

"You said... we did"

Meeting the promise of measuring
parents' experience of neonatal care



1st edition, 2013
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"The Neonatal Nurses Association seeks to ensure that the delivery of high-quality neonatal care is the priority of all our members, whether they are nurses or allied health professionals. Listening to what parents have to say about the experience, and reflecting on what this means for our own practice, is a powerful learning tool. We need to use this to identify how we can improve families' journeys in the future."

Tina Pollard, Chair NNA

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Registered charity no. 1002973
Scottish registered charity SC040878

Introduction

In 2008, Lord Darzi's High Quality Care for All – NHS Next Stage Review¹ stated that quality measures would “go beyond mortality rates for surgery to include patient-reported outcomes and patient experience of services”. More recently, the Francis report² reinforced “the need to put patients first at all times”.

The direction of travel in the NHS is to make ‘patient experience’ a concern equal to those of service safety and effectiveness, and the reasons are clear: good patient experience not only helps recovery, it informs quality improvement and saves money. The challenge is to ensure that capturing and responding to patient experiences is a routine practice, embedded in health service delivery.

And it's a commitment now rooted in more than a decade's worth of official plans and frameworks. The NHS Plan 2001 aimed to “put patients at the heart of healthcare”, and make measurement of patient experience mandatory. This aim is strengthened in the NHS Outcomes Framework 2013/14 (Domain 4), committing to “ensuring that people have a positive experience of care”, and in the NHS Operating Framework that states that “NHS organisations must actively seek out, respond positively and improve services in line with patient feedback”.

The focus of this report is neonatal care, and outlines specifically what ‘good practice’ looks like in terms of measuring parents’ experience of that care, and ways to promote and embed it in neonatal units across England. This itself is a commitment set out in several NHS frameworks, not least the NHS Toolkit for High-quality Neonatal Services (Principle 3) and the NICE Specialist Neonatal Care Quality Standard (Statement 5)³.

With the establishment of new NHS structures, now is the perfect time to capture and share best practice to ensure measuring and utilising parent experience of neonatal care to improve neonatal services is undertaken effectively in all neonatal units.

“Evidence of regular surveys on parent experience: Parents’ experience is monitored through satisfaction surveys and the evidence used to inform learning and change for improvement.”

NICE Specialist Neonatal Care Quality Standard, Statement 5, Quality measure c.

How we prepared this report

To get a snapshot of how parent feedback on their experience of neonatal care is currently gathered and measured in England, we conducted the following:

- A survey of neonatal networks to identify their priorities and examples of good practice around parent experience.
- A survey of parent representatives to identify examples of good practice.
- Participation in regional/network meetings to explore priorities around parent experience.
- One national-level meeting, to which 20 representatives including nurses, doctors, parents and network managers were invited to review the main findings from our survey and consultations, and agree priorities to take forward.

Patient experience: capturing the uniquely difficult journey of parents in neonatal care

The mothers and fathers of babies in neonatal care are on a difficult journey, often with limited control or involvement in their baby's care. They are in a stressful position – not only are they the anxious relative, but also the 'proxy patient', as their baby cannot speak for itself. For this reason, parents whose babies need neonatal care are in a uniquely challenging position.

But what is inevitably never a good situation can be made as bearable as possible if we make the effort to ask parents how they are during the journey, and show willingness to listen and learn from what they are feeling and experiencing.

The best way to ensure a good experience for parents entering the world of neonatal care is to measure their experience throughout their journey, from admission to discharge, so we learn how changing needs can be met along the way, in the interest of a better outcome for both baby and family.

"We need to canvas the views of parents on the services provided as there is nothing more powerful than a parent's experience. To understand the impact of the parents' journey, look at their feedback from admission to discharge. It's not just about outcomes, but the experience of the journey. They may be relieved and gratified at the end, but what was the journey like?"

The clinician's view: Heather Naylor, lead nurse, North West London Perinatal Network

The value of measuring parents' experience

Measuring parents' experience of the care and support provided to them and their baby [sheds light on what they are going through and reveals evolving needs](#) – a parent's understanding and feelings when their baby is first admitted to the unit will be very different to those when they are discharged a few weeks later.

Measuring and understanding the experiences of both mothers and fathers can help assess if the level of parental involvement in care and decision making is right, and [can identify if appropriate support and information are being provided](#) (from information on treatment and prognosis to advice on breastfeeding). Feedback can also be gathered on parents' views on the services and facilities provided by the unit, from an overnight stay room to the kitchen facilities, and on the effectiveness of communications given by the unit. Are they in an appropriate format/language? Are they given at the right time?

