



The mapping of palliative care provision in neonatal units in England using the Together for Short Lives Neonatal Service Self Assessment Tool

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Introduction and aims

It is estimated that there are 80,000 babies admitted to a specialist neonatal unit for care in the UK and on average there are 2,109 neonatal deaths each year from causes likely to require palliative care.¹ Statistics show that 98% of neonatal deaths occur in the hospital with very small numbers of babies receiving palliative care at home or in a children's hospice.

Some of these babies for whom there is no hope of cure or who are at the end of their life could benefit from being transferred to the family home, to a children's hospice or to a hospital closer to home so that they can make the most of the short time that they have together and enable more members of the family to be involved in the final days of the baby's life. Together for Short Lives and Bliss share a belief that families should, wherever possible, be given more choice in the place of care and place of death of their baby.

Many children's hospices and community children's nursing teams have already adapted their services to meet the needs of families with babies requiring palliative care and to enable families to have choices about their baby's care. Yet there is still a way to go in enabling more families to access this palliative care support in the community.

In 2009 the former charity ACT (which has now merged with Children's Hospices UK to become Together for Short Lives) published a Neonatal Pathway for Babies with Palliative Care Needs which contained six standards of best practice in neonatal palliative care. This pathway has an associated self-assessment questionnaire which enables neonatal services to assess how well they are delivering care against the standards and goals along the pathway of care.

This report has been produced by Together for Short Lives and Bliss as the result of a project that was commissioned by the Department of Health (England), as part of the £30 million funding programme for children's palliative care, to map the provision of palliative care in neonatal services across England. The aim of the neonatal palliative care mapping project was to establish a baseline of data on how well neonatal units were providing palliative care, to raise awareness of the Neonatal Pathway for Babies with Palliative Care Needs and to identify areas for future development.

As part of the Department of Health funding programme, the former charity ACT and Bliss also worked in partnership to deliver a series of study days and quality improvement workshops on neonatal palliative care.

The Bliss Quality Improvement Programme (BQIP) was a successful initiative for frontline health care professionals working in neonatal units. The tools and techniques that were taught at the BQIP workshops helped to guide the delegates through a systematic approach of looking at the current services they provide for babies at the end of life. Delegates were asked to identify gaps within palliative care provision and put together plans for change and improvement. There was an acknowledgement that some units were limited by time, staff, financial resources and individuals' apprehension towards changed working practices. However with this in mind, the units that participated in the workshops have been able to work within their constraints to begin this process. Delegates found the workshops to be informative and educating, whilst providing an

opportunity to work in their teams and to start planning. Delegates also enjoyed being able to network across units and to share their knowledge and experiences throughout the workshops.

Throughout this project it has become apparent that practice around planning for a dying baby is very inconsistent within the UK. In bigger units and those with intensive care cots, where the likelihood of a baby dying is greater, there is some consistent work - care pathways have been put in place, there is good communication with parents and a multidisciplinary team has been established. However, there is still much to learn. It is noticeable that in smaller units where death is rare, staff find it very difficult to know how to support the baby and their family both on a practical and an emotional level. There needs to be a framework for staff - within their networks - that they can refer to when caring for a dying baby and their family. The 'Neonatal pathway for babies with palliative care needs' is acknowledged as the best place to begin to develop this framework.

Method

Survey design:

A simple online survey was developed based on the Together for Short Lives Neonatal Pathway Service Self-Assessment questionnaire to allow services to rate their performance according to the standards and goals set out in the *Neonatal Pathway for Babies with Palliative Care Needs*.

Within the pathway there are six standards and related goals relating to different stages in the palliative care pathway:

1 st Standard	<p>Breaking News</p> <p><i>Every family should receive the disclosure of their baby's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language they can understand.</i></p> <p>Key goals relating to standard 1:</p> <p>a) Is news shared in a face-to face discussion in privacy? b) Are parents together to hear the news? c) Is helpful written material provided and information conveyed in readily understandable language?</p>
2 nd Standard	<p>Planning for going home</p> <p><i>Every baby and family should have an agreed transfer plan involving the family or carers, hospital, community services and hospice services. The family should be provided with the resources they require before leaving hospital.</i></p> <p>Key goals relating to standard 2:</p> <p>a) Are community services notified as soon as possible?</p>

	<ul style="list-style-type: none"> b) Is community in-reach available? c) Is a transfer plan developed as soon as possible? d) Is a lead community children's nurse identified? e) Are shared medical arrangements in place? f) Is equipment (and supplies) provided before transfer? g) Are training needs of carers considered? h) Are clear lines of communication agreed? i) Are home visits arranged on the same day as the transfer? j) Is a 24 hour contact number provided to the family? k) Is a key worker identified?
3 rd Standard	<p>A multi-agency assessment of the family's needs</p> <p><i>Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.</i></p> <p>Key goals relating to standard 3:</p> <ul style="list-style-type: none"> a) Do babies and families have their needs assessed as soon as possible after diagnosis or recognition that their condition is life-limiting? b) Are holistic and multi-agency approaches used to avoid the need for multiple assessments? c) Is the assessment of needs made in partnership with the family? d) Is the baby kept central to the process? e) Are the needs of fathers and siblings considered? f) Is individuality and ethnicity respected? g) Is straightforward and jargon-free language used? h) Is assessment information made available to the family? i) Is there clarity in respect of the lead role? j) Do those undertaking needs assessments have appropriate skills and local knowledge?
4 th Standard	<p>A multi-agency care plan</p> <p><i>Every family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.</i></p> <p>Key goals relating to standard 4:</p> <ul style="list-style-type: none"> a) Does every family have a key worker to co-ordinate their plan? b) Is information available to the family? c) Does the plan include the whole family and take account of the baby's symptoms and personal care? d) Does the plan include psychological care for the baby's siblings

