Caring for sick babies

The case for change: supporting neonatal services in Norfolk, Suffolk & Cambridgeshire

In association with the East of England Perinatal Networks

Outcome summary
Your feedback and our response
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What we did

To improve services for the smallest and sickest babies and make sure that they have the best chance of surviving and living full and healthy lives, we needed to make some small changes to services in some areas in Norfolk, Suffolk and Cambridgeshire.

This in turn helped us to secure the future of neonatal care in your local hospital, allowing us to invest in staff where it is most needed.

We wanted to make sure that, whilst these changes had to take place so that services meet national medical standards, we had still asked local parents and families about how we could support them if their baby was born sick or small and needed highly specialist care.

Why?

The majority of babies are born with no complications, but for the very small numbers who require intensive care (around 140 out of around 30,000 births in the three counties), it is important that they are cared for in hospitals where staff have regular experience of their complex conditions. These units are known as Neonatal Intensive Care Units (NICU).

There are also national quality standards issued by the Department of Health and clinical standards issued by leaders of neonatal care, which all units have to meet.

This means that some hospitals have or will experience a small change in the types of babies that they can treat in the long term, but all units have to be able to stabilise and care for babies who are born unexpectedly very small or sick until they can be transferred to a NICU.

However, once a baby’s condition has improved during their stay in a NICU, they will be transferred back to their local hospital to receive ongoing care.

High quality services and staff are available, and will remain, at all units in Norfolk, Suffolk and Cambridgeshire, here’s how:

There are three types of neonatal unit:

**Neonatal Intensive Care Unit (NICU)** – Addenbrooke’s Hospital and Norfolk and Norwich University Hospital – where all babies from Norfolk, Suffolk and Cambridgeshire requiring intensive care can be treated, as well as providing high dependency and extra support for babies in their catchment area.

**Local Neonatal Unit (LNU)** – Ipswich Hospital, Queen Elizabeth Hospital in King’s Lynn and Peterborough City Hospital – where babies who require intensive care for less than 48 hours, high dependency care and all other extra support are treated.

**Special Care Baby Unit (SCBU)** – Hinchingbrooke Hospital, James Paget Hospital and West Suffolk Hospital – where babies who require high dependency and extra support are treated.

For the 140 babies a year that require the most specialist intensive care at a NICU, there are hundreds more that need high dependency care and extra support (known as special care) when they are born. This is why these services and the babies that need them will remain at their local hospital – because they are needed and they provide excellent care.
Whilst we understand that some parents and families will have to travel further than their local hospital to visit their baby (on average 10 babies or 10 families from each unit per year), we have been clear that this change needed to happen to secure improvements in care, meet national clinical and quality standards and allow us to carefully invest in staff in the right places.

This is why we wanted to speak to people about how they thought the changes would affect parents and families, so that we could reduce the impact of having a baby admitted to a NICU.

**How we did it**

We sent information packs about the small changes and how people could feedback to us to:

- All 8 neonatal and maternity units for distribution to their staff, parents and families on the unit
- Some 300 GP surgeries
- 4 Local Involvement Networks
- Bliss
- 17 Parent support groups
- 4 Local council Health Overview and Scrutiny Committees
- 8 Surestart Children’s Centre Managers for onward distribution to their networks

We also wrote to all MPs and GPs to explain what we were doing, and uploaded the information packs onto our website.

We held nine discovery events in June and July to speak to parents, families and the public about how we could make things easier for people whose babies might be admitted to a NICU. These were mostly held in SureStart Children’s Centres, where they were advertised through posters (which were also sent to the same places as the information packs) and were accompanied by news releases to local media.

We also attended some nursery fun days and a baby fair:

- Bury St Edmunds Library
- Huntingdon Children’s Centre Family Fun Day
- West Suffolk Baby and Toddler Fair
- East City Children’s Centre, Norwich
- Meredith Children’s Centre, Ipswich
- The Priory Centre, Great Yarmouth
- Homerton Children’s Centre, Cambridge
- Acorn Children’s Centre, Peterborough
- St Augustine’s Children’s Centre, King’s Lynn

Before doing all of this, we also visited each hospital’s Maternity Services Liaison Committee which is made up of midwives, health visitors and mums and dads.

