7	23
Degenerative neuromuscular disorder	5	17
Severe global cerebral palsy	10	33
Microcephaly/Lissencephaly	6	20
Life-limiting metabolic disorder	2	7

### Age Range

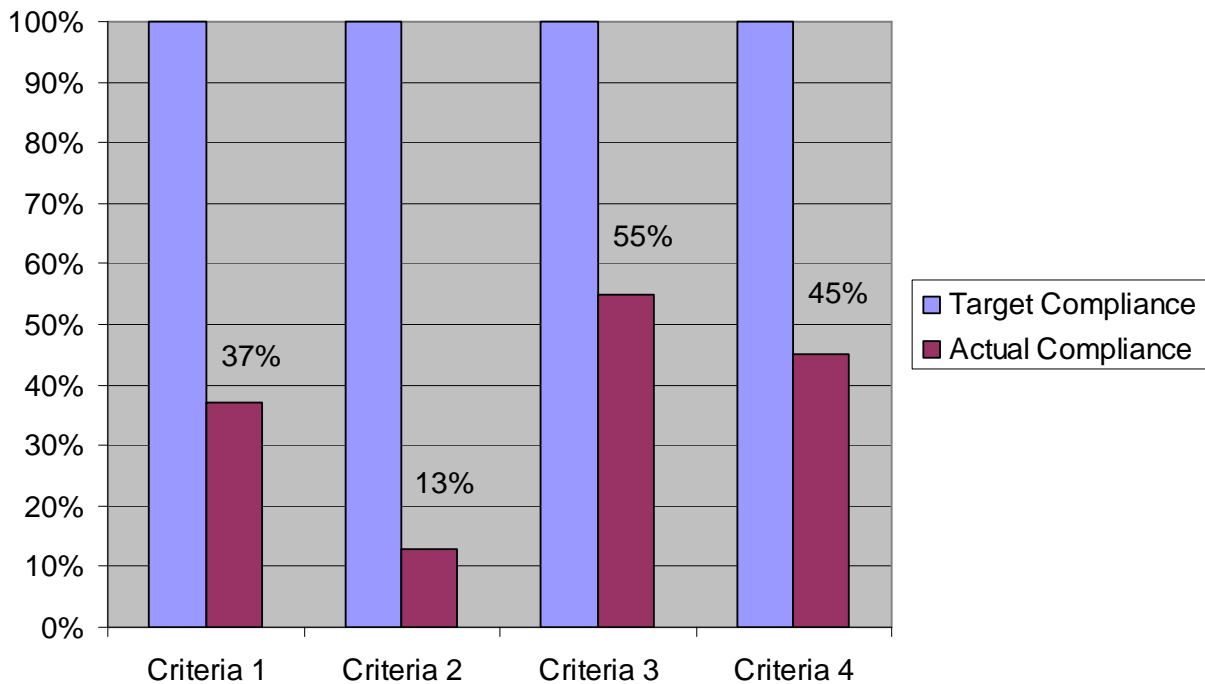
The age of children in the audit was 5 months-20 years of age. The chart below provides a detailed breakdown of children's ages



**Standard 1** – Every family should receive the disclosure of their child’s prognosis in a face-to-face discussion in privacy’. (Audit proposal, Appendix 5)

	<u>Standard Criteria</u>	Target (%)	Results (%)
1.	Time should be made available for the face-to-face discussions including opportunities to ask questions: (n=30)	100%	37% (11/30)
2.	Written material should be given: (n=30)	100%	13% (4/30)
3.	Parents should be together where appropriate when receiving the news, or at least be accompanied and supported by a friend or relative : (n=11)	100%	55% (6/11)
4.	Privacy should also be provided when breaking bad news: (n=11)	100%	45% (5/11)
5.	The information given should be in an appropriate language: (n=0)	100%	N/A*

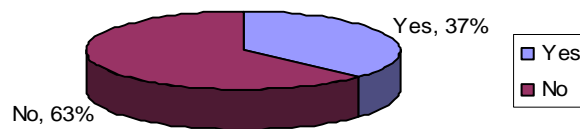
\*Of the 30 sets of notes reviewed, no need was identified for the information to be given in any other language other than English.