	<p>and parents?</p> <p>e) Is information about how to access benefits and financial assistance provided?</p> <p>f) Is information about how to access flexible short breaks provided?¹</p> <p>g) Is information about how to access aids and equipment provided?</p> <p>h) Are tailored out-of-hours plans provided?</p>
5 th Standard	<p>An end of life plan</p> <p><i>Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.</i></p> <p>Key goals relating to standard 5:</p> <p>a) Are professionals open and honest with families when it is recognised that the baby is approaching its end-of-life?</p> <p>b) Does joint planning with families and relevant professionals take place as soon as possible?</p> <p>c) Is a written plan of care for the baby and family agreed?</p> <p>d) Are emergency services informed along with all other services/professionals involved in the baby's and family's care?</p> <p>e) Are care plans reviewed regularly?</p> <p>f) Are end-of-life plans reviewed with the GP or doctor at least every two weeks?</p> <p>g) Is there 24-hour access to pain and symptom control including access to medication?</p> <p>h) Are those managing the control of symptoms suitably qualified and experienced?</p> <p>i) Is emotional and spiritual support available to the family and carers?</p> <p>j) Are families supported in their choices and goals for quality of life to the end?</p> <p>k) Do staff involved have access to their own lines of support and supervision?</p> <p>l) Are the needs of siblings and grandparents considered and included at the time of death and immediately afterwards as part of the end-of-life plan?</p> <p>m) Is fully informed consent sought for post-mortem?</p> <p>n) Are families informed of post-mortem findings by an informed professional that they know in a face-to-face setting?</p> <p>o) Are professional contacts informed of the baby's death immediately?</p> <p>p) Is practical advice and written information given about care of the baby's body, official procedures and entitlements?</p>

¹Provision of information about short breaks may not be appropriate in the majority of cases where the baby has not been transferred to services in the community. Participants in the survey were asked about this goal, but we have not included their responses in our analysis of the results as these would have been misleading. If you would like to know more about this, please contact Together for Short Lives.

	q) Are possible heart valve donation and consent issues discussed? ²
6 th Standard	<p>Continuing bereavement support</p> <p><i>Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond.</i></p> <p>Key goals relating to standard 6:</p> <p>a) Are the family allowed time and privacy with their baby? b) Are parents able to follow their own choices and wishes? c) Is bereavement support offered based on assessed needs? d) Are the bereavement needs of siblings recognised and supported? e) Are the needs of care staff considered? f) Are parents provided with details of who they can contact to discuss any plans for a future pregnancy or if they need to make contact with a genetic service? g) Are midwives sensitive to the mother's needs in future pregnancies?</p>

Respondents were asked to rate how often they were able to achieve these goals, rating their scores in the following 5 categories:

- Yes, always
- Yes, most of the time
- Yes, sometimes
- Rarely
- No, never

In addition to questions based on the Neonatal Service Self Assessment tool, further questions were asked about areas for improvement in neonatal palliative care, and any identified needs for further training and education.

Survey methodology:

Bliss contacted the managers of each of the 23 neonatal networks in England, asking them to provide details for the palliative care or clinical leads in each unit in their network. Bliss then wrote to these people where direct contact details were available with a description of the project and a link to the online survey. Recipients of the survey were initially given 6 weeks to complete the online survey, but this deadline was extended and further reminders were sent out to encourage more participation.

²Participants in the survey reported that heart valve donation issues were very rare and so it was difficult to answer the question in the way it was phrased. Therefore, we have not included responses to this question in our analysis of the results, as to do so would have been misleading. If you would like to know more about this, please contact Together for Short Lives.

All 3 levels of neonatal unit in England were invited to respond to the survey. According to data from the RCPCHⁱⁱ, there are 170 neonatal units in England, of which:

- 44 are level 1 units
- 80 are level 2 units
- 46 are level 3 units

These three levels of neonatal unit are differentiated by the types of services they provide:

- Level 1 - Special Care Units or Special Care Baby Units (SCU or SCBU):
These provide special care for their own local population. They also provide, by agreement with their neonatal network, some high dependency services.
- Level 2 - Local Neonatal Units (LNU):
These provide special care and high dependency care and a restricted volume of intensive care (as agreed locally) and would expect to transfer babies who require complex or longer-term intensive care to a Neonatal Intensive Care Unit.
- Level 3 - Neonatal Intensive Care Unit (NICU):
These are larger intensive care units that provide the whole range of medical (and sometimes surgical) neonatal care for their local population and additional care for babies and their families referred from the neonatal network in which they are based, and also from other networks when necessary to deal with peaks of demand or requests for specialist care not available elsewhere. Many will be sited within perinatal centres that are able to offer similarly complex obstetric care. These units will also require close working arrangements with all of the relevant paediatric sub-specialties.