Parents' feedback [can be used by units to benchmark themselves](#) against NHS, NICE and BAPM (British Association of Perinatal Medicine) standards, and against others in their network, and nationally.

Measuring parents' experience also [provides evidence of performance and quality in the delivery of family centred care](#) – part of the NHS's vision for neonatal services. It can reveal whether the family-centred approach is enhancing the attachment between babies and their families, meeting their physical, psychological and social needs.

“You said.... we did.” Best practice for measuring – and acting on – parents’ experience of neonatal services

Our research showed that both frontline staff and parents feel communication and understanding between the two can be improved. Having an ‘identified’ person on each unit to receive concerns from parents would help, as would a greater ‘let’s see what we can do’ attitude and willingness to try doing things differently on the part of doctors and nurses. There was a feeling on the part of parents of a need to have a greater voice in their baby’s care, which was matched by a desire on the part of unit staff to generate more involvement from parents in feeding back on the care received.

Ensuring feedback is used for learning and turned into action plans – i.e. ‘closing the feedback loop’ – was seen as a crucial activity, giving staff ‘real time’ constructive feedback.

Measuring experience: our survey snapshot (based on responses from 16 networks)

- The main way units currently measure parent experience in neonatal units is overwhelmingly through their own surveys – 73 per cent of units represented did this because it is seen to be quick, targeted and can produce swift action on problem areas.
- Another important measure highlighted (by 40 per cent of units) is the National Parents’ Survey run by the Picker Institute. This has helped units and networks see what are local, regional or national issues, and facilitates the development of network-wide solutions.
- More than half (53 per cent) said they used and valued mechanisms for more immediate feedback, such as exit or oral questionnaires, suggestions boxes, parent buddy support groups, ‘wishing trees’ (boards where parents can write up suggestions for improvements they would like to see) and weekly parent support group meetings – showing a broad ‘menu’ of strategies to encourage parents to talk about the impact of their experience so it can be measured.
- There was wide variation in who reviewed feedback data and who results were shared with: unit managers were most likely to be involved (18 per cent); the clinical governance team was cited by 15 per cent of respondents, and the directorate/trust level by 10 per cent.
- The commitment to measuring patient experience unquestionably exists, but neonatal teams need support, skills-training and appropriate tools to do it.
- The main priorities suggested to take forward are:
 - o Regular, national, independently-run survey of parents’ experience that all units use and which provides comparable data
 - o Greater emphasis on providing parents with opportunities for real time feedback
 - o More efforts to ensure feedback from families is translated into learning and action; and to close the feedback loop.

A parent’s view: Kim Caddy

Kim Caddy’s daughter was admitted to hospital at 27 weeks. She feels parents would feel more involved if they felt listened to more, and had their views taken into account while on the ward.

“Measuring parents experience can improve outcomes, but for the data to be useful there needs to be a clear method for gathering, analysing/recording and crucially, acting upon the information. Parents have concerns that gathering their feedback is a box-ticking exercise.

“[There needs to be a] clear method communicated to parents on admission for how they record issues they want specifically logged and dealt with, not just “complaints” but also information and observations/suggestions etc... – perhaps a ‘parents’ section of the notes.”

Examples of 'good practice' in measuring parents' experience

- **Central Newborn & Trent Perinatal Networks:** each unit has two named members of staff who are Parent Champions and who meet regularly with the network lead nurse to explore solutions that can be taken back to units to roll out. Parents know who they are and can raise issues with them.
- **SW Midlands Newborn Network:** the network team supported a parent-led survey on families' experiences of care following bereavement. This involved parent-to-parent data gathering and dissemination of findings to 500 staff.
- **NICU St Mary's Manchester:** the unit collects feedback from families using a wide range of tools including national surveys, listening events with parents, Patient Opinion, and real-time feedback from hand-held devices. The unit's 'You said, we did' approach means parents' feedback has directly contributed to development of the breastfeeding support team, improvements to parent rooms and use of more volunteers.
- **Shropshire Staffordshire & Black Country Newborn and Maternity Network:** a network team supported parent reps to take the lead on feeding back to each unit in the network on results from the 2010 national parent experience survey – including giving an indication of how each unit fared against the national benchmark.
- **Greater Manchester Neonatal Network** set up a Parent Advisory Group in 2011 with parents from units across the network; a representative sits on the network governance board to ensure the voices of local families are heard when decisions about services are made.

"Care with compassion – we need to show that's what we're giving. It's wonderful to show photos of the faces of 23-week-olds that we have saved, but it's also essential that we know what the parents' experience has been too – because if it doesn't end up being a positive experience then we shouldn't be doing it that way."