**Standard 4** – ‘Every family should receive a multi-agency assessment of family’s needs as soon as possible after diagnosis – Evidence of dissemination of information to the multi-disciplinary team’. (Audit proposal, Appendix 5)

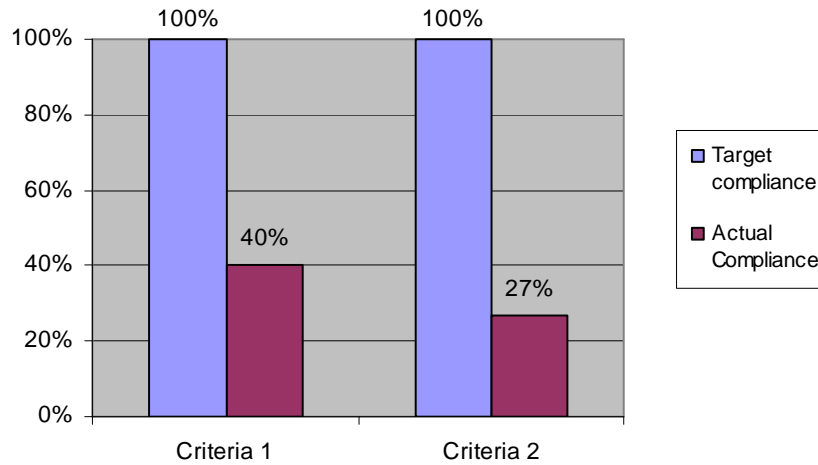
The chart below shows the number of notes found to have any evidence of correspondence to other healthcare professionals regarding any of the standards being assessed. Evidence found included letters to GP’s, minutes from multi-disciplinary team meetings and documentation of telephone conversations to other allied healthcare professionals.

**Evidence of correspondence to other healthcare professionals regarding End-of-Life planning**



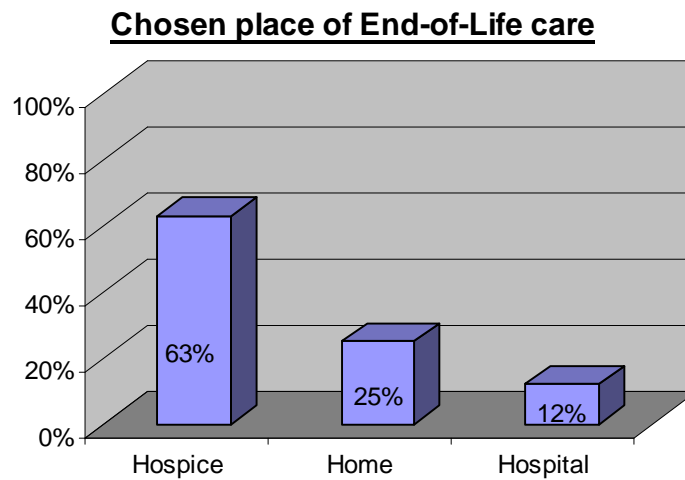
**Standard 2 & 3** – ‘Every child and family should be helped to decide on an ‘End- of- Life’ plan and should be provided with care and support to achieve this as closely as possible’. (Audit proposal, Appendix 5)

	<b><u>Standard Criteria</u></b>	<b>Target (%)</b>	<b>Result (%)</b>
1.	End-of-Life plans should be made and documented: (n=30)	100%	40% (12/30)
2.	The child and family should be given a choice in the place of care (n=30)	100%	27% (8/30)



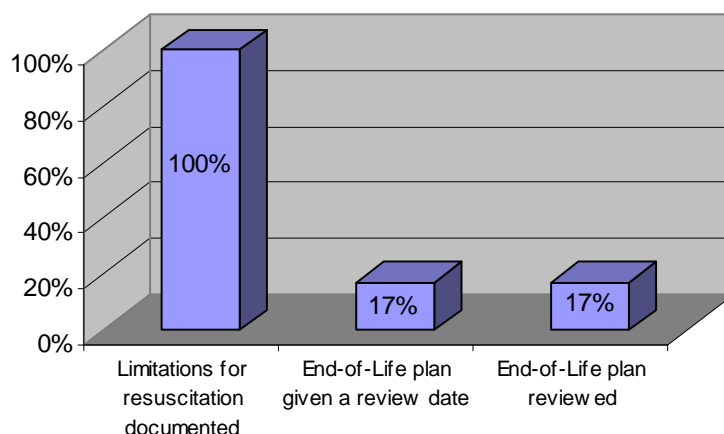
**Standard two & three results cont.....**

The chart below shows the chosen places of End-of-Life care of those eight children who had such plans specified in their notes. (n=8)



The chart below shows what elements were included in the End-of-Life plans of those twelve children found to have such documentation in their notes. (n=12)

### What was included in the End-of-Life plan



### Findings

As the previous tables and charts show, standards are not being achieved for End-of-Life care. Some areas show more striking shortfalls than others. The major findings of the audit are listed below:

1. Only **37% (11/30)** of families with children being diagnosed with a life-limiting illness have documented evidence stating that a face-to-face discussion took place. *(Standard 1)*
  - 1a. Of the **eleven** cases with evidence of a face-to-face discussion **55% (6/11)** had both parents or a friend/relative present. *(Standard 1)*
  - 1b. Out of all notes reviewed only **13% (4/30)** were found to have evidence that written material regarding the child's diagnosis/prognosis was provided to the parents. *(Standard 1)*
2. Evidence of dissemination of information to other healthcare professionals was **37% (11/30)**. *(Standard 4)*
  - 2a. **40% (12/30)** of those reviewed had a documented End-of-Life plan.