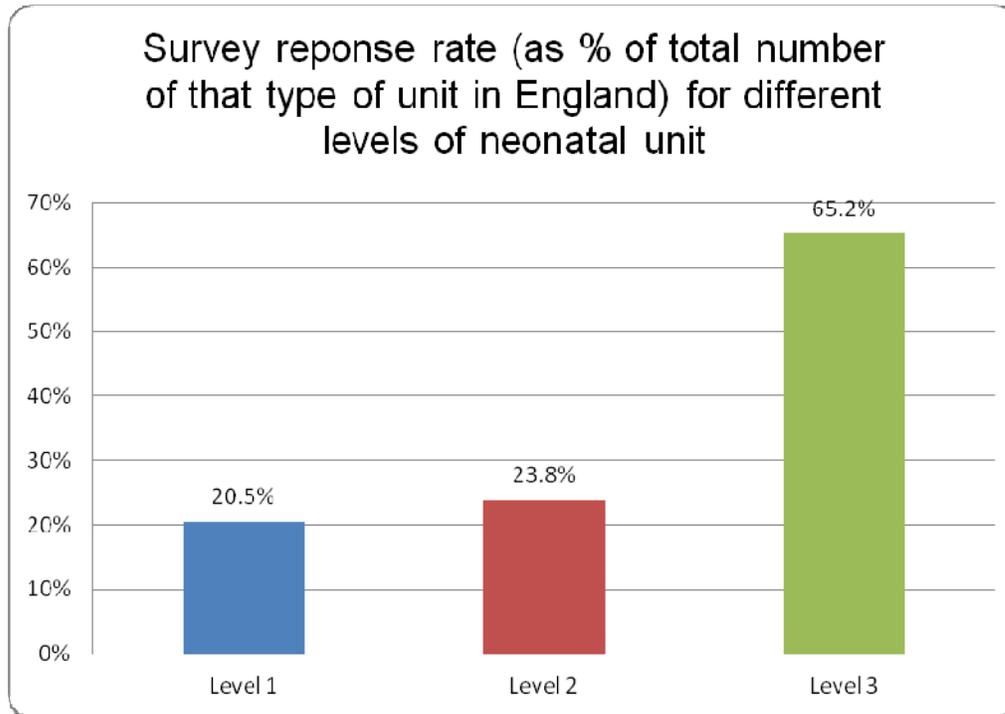
The exact number of each type of unit and the precise definition of their role will vary between networks but each network will have at least one Neonatal Intensive Care Unit. Access to a specialised transport service is also essential for each network. The transport service should facilitate not only the transfer of babies needing urgent specialist support but also enable the timely return of babies to their “home” unit as soon as clinically possible. ⁱⁱⁱ

Results

Responses received:

58 units (34.1% of the 170 neonatal units in England) submitted responses.

This bar chart shows how the response rate varied between the different levels of neonatal unit.

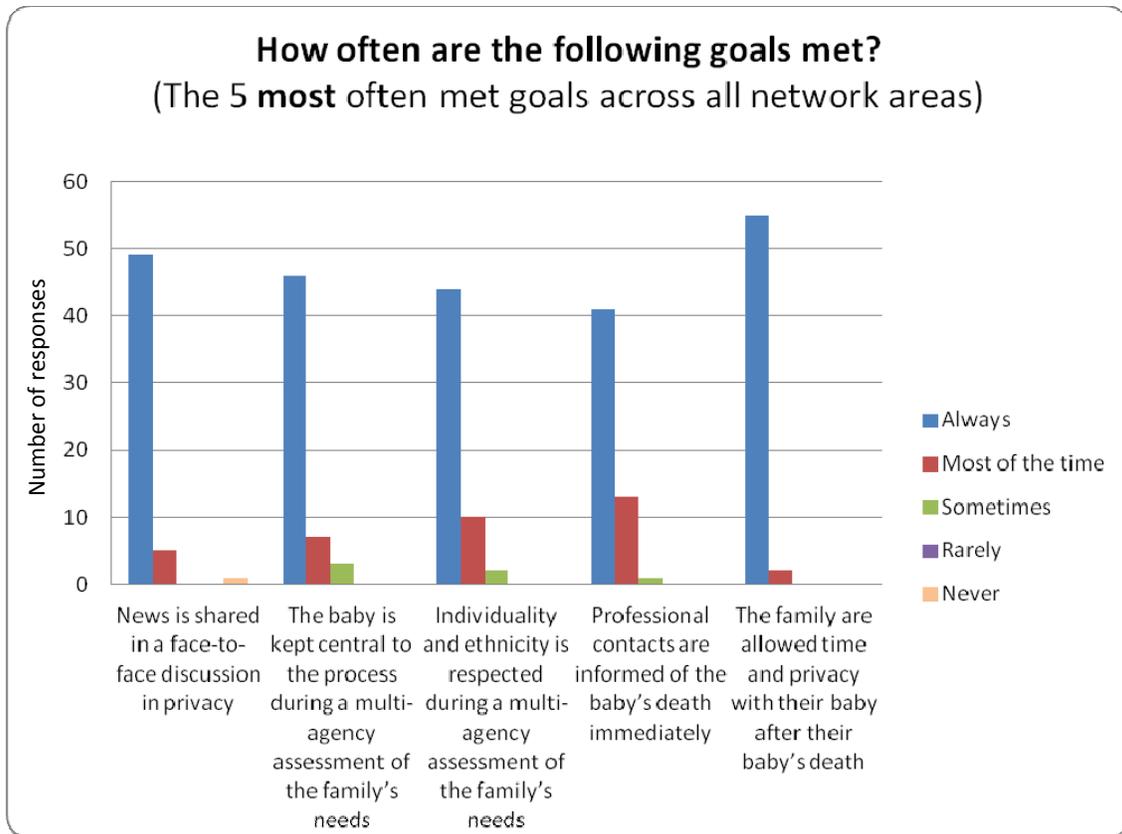


The lower response rate from level 1 and 2 units can be attributed to the fact that caring for a dying baby is not a common occurrence in these units, as very sick babies will usually be in a level 3 unit.

Responses were received from 21 out of the 23 neonatal networks in England.