The period in which people could feedback to us ran from 16 May until 15 August, 2011.
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What we asked

1. To help improve the service across the east of England, what advice and support can we offer to parents and families if their babies are admitted to a neonatal unit?
2. What effects, if any, do you think having a baby admitted to a Neonatal Intensive Care Unit could have on parents and families if this unit is not their local hospital?
3. What do you think we can do to help encourage a positive experience for families or minimise any effects?
4. If you have experience of neonatal care, what worked well and/or perhaps not so well in your opinion?
5. Are there any other comments you would like to make about neonatal services in Norfolk, Suffolk and Cambridgeshire or the plans?

What you said

There were 18 written feedback forms returned to us, including a response from premature and sick baby charity Bliss. 52 people also attended the discovery events to speak to us about the changes and all of this was recorded and analysed too.

Whilst we were looking at all of the responses, we found that there were two clear areas of feedback that people had given us. These are shown below with the top five suggestions from each listed in order of the number of responses given. Respondents gave more suggestions to improvements to services than issues and impacts of the changes.

The whole body of feedback can be found in the full feedback analysis report, available at www.eoescg.nhs.uk

Cheryl France, Parent Representative

“I have been involved in this project from the beginning and have had the opportunity to influence and shape the decision making. The feedback to the engagement process has been fantastic, it was wonderful to have so many parents and families provide useful comments that have been reviewed and considered by the SCG Board. Those involved in this project want what is best for the smallest and sickest babies and have been working hard to ensure that the infrastructure and staffing is of the upmost quality, whilst ensuring safety and family centred care.”
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Suggestions for improvements to services

1. Information

People felt that providing leaflets on equipment, transfers and treatments was most important. Informing parents about the available facilities, for example where a mother could express breast milk privately, would also be useful. Similarly, units should also tell parents about the available services, for example how to access free car parking if it is available.

There was also a feeling that parents should be informed of who is who on the unit and also to be aware of the routine of the unit i.e. what happens when.

A debrief with maternity staff when mum returns home was cited as something that worked really well.

Some other suggestions of types of information that would be useful were also made:

- Plenty of leaflets on a wide variety of information available in all languages
- Someone to explain what happens on a NICU and during transfer
- More information about Necrotising Enterocolitis and other conditions
- Where consultants are available to meet parents, this should be made more widely known
- Explanation of different levels of care
- Inform parents exactly what is happening – i.e. the reason for not seeing a doctor is because their baby does not require it
- Warn parents of the severity of the situation
- Warn parents if procedures need to be carried out
- The parent support group should be publicised more
- With particularly strange treatments (such as phototherapy) it would be useful to have a leaflet etc to explain what is happening
- A welcome pack (containing dummies, bottles and information on where to buy clothes)
- Information on weaning premature babies

However, an awareness that leaflets are useful but that the information does not always register with parents was cited as important.

Consistency of information and for the same to be given to all parents about facilities, services and processes was highlighted.

2. Communication

People felt that another important aspect of care was to explain all information to parents clearly. Where respondents were informed clearly, they felt that this made things much easier and conversely where they were not it made their stay on a neonatal unit more difficult.

Respondents also felt that constant communication was important to keep parents informed of what is happening with their baby, and that regular progress reports were essential to plan for baby’s home-coming or otherwise.

Parents said that the help and support received from staff was crucial during their stay on the neonatal unit. Where communication of procedures occurred and explanations were given, they felt more at ease.

A respondent also felt that a phone call the day after discharge was reassuring.
3. Staff

The importance of supportive and positive staff was cited as essential and where this occurred respondents felt that their stay was much easier. Respondents felt that staff were very good at providing excellent care, both for parents and baby.