*(Standard 2)*

**2b.** Of these **twelve** care plans **all** had included in their plan 'limitations of resuscitation'. **17% (2/12)** of these plans were given review dates. *(Standard 2)*

**3.** For those children who had their chosen place for End-of-Life care documented in their notes, **63% (5/8)** requested for this care to be given in a Hospice. *(Standard 3)*

**3a.** Of the **30** reviewed cases, **six** died during their documented admission to PICU. Of these children, three (**50%**) had evidence of an End-of-Life plan at their time of death. *(Standard 2)*

### **Discussion**

In addition to the findings contained in this report, there were certain other trends that were observed whilst examining the patient's notes in the audit. These observations are noted below:

The majority of End-of-Life plans were initiated and made by Geneticist's and Neonatologists. Therefore, if the child in question had an antenatal diagnosis of a life-limiting condition or a genetic life-limiting condition then they appeared more likely to have an End-of-Life plan in their notes.

This was also the case for 'Breaking bad news' on diagnosis/prognosis. It was also noted that the children who were primarily under the care of a Neonatologist or Geneticist appeared more likely to have evidence of such a discussion in their notes.

A high number of children reviewed were in contact with the local children's hospices. This was an encouraging finding as the hospices offer a great deal of support to the child and family. They also have a policy of making End-of-Life care plans; unfortunately these did not always appear in the medical notes. The care plans which were found in the notes were incredibly comprehensive and clear.

In the vast majority of cases where a child suffering from cerebral palsy or microcephaly had an End-of-Life plan, this was made and sometimes subsequently reviewed in well documented Multi-disciplinary team (MDT) meetings.

It became apparent very early in the audit that, although documentary evidence of End-of-Life planning was found in some sets of notes, it was often very difficult to find. For example: Hand-written documentation of End-of-Life planning which is 'hidden' within patients notes consisting of 6 volumes would not prove very accessible in the event of an emergency admission to PICU.

It is also interesting to note that all of the children who had End-of-Life plans that died during their admission to PICU had requested to die in a hospice and not in hospital. The reasons for non-compliance with this request were not clear.

It is important to recognise the limitations of this audit in that all findings were based solely on the patient's notes with no other point of reference. It is quite possible that in some instances whether due to poor documentation or filing error, some of the evidence required to meet the selected standards may have been in place. However, in legal terms healthcare professionals should be all too aware that what is not accurately documented in the medical notes could be assumed never to have happened in the event of any legal dispute.

In conclusion the results of this audit show that all four of the selected standards are not being met.

## **Conclusion and Recommendations**

The findings of this audit have highlighted several areas for improvement and further research/audit. The main recommendations are listed below:

### *Standard One*

1. Improvement in documentation of discussions with families relating to the child's diagnosis/prognosis is required. This should indicate who was present at the time and where and when the discussion took place. The analysis of the notes regarding this standard could have been misleading. If it was not documented that both parents were present and that the discussion took place in a private location, the notes failed this standard.
  
2. The standard with the poorest compliance in the audit was that of providing the family with written information at the time of diagnosis. Further research would be required to ascertain the reasons behind this. It may have been that no appropriate literature was available at the time. A suggestion for improvement is that a selection of approved literature should be made available in clinics for healthcare professionals to distribute. However, it could be argued that it may not be deemed necessary, unless specifically required, to document that a leaflet was given to the parents.

### *Standard two and three*

3. The number of children with an identifiable life-limiting condition who had an End-of-Life plan was 40%. This needs to be greatly improved if standards are to be met. It cannot be said that this figure may be inaccurate due to poor documentation or filing error as written documentation available to all professionals is the only form of End-of-Life plan. Further and extensive research is required into the reasons for this. Agreements between different professional disciplines as to whose responsibility it is and how it should be documented are just two key issues that have been brought to light in this audit. It would seem that standardised paperwork with agreed review dates would make using and implementing such plans more efficient and as a result improve patient End-of-Life care. A brief discussion that is documented within a large set of notes is not practical and is likely to result in time being wasted to finding it. In other areas such as child protection, a standardised green form is used. This enables healthcare professionals to recognise it immediately and know how to implement the information. It is therefore recommended that an End-of-Life plan framework such as Appendix 6 be trialled. It would also be of benefit to speak to key healthcare professionals who care for children with life-limiting conditions to ascertain their opinion on the matter.
  