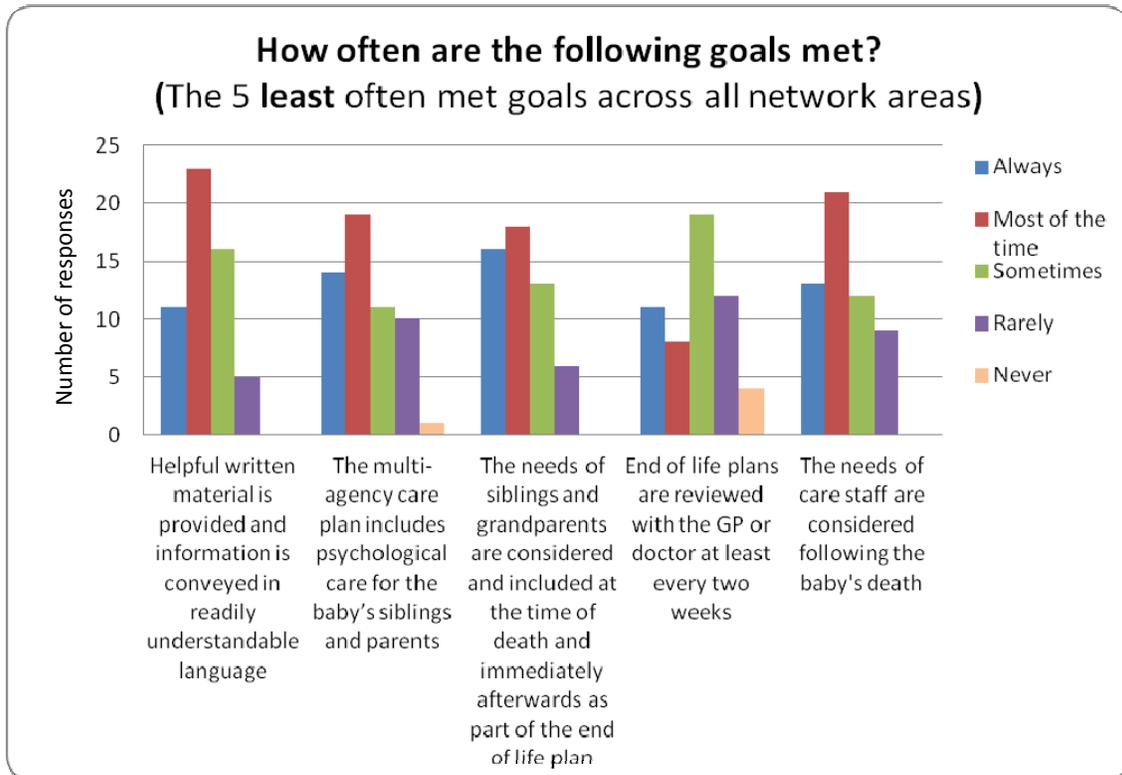
Areas of success

Across all respondents, the goals that were rated as being most often achieved are displayed in the chart below:



Areas for improvement

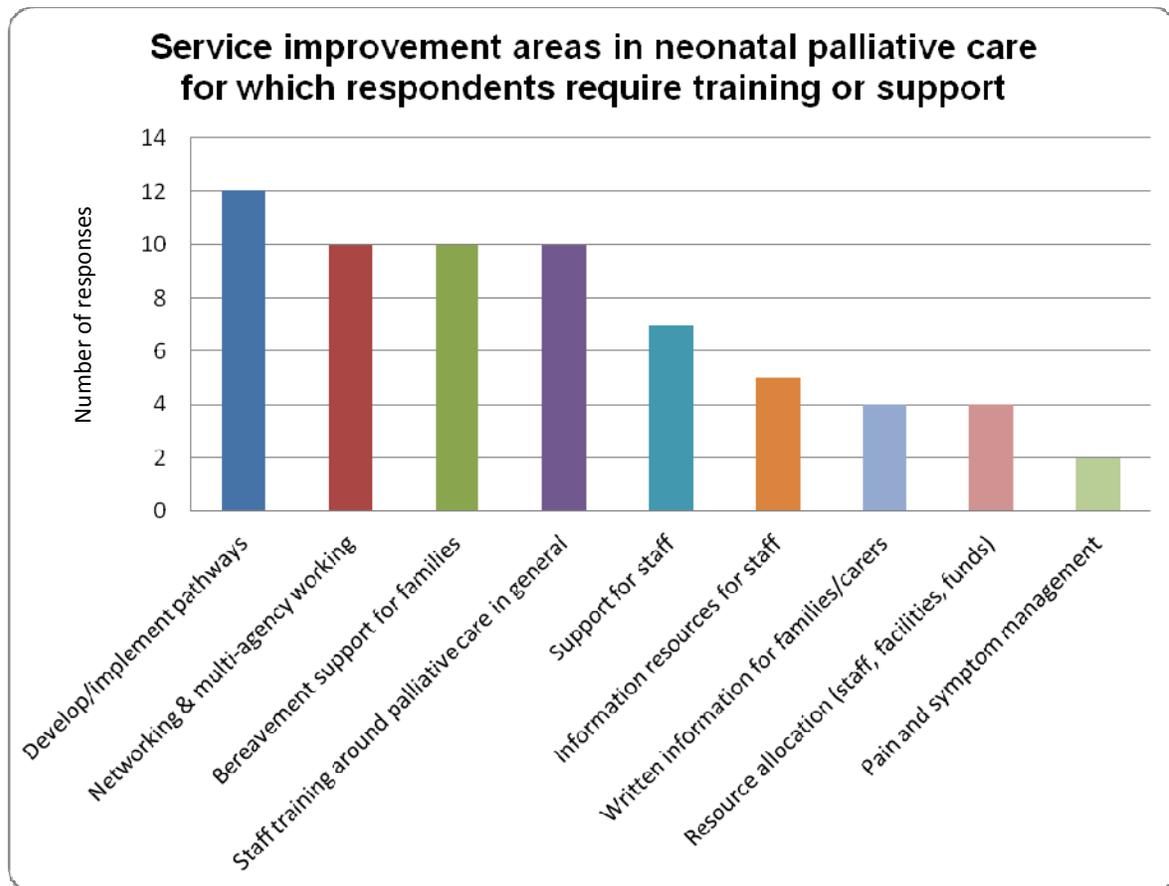
Across all respondents, the goals that were rated as being least often achieved are displayed in the chart below:



Overview of responses:

- 12 of the 58 respondents felt that neonatal palliative care was rarely required.
- 10 respondents reported a need for better provision of bereavement support for families.
- 10 respondents identified a need to develop neonatal palliative care pathways.
- 9 respondents reported a lack of available information and resources around neonatal palliative care – both in terms of practical information for staff and information about what support is available for families.
- 7 respondents felt that staff needed more emotional support.