However conversely others felt that staff were more there to care for the babies rather than for parents. This didn’t mean that the care they had received was poor, just that they could have perhaps been given more support.

Respondents felt that nurses were best placed and important for reassuring families, but they also felt that introductions to senior staff were required. Some people felt that more staff were needed, despite others feeling that the availability of unit staff was good.

Other suggestions/comments made about staffing included:

- Roaming staff instead of transport service, where a team of doctors and nurses respond to hospitals rather than transferring babies in an ambulance
- Nursing shifts are too long
- Registrars good
- Availability of unit staff is good
- Specialist training for health visitors on weaning premature babies
- Consistency of staff is good for parents (and is much better in smaller units)
- Realism, honesty and support of unit staff is important
- Nurses could stand at incubators during ward rounds and report back what consultants had said
- There is more continuity of staff in the smaller units, but the NICUs tend to involve parents more in care

4. Emotional support

Respondents felt that counselling should be made available for parents and that drop in sessions should be provided for parents.

This was elaborated on by several people who said that it was important to establish a wider support network. An example of this was access to parent support groups. Where support groups do exist, for example where provided by Bliss, respondents felt that they were useful in helping them come to terms with having a premature baby.

Examples of where support networks worked well or not so well were cited:

- In smaller units the support network is lacking, whereas in at least one NICU respondents felt there are lots of people to speak to
- Emotional support at NICU is good, but has since declined as visits only take place once a week by a parent
- The support received from the visiting parents was very good for advice on how to bond with baby
5. Financial assistance

Respondents gave lots of suggestions of where financial assistance could be given to parents and families:

- Subsidised meals
- Free car parking
- Help with transport costs
- Provide free, reactive transport (rather than just at set times)
- Discount cards
- Food vouchers
- Food costs and quality
- Nappies for premature and small babies to be made available on the units, as they are more expensive and harder to source than normal nappies

Other suggestions for improvements to services and things that worked well for parents:

- Accommodation for parents (and siblings) is essential and should be guaranteed
- More should be done to highlight premature birth and at an earlier stage of pregnancy (through leaflets and DVDs), so that parents have a chance to consider what they might do if they were to go into early labour, or if their baby was sick
- Community aftercare is very important to parents
- It is helpful to have good news stories of babies displayed or available for parents to view, whether in the form of display boards or photo-books
- Parents and families should have open access to their baby at all times
- Grandparents and wider family members should also be more involved in care on the unit
- Encouraging parents to be involved with their baby’s care worked well
- Reduce transfers because of capacity, but where they were necessary every effort should be made to get baby back close to home as soon as possible
- Parents should be moved with baby
- Mother and baby should be cared for in the same hospital
- It is important to encourage parents to challenge decisions made about their baby, particularly where transfers were being made and the location of the receiving hospital
- Respondents felt that a tour of the neonatal unit helped them to cope much better
- A consistent approach to parental support should be built across all hospitals. This includes financial and emotional assistance
- Quiet room
- Toilets
- Having issues dealt with promptly
- Correct discharge thresholds
- Parents to be allowed to remain with their baby during doctors rounds
- Cleanliness
- Appropriate security
- Provision of small baby clothes
- One to one care for each baby
- Keeping multiple siblings together
- Facilities for other children at unit (crèche)
- Homely environment on the unit, with a kitchen to make food
- Listening to parents
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- Staff to wear name badges with job titles
- Acute Neonatal Transport Service (ANTS) was very good
- Availability of milk
- More transitional care cots are needed – it is good to be able to room-in especially for fathers
- Emotional therapy and training – what to look out for as baby grows up
- Entertainment on unit for siblings during visiting
- Provision of a diary for parents to record their thoughts
- Breastfeeding – where there was no pressure to do it and was made to feel like the parents choice
- More privacy on the neonatal unit, similar to that of the maternity ward
- A pack to be made available to parents in event of a transfer to contain food vouchers, taxi tokens etc

**Impacts and issues of the changes**

1. **Emotional effects**

People felt that having a baby on a neonatal unit is emotionally challenging as you can feel isolated and lonely. They also said that all of the machines and equipment were particularly intimidating.