4. All children with End-of-Life plans had details in their notes regarding any limitations of resuscitation. However, very few had any review dates documented. It is therefore apparent that the importance of information regarding resuscitation is clear. However, professionals need to be aware that a child's medical condition can change and as a result their resuscitation status needs to be regularly reviewed if it is to remain applicable and appropriate to that child. Communication of this is recommended in order to meet targets.
  
5. The importance of children being admitted to the PICU with a life-limiting condition and having an End-of-Life plan was highlighted during the audit. It showed that of the children reviewed who subsequently died on the unit, only half had an End-of-Life plan. 1 in 2 children were not given the rights of choice the 'ACT Pathway' recommends. It was also observed that of those children who died on the unit with End-of-Life plans, all had requested to die elsewhere. This issue in particular needs to be investigated as to why their wishes were

not met. It could be for medical reasons that this did not happen or, it could possibly be due to the End-of-Life plan not being found or adhered too.

*Standard four*

6. Evidence of dissemination of information to other healthcare professionals could generally be construed as letters to GP's and other allied healthcare professionals. It is normal protocol to copy all letters into the patient's notes. Therefore reading the notes should be an accurate way of assessing if any communication of this kind took place. Less than half the notes reviewed were found to have such evidence. All of the children who were reviewed had a multi-disciplinary team and therefore such correspondence would be necessary. It is therefore concluded that improvements in communication across the healthcare professions needs to be implemented if standards are to be met.

## ***Appendix 9: Child & Family Wishes Document - guidance notes for end of life planning discussions***

The Child Family Wishes guidance notes, developed by members of the End of Life project team, are reproduced in full on the following pages.

The document has been approved for use by the Clinical Effectiveness Committee of United Hospitals Bristol and is in use within the Trust and local PCTs.

The project team consent to other service providers using the document, if they feel it is appropriate, but ask that its' origin is acknowledged and that local permissions are sought.

The document can be downloaded from the ACT website at:

<http://www.act.org.uk/index.php/act/south-west-england.html>

## GUIDANCE FOR DISCUSSIONS ABOUT CHILD & FAMILY WISHES

### WHEN LIFE IS LIMITED: advance care planning for the end of life

Advance care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision making.\*

This document is offered as a *guide*, **to be used by any member of the Healthcare Team** in co-ordination with colleagues, in response to family needs and requests. These are difficult but necessary discussions and this guidance is offered to support the process. Staff should not feel under pressure to complete every aspect of the form by a certain time or at one sitting, but to be **led by the needs of the family** as to which parts need to be discussed or reviewed – with whom, where and at what time.

Staff should aim to offer all families an opportunity to talk about end of life issues (concerns or wishes) but with the awareness that in some cases, families will not want to take this up, or may need more time before they are ready to do so. A list of information resources and contacts can be found on the last page of this document.

#### Begin by asking yourself the following questions:

- Would you be surprised if this child died prematurely due to a life-limiting illness?
- Would you be surprised if this child died within a year?
- Would you be surprised if this child died during this episode of care?
- Do you know what the child's and family's wishes are for the end of life?

**If the answer to any of the above questions is "No", this guidance is relevant.**



#### The next steps are to:

- Find out who else is involved in the care of the child & family, e.g. a palliative care service.
- Find out if the family have already discussed an End of Life and/or resuscitation plan.  
(Prompt: *'has anyone had a discussion with you about what you would like to happen if your child becomes seriously ill?'*)

If the family already have a plan, you may wish to review it with them, to ensure that it is still relevant or to update it if required. If there is no plan, you can use **any or all** of the following pages to document the discussions using the templates, and the suggestions in the table below, as a guide.

The first page of the document should always contain [general information](#) about the child and family.

	CHILD	FAMILY	OTHERS e.g. friends, school
<b>WISHES DURING LIFE</b>	e.g. <a href="#">special holiday</a>	e.g. <a href="#">family holiday</a>	e.g. <a href="#">fundraising</a>
<b>PLANS FOR WHEN YOUR CHILD BECOMES UNWELL</b>	e.g. <a href="#">treatment options</a>	e.g. <a href="#">what may happen?</a>	e.g. visiting
<b>ACUTE LIFE THREATENING EVENT</b>	e.g. <a href="#">preferred place</a> of care,	e.g. <a href="#">treatment options</a>	
<b>AFTER DEATH</b>	e.g. <a href="#">funeral preferences</a>	e.g. <a href="#">spiritual</a> & cultural wishes	

After discussion with the family, please ensure that a copy of the plan is included in all medical notes and a copy is given to the family, the child's GP & all other relevant services.