Respondents identified a number of areas in which they felt that further training and development was required. Their responses fitted into 9 broad categories. These results are set out in the chart below:



Results by unit level

Level 1 units

9 responses were received from level 1 units.

Respondents rated their performance in these areas most favourably:

- Planning for going home.
- Multi-agency assessment of the family's needs.

Goals that respondents reported as being achieved most often:

- When breaking news, news is shared in a face to face discussion in privacy.
- A 24 hour contact number is provided to the family.
- The family are allowed time and privacy with their baby's body.
- The plan includes the whole family and takes account of the baby's symptoms and personal care.
- Parents are able to follow their own choices and wishes

Goals that respondents reported as being achieved less often:

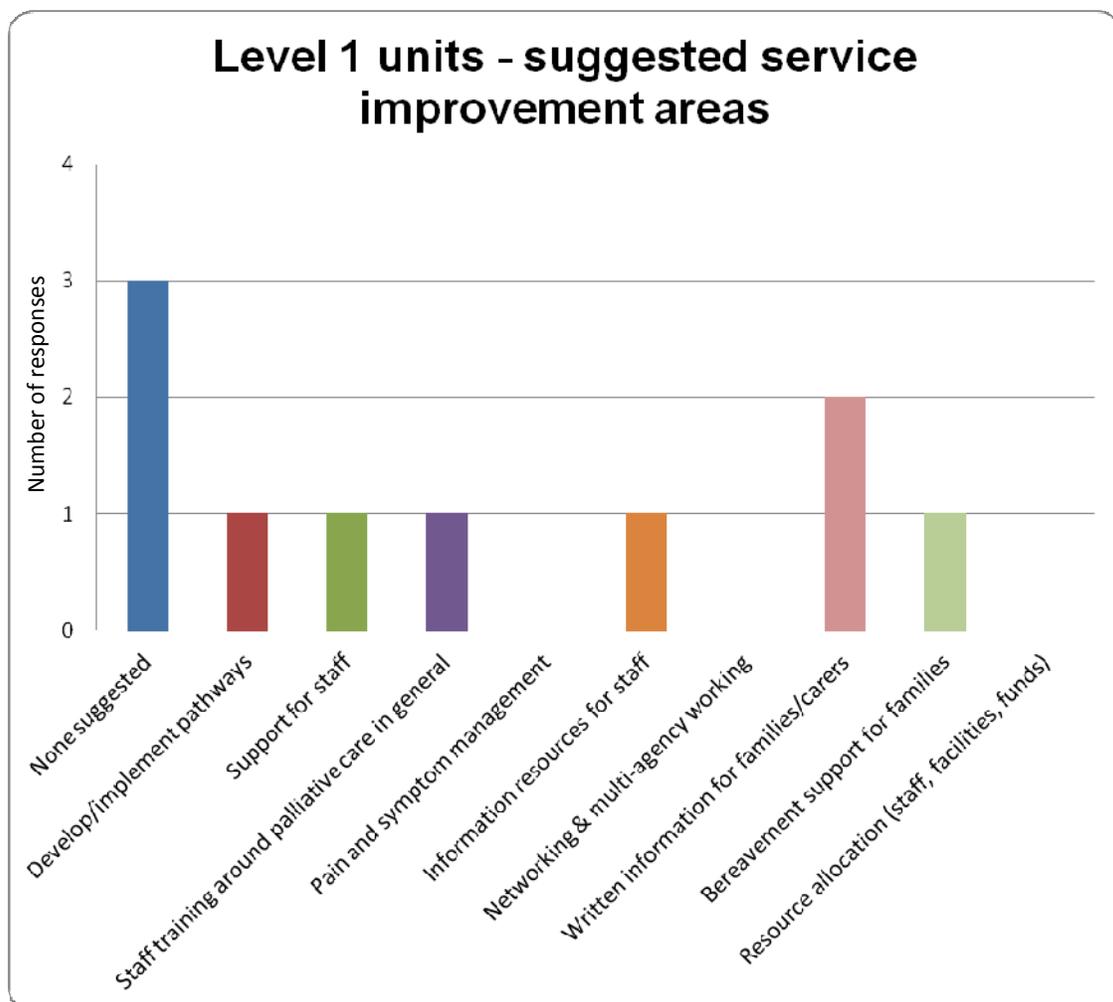
- End of life plans are reviewed with the GP or doctor at least every two weeks.
- The needs of care staff are considered in planning continuing bereavement care.
- Staff involved have access to their own lines of support and supervision.
- When breaking new, helpful written material is provided and information conveyed in readily understandable language.
- Community in-reach is available prior to the baby's discharge home.

Service improvement areas identified by respondents

Of the 9 responses received from level 1 units, 2 highlighted the need for more written information for families and carers:

"More guidance on information for parents/siblings/grandparents during palliative care and neonatal death. Also psychological/spiritual guidance/information for parents."

Other suggested areas for service improvement are displayed in the graph below:



Level 2 units

19 responses were received from level 2 units.