They said that the emotional effects of having a baby transferred would be the most difficult aspect of the changes, for example not having your baby close by if there is a problem.

Respondents also stated that returning home can be daunting after stay on the unit.

2. **Financial impacts**

The burden on families of travelling further away to visit their baby was challenging as well as the associated costs of food, parking and childcare for other siblings.

Other financial impacts included:

- Impact on other family members because of extra travelling to visit a unit further away
- Parents losing out unexpectedly on pay they had planned on receiving in a full-term pregnancy
- Fathers having to travel (and also having to return to work earlier)
- Fathers having to travel to and from the unit with other family members
- Having a c-section meaning mothers cannot drive to the unit (and may have to get a taxi)

3. **Impact on wider family, father and siblings**

People felt that having a baby at a unit further away would impact on the wider family unit, as they would not be able to visit as easily.

However they felt that the impact of having a child in a NICU would have the most impact on fathers and siblings. This was particularly the case where respondents had other children at home whilst their baby was on a neonatal unit.

There was concern that having a baby in a unit further away could potentially exclude fathers further, as there is not a lot of opportunity to bond with baby once they are born anyway.

Fathers found having a baby on a NICU daunting.
4. Support network

People were concerned that not having family close by would put extra strain on parents. They also felt that the lack of availability of support locally from staff in the NICU (when a baby is discharged home from a NICU or to a unit closer to home) would have an impact on families.

There was again concern that there are not enough parent support groups.

5. Travel

Access to public transport can be poor, especially in rural areas, meaning it would be more difficult for families in these areas to get to a NICU.

Additionally people said that some families only have access to one car, if at all, and that this would make it difficult for them to travel to visit their baby.

The distance of some areas from the NICU also concerned respondents, as travel times would be increased.

The other impacts and issues of the changes fed back are listed below:

- Parents found that having a baby transferred away from the nearest hospital was quite distressing. They were concerned that having a baby transferred away from home would be worrying for families because of the journey times if their baby’s condition deteriorated.
- Staff in smaller units would lose skills if the most acute care was delivered at specialist centres.
- Where a multiple birth occurs, there was concern that babies would be placed in different hospitals if one required intensive care and the other did not.
- Parents found it difficult being on the maternity ward with other mothers and healthy babies, when their baby was on a neonatal unit.
- Some people said that they did not receive any community aftercare and felt like they were left on their own to care for their baby after discharge.
- There was concern that mothers would be impacted by the changes because they would not be able to be there for their baby as much in some cases. Where mum cannot be transferred with the baby or to see baby because of a c-section, this has an impact on the mother baby bond.
- The amount of time families could spend on the neonatal unit would be reduced because of the extra travel times to and from a NICU from home, and where parents have to rely on other people for lifts.
- There was concern that there can sometimes be a long delay between giving birth and being able to visit baby.
- Special consideration should be given to people who live in rural areas as transport could be an issue for them.
- NICUs are not always very accessible, especially as they are on busy roads around cities where traffic can be an issue.
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- There would be increased pressure on the ANTS team as a result of the changes, because more babies would be transferred out rather than remain in their local unit
- Accommodation was often over-subscribed and, in some cases, side rooms were only available if parents were willing to pay or mum had a diagnosis of a virus
- Some maternity units lacked facilities for families in terms of space and accommodating their other children
- There was the potential for conflict between maternity and neonatal unit staff because, for example, maternity staff would want mum to rest, whereas unit staff would want her to visit baby as soon as possible
- Responsibility for a woman (GP or hospital) if there are complications after discharge, and that the lack of clarity around this can be frustrating
- The continuity of midwives could be improved, but having one person with you throughout a caesarean-section was particularly positive
- It was difficult for mothers to organise a return to a unit to breast feed their baby
- There was excellent care for baby, but lack of support for post natal mums, especially with breastfeeding. There was also not enough space for private breast-feeding
- Where new mums come onto the neonatal unit, it was felt that they should be asked if they intend to breast-feed or not, rather than assuming they will bottle feed. Staff should also avoid discouraging mum from breast-feeding if she is finding it hard
- Sometimes unit staff could be heard talking about the difficulties of other parents and babies