\*Ref: L. Brook et al (2008) *A Plan for Living and a Plan for Dying: Advanced Care Planning for Children*; Arch Dis Child 2008; 93 (suppl): A61-A66

## GENERAL INFORMATION

**Name:**

**Date of Birth:**

**Name of Parents:**

**Name and Age of Siblings:**

**Address:**

**Telephone No:**

**Diagnosis & Background Summary:**

**Key Professionals involved:**

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

Name:	
Position Held:	
Organisation:	
Tel no:	E-mail

<b>This page discussed by:</b>	
	Child / Parent / Carer
	Professional [Full name & job title]
Date	



<b>WISHES DURING LIFE</b>
---------------------------

<b>Name:</b>	<b>Date of Birth:</b>

**Child's wishes during life:**

**Family wishes during life:**

**Other's wishes during life:** [e.g. school friends, siblings]

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Date	

**PLANS FOR WHEN CHILD BECOMES MORE UNWELL**

<b>Name:</b>	<b>Date of Birth:</b>
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**What may happen?**  
 E.g. deteriorating mobility, feeding, cognitive function, worsening seizures.

**Preferred place for care:**

**Preferred treatment options:** (Indicate if not applicable or inappropriate)

- Antibiotics - e.g. Oral / IV / 'Portacath'**
  
- Feeding - e.g. NG tube / gastrostomy**
  
- Respiratory Support - e.g. mask ventilation**
  
- Seizure Management Plan**

**If child deteriorates further, preference(s) for place of death & persons present.**

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## PLANS FOR CARE DURING AN ACUTE LIFE-THREATENING EVENT

	<b>YES</b>	<b>NO</b>
Oxygen via face mask/nasal cannulae	<input type="checkbox"/>	<input type="checkbox"/>
Airway management using oral/ nasopharyngeal airway	<input type="checkbox"/>	<input type="checkbox"/>
Bag & mask ventilation	<input type="checkbox"/>	<input type="checkbox"/>
Endotracheal tube & ventilation	<input type="checkbox"/>	<input type="checkbox"/>
External cardiac compressions	<input type="checkbox"/>	<input type="checkbox"/>
Defibrillation & adrenaline	<input type="checkbox"/>	<input type="checkbox"/>
Advanced life support requiring PICU admission [Including inotropic drugs and advanced renal replacement therapy]	<input type="checkbox"/>	<input type="checkbox"/>

**Please give further details if required:**

**Other issues discussed:**

**If child deteriorates further, preference(s) for place of death & persons present.**

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## WISHES FOR AFTER DEATH

**Preferred place of care of child's body:**

**Funeral preferences:**

[Seek detailed information or further advice if needed]

**Spiritual & cultural wishes:**

**Other child & family wishes: e.g. what happens to possessions?**

**Organ & tissue donation:**

**This page discussed by:**

	Child / Parent / Carer
	Professional [Full name & job title]
Date	

## RESOURCES & SUPPORTING INFORMATION

1. ACT The Association for Children's Palliative Care <http://www.act.org.uk/>
2. Children's Hospices UK <http://www.childhospice.org.uk/>
3. Child Bereavement Trust <http://www.childbereavement.org.uk>
4. Department of Health guidance relating to children's deaths:  
<http://www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview>  
Since April 1<sup>st</sup> 2008, there has been a statutory requirement to investigate **unexpected and unexplained** children's deaths. The website summarises these processes.
5. Child Bereavement Network <http://www.childhoodbereavementnetwork.org.uk>
6. CLIC-Sargent (Cancer and leukaemia in childhood) leaflets/booklets, including; 'When there is no Longer a Cure', 'When our Child Has Died', 'Living Without your Child', available at [www.clicsargent.org.uk](http://www.clicsargent.org.uk)
7. Children's cancer and leukaemia group (CCLG) leaflets, including; 'Choices: When it seems there are none', 'Facing the Death of Your Child', 'Bereavement: Where to go for help', available at [www.cclg.org.uk](http://www.cclg.org.uk)

**This Child & Family Wishes Document has been developed by members of the Service Improvement Network Project (listed below) to support, and promote, End of Life planning for children with life-limiting conditions.**

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