Respondents rated their performance in these areas most favourably:

- Planning for going home.
- Continuing bereavement care.

Goals that respondents reported as being achieved most often:

- The family are allowed time and privacy with their baby's body.
- Professional contacts are informed of the baby's death immediately.
- When breaking news, news is shared in a face to face discussion in privacy.
- Fully informed consent is sought for post-mortem.
- A 24 hour contact number is provided to the family.

Goals that respondents reported as being achieved less often:

- End of life plans are reviewed with the GP or doctor at least every two weeks.
- Staff involved have access to their own lines of support and supervision.
- Emergency services are informed about the baby's end of life plan, along with all other services/professionals involved in the baby's and family's care.
- The multi-agency care plan includes psychological care for the baby's siblings and parents.
- The needs of siblings and grandparents are considered and included at the time of death and immediately afterwards as part of the end of life plan.

Service improvement areas identified by respondents

A fifth of responses from level 2 units reported the need for more staff training around palliative care:

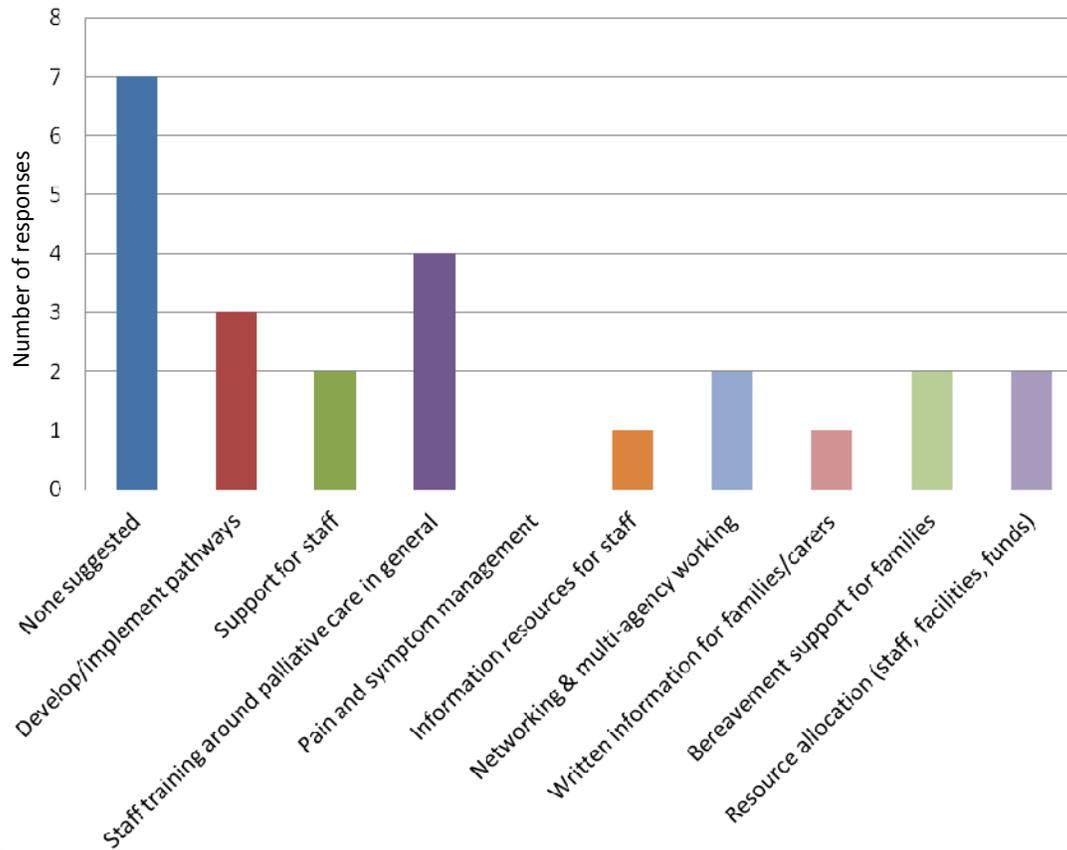
"Support to help neonatal staff recognise when palliative care begins."

Another important service improvement area that respondents identified was around the development and implementation of care pathways:

"We are in the process of drawing up a Care pathway from the antenatal period that extends to late childhood. We have recently attended a palliative care conference and are adapting some care pathways for our local use."

Other suggested areas for service improvement are displayed in the graph below:

Level 2 units - suggested service improvement areas



Level 3 units

30 responses were received from level 3 units.

Respondents rated their performance in these areas most favourably:

- Multi-agency assessment of the family's needs.
- Planning for going home.

Goals that respondents reported as being achieved most often:

- The family are allowed time and privacy with their baby's body.
- A 24 hour contact number is provided to the family.
- The baby is kept central to the process during the multi-agency assessment of the family's needs.
- When breaking news, news is shared in a face to face discussion in privacy.
- The training needs of carers are considered when making plans for the baby to leave hospital.
- Individuality and ethnicity is respected during a multi-agency assessment of the family's needs.
- Professionals are open and honest with families when it is recognised that the baby is approaching its end of life.

Goals that respondents reported as being achieved less often:

- End of life plans are reviewed with the GP or doctor at least every two weeks.
- When breaking news, helpful written material is provided and information is conveyed in readily understandable language.
- The multi-agency care plan includes psychological care for the baby's siblings and parents.
- The bereavement needs of siblings are recognised and supported.
- The needs of care staff are considered.

Service improvement areas identified by respondents

The greater number of responses from level 3 units makes it easier to see some clear consensus in how to improve neonatal palliative care services. The 3 main areas identified were around developing and implementing care pathways:

"Though almost all components of this pathway are available, it has not been formalised into a care pathway. We would welcome support to evolve such a package."