Sue Rubin, Lead Clinician

“As Lead Clinician for the Eastern Perinatal Network and one of the clinical representatives for the project, I have been involved right from the start. It is really great that we have been able to speak to parents and families about how we can more closely match services to their needs – their views have all been taken into account by the SCG Board.

“We will continue to involve people who use the services, so that we can continue to improve support for families to ensue safe and sustainable neonatal services across Norfolk, Suffolk and Cambridgeshire.”

Great Yarmouth and Norfolk

We received a particularly high response from people in the areas surrounding the James Paget University Hospital, when compared with other postcodes.

We understand that people in this area had concerns about their local hospital, especially when it came to what they told us was the removal of services and the extra travel distances for families to the Norfolk and Norwich University Hospital.

We want to be clear that the excellent service provided by the unit staff at the James University Paget Hospital will continue, and that we are investing nearly £400,000 in staff there to secure this. However, the average of 13 babies that may need to be transferred out from there to a Neonatal Intensive Care Unit will be seen by staff who have more regular experience of their complex conditions. Medical research shows that this will improve outcomes for those babies.

Of course, as one person told us, these are not just 13 babies but 13 families and we will do everything we can to make sure that they are supported by using the feedback given by the people who responded to us. This includes recruiting a specialist nurse who will be dedicated to supporting families (see page 11)

There are still a number of things that we need to work on with the James Paget University Hospital and Norfolk and Norwich University Hospital, especially around things like clinical support between the two hospitals.

However, both hospitals now have Midwifery Led Birthing Units which means that more beds
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will be available for mothers who might need extra help with giving birth.

We are also clear that no babies will be transferred from the James Paget University Hospital to the Norfolk and Norwich University Hospital until we are sure that everything is in place to properly support them and their families.

More detail about the investment in staffing and what we are doing to support families can be found on the following pages.

What we’re doing in response

The East of England Specialised Commissioning Group (SCG) Board met on 26 September, 2011 and looked at the feedback given to them by parents and families with experience of neonatal care.

They agreed that:

- The clinical leaders of neonatal care in Norfolk, Suffolk and Cambridgeshire should continue to work with premature baby charity Bliss and their local champions on ways to support local parents and families
- They would do this through a ‘Family Centred Care Nurse’ which will only be the second of its kind in the UK. The nurse will be based at the Norfolk and Norwich University Hospital and should be in place by the end of 2011 (see below)
- In a number of units there should be a single policy to support parents and families with car parking costs, travel arrangements and breast-feeding
- More work should be done with young people, disabled people and ethnic minorities through local Children’s Surestart Centres

They also heard about things that had already been put in place:

- A parent information leaflet which explains where babies could be transferred if required and what would happen, as well as the support they can expect to receive
- How the £1.4 million investment in staffing in this year alone is already being spent in units across Norfolk, Suffolk and Cambridgeshire (see page 12)

Bliss Nurse – only the second of its kind in the UK...

Much of the feedback we received was based around the need to care for parents and families as well as for babies. When we coupled this with parent experience that we already knew about, we knew that we needed to try and introduce some extra support.

Working with Bliss, the charity for babies born too soon, too small and sick, the East of England Perinatal Networks (who are the clinical network responsible for neonatal care in this region) have decided to use some of the investment money from the SCG to recruit a Bliss Nurse.

This will only be the second of its kind in the UK and will be based at the Norfolk and Norwich University Hospital where they will provide support to parents and families at Ipswich Hospital, Queen Elizabeth Hospital in King’s Lynn and the James Paget University Hospital.
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They will be responsible for introducing new procedures that will make sure that parents and families are always placed at the centre of care, and will encourage them to feedback their views more regularly. This will mean that services will always be responsive to the needs of parents and families.