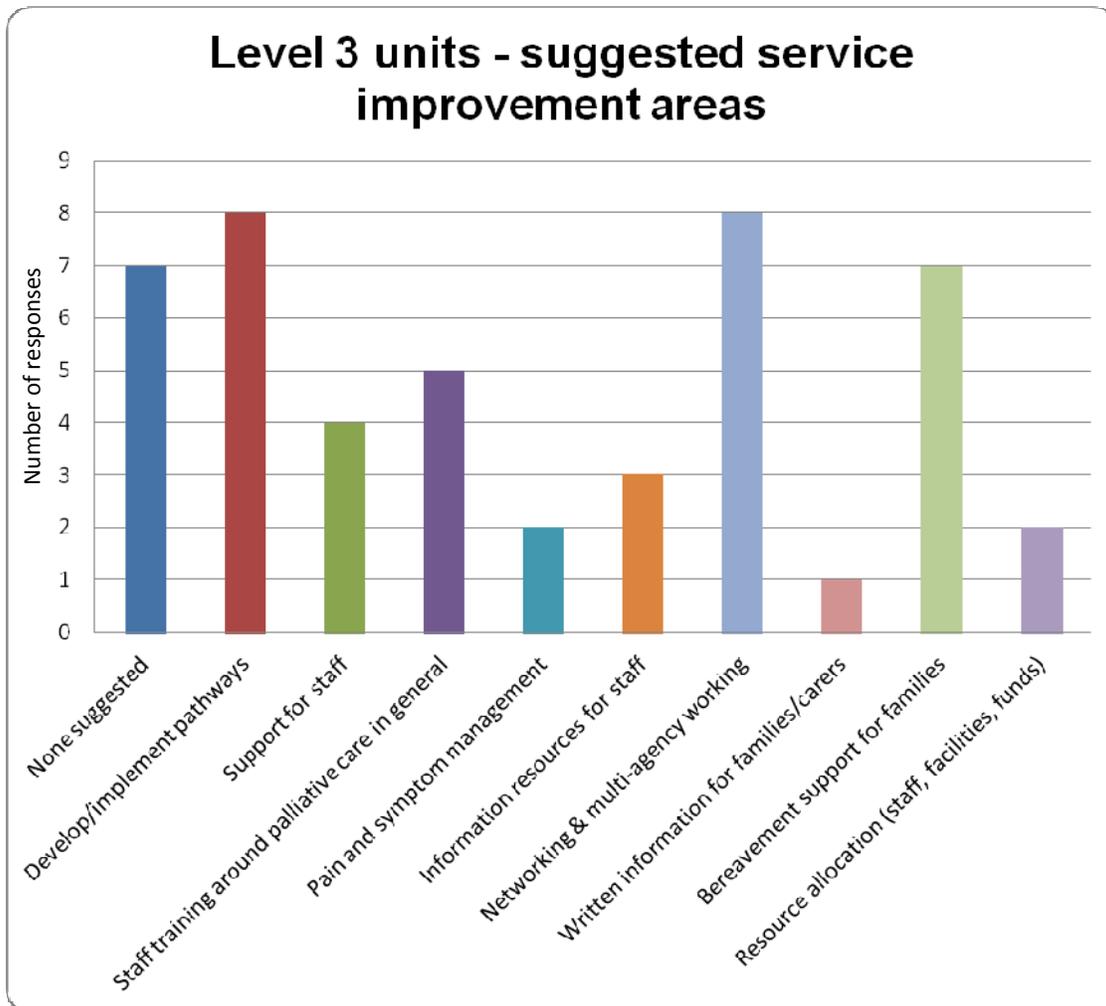
Facilitating networking and multi-agency working:

"We are a level 3 NICU and one of our difficulties is that many of our babies come from 'out of area'. How do we tackle making the links with all necessary services when it is over such a wide area?"

Providing bereavement support to families:

"There is a serious shortage of trained psychological support for families of ALL babies admitted to the unit."

Other suggested areas for service improvement are displayed in the graph below:



Access to training

Respondents were also asked about their access to regular staff training and education in palliative care. This was an open question, but the responses give a snapshot of the way that training on palliative care is prioritised differently between units and networks.

- 22 respondents (37.9%) reported that they didn't have any access to regular training or education on palliative care, or did not answer this question.
- 10 respondents (17.2%) gave examples of how they were able to access such training through their local neonatal network.

"Staff have been attending Network funded places at the Alder Centre at Alder Hey Hospital in addition to local induction information."

- Several responses mentioned conflicting priorities around the provision of training:

"There are opportunities to access Hospice training days and hospital study days but the staff do not seem to be able to take time off to attend these study days."

"Competes with other CPD needs currently as no ring-fenced money."

- A number of responses showed how training and education around palliative care is given a high priority in some units.

"We have a bereavement support team (4 nurses, 2 involved in staff education and 2 as trained bereavement support counsellors) who provide training in this area and we also recently had a training session from a nurse consultant in palliative care which was the national training scheme done in coordination with ACT."

Conclusion

This report provides some interesting baseline data about how well palliative care is provided for neonates across England. Although it is not possible to establish a comprehensive picture, the responses show a growing awareness within neonatal units of how palliative care can be improved for babies and their families, either providing better palliative care within the neonatal unit itself or enabling the baby to go home for their end of life or palliative care.

This growing awareness should be supported by a consistent approach between neonatal networks to monitoring the provision of palliative care. Neonatal units currently report on their services through SEND/Badgernet³, and we recommend that this is where information about the provision of neonatal palliative care should be recorded. Bliss has also produced an audit tool as part of their [Bliss Baby Charter standards](#) which can be used by units to assess their provision of palliative care in reference to the wider context of family centred care.

All but two of the neonatal networks responded and this is very encouraging that at a strategic level the needs of babies who are unlikely to survive are being addressed. There are clearly some regions of England which are developing some excellent models and pathways of palliative care for their neonatal population.

We will be working with these regions to share the good practice that they have developed. We also look forward to working with the services that have identified further training and development needs to support them in working in closer partnership with their local children's palliative care and community services and developing their own regionally focussed palliative care pathways for neonates and their families.

An example of good practice

Implementation of the Neonatal Palliative Care Pathway in Cambridgeshire

This project aimed to implement a palliative care pathway throughout Cambridgeshire between Addenbrookes and Hinchingsbrooke Hospitals and East Anglia Children's Hospice (EACH) Milton Hospice Services and the Children's Community Nursing Team.

The development of a neonatal care pathway between the Norfolk and Norwich (N&N) Hospital and EACH Quidenham in 2008 pioneered the use of a neonatal care pathway approach and made a significant contribution to the evidence base for the development of the *ACT Neonatal Pathway for Babies with palliative Care needs (2009)*.

A multi-disciplinary core project group was set up at both Addenbrookes and Hinchingsbrooke Hospitals in Cambridgeshire to look at developing a similar pathway for this part of East Anglia. With EACH already a key partner in the established Norfolk pathway, both groups decided to adopt and modify this pathway to meet local needs and governance compliance.

³ The BadgerNet Platform provides users with a data management system and has a specific module that follows the natural workflow within neonatal units.

The pathway facilitates the rapid transfer of the baby to the preferred place of care with detailed planning by the multi-disciplinary team to meet the immediate and short-term symptom management and care needs of the baby and the psychological and emotional support needs of the parents, siblings and extended family.

Two pathways have been created, one with Addenbrookes Hospital and the other with Hinchingbrooke Hospital.

A range of training has been offered to staff in relation to the pathways.

The EACH library and information service has developed a catalogue of books and articles relevant to the pathway, accessible to staff from all the services and new resources are highlighted in the regular library bulletin.

A poster and leaflets, giving information about EACH services for families are now on display and available in the neonatal units.

Recommendations from the project

1. Further training for staff at Hinchingbrooke (staff shortage limited numbers trained during project period).
2. Internal protocols for referral between EACH localities needs disseminating.
3. Ipswich team need to undertake training with regard to the pathways process.
4. Further information should be disseminated to Children's Community Nursing Teams, which engages these teams and explores their pivotal role in the pathway.
5. The development of EACH link nurse role to ensure continued communication and coordination between teams and families.
6. The on call arrangements for the EACH nursing and support services team needs reviewing to ensure 24/7 availability of the appropriate staff.
7. That the core project groups undertake an audit and review of the pathway after ten babies have used the pathway or in six months time, whichever occurs first.
8. The Addenbrookes Hospital Neonatal Unit provides care for babies who live outside EACH catchment area. Liaison needs to take place to ensure that teams and service providers in these areas are working with the pathway so that all families have equal access to the care and support that the pathway can provide.

Statistics from the first 6 months of the pathway between EACH Milton and Cambridge University Foundation Trust

- 17 babies used the pathway between 1st March to 20th September 2011
- 3 have continuing care needs
- 2 transferred to other hospices
- 4 referrals were the after death of the baby

Of the remaining 8 babies the location of death matched the parental choice in 4 of the eight cases. See table below:

Location of death	Parental choice for preferred location of death	Actual place of death
NICU	0	4
Hospice	2	1
Home	2	2

Local Hospital	1	1
Not recorded	3	n/a

Reasons for this discrepancy:

- The baby died unexpectedly quickly.

Appendix

For each of the 23 neonatal networks we have identified the number of level 1, 2 and 3 units and mapped the children's hospices services that are based in that network region. Further details of all the children's hospice services can be found at www.togetherforshortlives.org.uk

1. [Bedfordshire & Hertfordshire](#)
2. [Central Newborn Network](#)
3. [Cheshire & Merseyside](#)
4. [Essex](#)
5. [Great Manchester Neonatal Intensive Care \(MCN\)](#)
6. [Kent Neonatal Network](#)
7. [Lancashire & South Cumbria](#)
8. [London - North Central London Neonatal Network](#)
9. [London - North East and North Middlesex Neonatal Network](#)
10. [London - North West London Perinatal Network](#)
11. [London - South East London Neonatal Network](#)
12. [London - South West London Neonatal Network](#)
13. [Norfolk, Suffolk & Cambridgeshire](#)
14. [North Trent Neonatal Network](#)
15. [Northern Neonatal Network](#)
16. [Peninsula Neonatal Network](#)
17. [South Central](#)
18. [Southern West Midlands Newborn Network](#)
19. [Staffordshire, Shropshire & Black Country](#)
20. [Surrey & Sussex Neonatal Network](#)
21. [Trent](#)
22. [Western Neonatal Network](#)
23. [Yorkshire Neonatal Network](#)

References

ⁱ Department of Health: Health and Care Partnership Analysis, 2007. *Palliative Care Statistics for children and young adults*. Written by Hugh Cochrane, Sanjaya Liyanage and Rosemary Nantambi.

ⁱⁱ Neonatal unit/trust/network list (version 7), RCPCH – National Neonatal Audit Programme. <http://www.rcpch.ac.uk/nnap>

ⁱⁱⁱ NHS & Department of Health: Toolkit for High-Quality Neonatal Services, 2009. Available from World Wide Web: <http://www.neonatal.org.uk/documents/4650.pdf>, in British Association of Perinatal Medicine, 2010: Service Standards for Hospitals Providing Neonatal Care, 3rd edition. Available from world wide web: http://www.bapm.org/publications/documents/guidelines/BAPM_Standards_Final_Aug2010.pdf