Most importantly, they will empower them to be more involved in the care of their baby, and encourage staff to deliver care that is tailored to suit the needs of each family. This will include educating parents and families, and introducing systems that parents can use to find out more about neonatal care and specific conditions that their baby may be suffering from.

**Andy Cole, Chief Executive, Bliss**

“Bliss is delighted to be working in partnership with the East of England Perinatal Networks to secure the second Bliss Nurse. Family-centred care is widely recognised as a crucial part of a premature or sick baby’s journey through the neonatal unit. The family’s experience should be at the heart of the baby’s care, giving parents the skills and information to be confident care providers to their baby.”

£6.2 million over the next four years…

Before we even began speaking to a wider number of parents and families about neonatal services in Norfolk, Suffolk and Cambridgeshire we had secured nearly £6.2 million to spend on staff in units across the east of England over the next four years. Over £1.4 million of this is currently being invested in units in Norfolk, Suffolk and Cambridgeshire with the rest spent over the coming few years. This is despite a tough economic climate, but we are pleased that we are able to support neonatal care in this way and to secure care in local hospitals for the majority of families.

Most of the money will be spent on nurses, but some doctors will also be recruited.

Sim+ – another leading project for the east…

Many of the people who came to our discovery events mentioned how impressed they were with new projects such as reducing diseases like Necrotising Enterocolitis (NEC) – a very serious condition which affects the digestive system of premature babies. This is a quality improvement project which aims to test whether simple evidence based processes can help to prevent babies developing NEC, and involves helping parents to get more involved with care of their baby.

The next innovation which is being introduced as we speak is a training programme for all neonatal units in the east called Sim+. The East of England Perinatal Networks recently won £150,000 from NHS East of England’s Regional Innovation Fund to buy equipment and train staff to improve their skills in resuscitating and stabilising babies who are born small or sick. All units are currently taking part in this training.
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The project involves using a life-like dummy to simulate a variety of different problems that babies can experience when they are first born. The east of England is the first to start this programme by involving all of it’s units at the same time.

Project group

The neonatal services in Norfolk, Suffolk and Cambridgeshire project group is dedicated to the improvements and changes to neonatal care in these three areas.

It has members from your local NHS, clinicians and a parent representative who have all discussed the feedback that was given and made the recommendations to the SCG Board.

It was also responsible for influencing the investment in staffing which was secured in February 2011.

Thanks

We would like to thank all of the people who took the time to feed back their comments to us, in particular Bliss who have been working closely with the East of England Perinatal Networks to recruit the new Bliss Nurse.

We would also like to thank the East of England Perinatal Networks for their ongoing clinical partnership with us, and their extensive help on this project.

Finally, we would like to end on the excellent work carried out around-the-clock by neonatal unit staff.

The feedback we received shows that parents and families would not have got through an incredibly difficult time without their help and support.

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Keep in touch…

We are always keen to hear from parents and families with experience of neonatal care, as part of ongoing efforts to make services as suitable to the needs of service users as possible.

There are a variety of ways to get involved with our work, whether it is with neonatal services or in another of our service areas.

Visit our website www.eoescg.nhs.uk to find out more or email communications@eoescg.nhs.uk

If you are interested in neonatal care, you can visit www.neonatal.org.uk or www.bliss.org.uk

Alternatively, you can email neonatal@eoescg.nhs.uk with your questions or comments.
This information is produced on behalf of the 13 Primary Care Trusts in the east of England:

NHS Great Yarmouth and Waveney
NHS Peterborough
NHS Cambridgeshire
NHS Norfolk
NHS Suffolk
NHS Mid Essex
NHS North East Essex
NHS South East Essex
NHS South West Essex
NHS West Essex
NHS Hertfordshire
NHS Bedfordshire
NHS Luton

The document is available from www.eoescg.nhs.uk

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