A consultant's view: Dr Anthony Kaiser, consultant neonatologist, St Thomas's Hospital

Capturing parents' experience for better neonatal services: how do we get there?

There is currently an incomplete picture of parents' experiences across neonatal services, but our survey and consultations show there is a desire on the part of unit staff to better measure parents' experience of care. And while there are perceived barriers such as limited resources, there is nevertheless a perception that better measurement can be achieved with a shift in the way staff may think about it, and by making a conscious decision to prioritise it.

And with additional resources to run a national survey, for example, and more time and coordination given to sharing best practice (for example, through an online repository of tried and tested best practice), significant improvements could be made to what is one of the least prioritised aspects of neonatal care.

Five 'good practice' activities when measuring parents' experience of neonatal care

Regular surveys at unit, network and national level: National level surveys facilitate benchmarking - which is a powerful incentive, as no-one wants to be bottom of the table - while local level surveys enable rapid and targeted responses within units and networks.

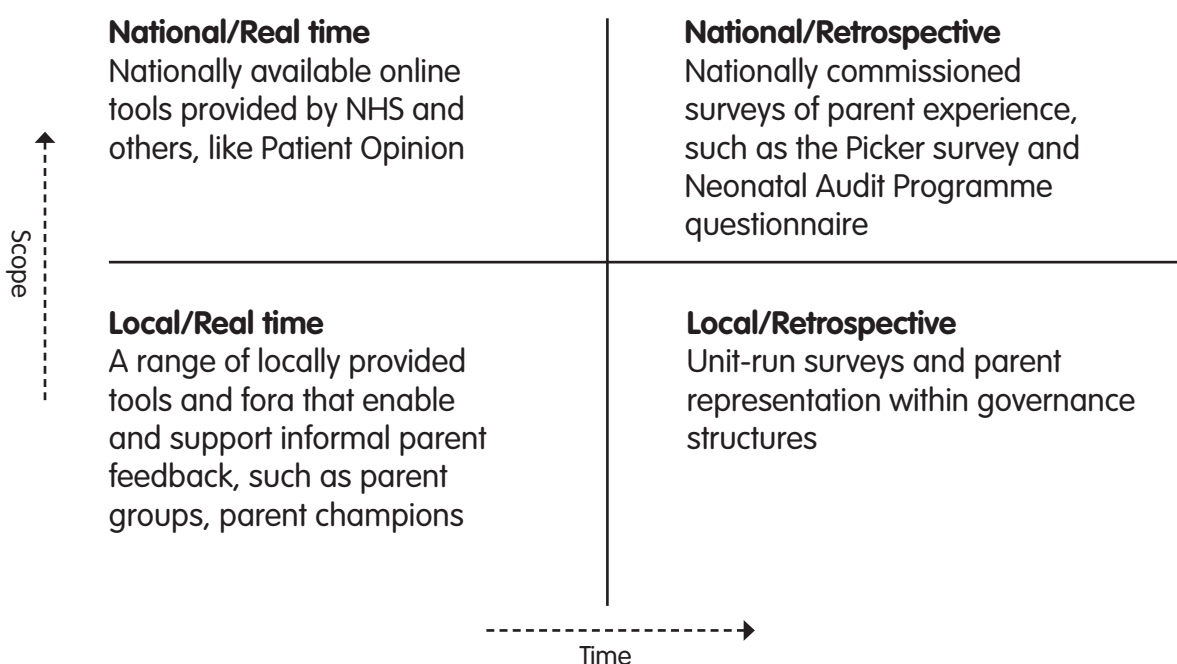
Enabling good parent representation: i.e. a culture of enabling parents to have a greater voice and represent others at both unit and network level is seen as crucial to generating valuable feedback and therefore improvement. This means not only providing channels for parents to feedback (fora for parents to discuss and support each other to identify issues and solutions, enabling parent-to-parent feedback etc.), but also ensuring that when parent representatives are trained to perform their role (particularly engagement in governance structures), it is done alongside unit staff, so both parents and staff learn together about ways to make feedback effective.

Locally developed initiatives: Appropriate to the context and able to respond quickly to local needs were also regarded as key to good practice. For example, 'You said, we did' boards in units do demonstrate action on parents' feedback.

While there is no perfect model or set of tools for measuring parent experience, feedback gained through our research suggests the need for a range of mechanisms and activities that balance real-time feedback with retrospective feedback, and national mechanisms with local ones (see Figure 1).

Figure 1

A range of tools and mechanisms can be combined to achieve a balanced approach to gathering parent feedback



Sharing successful strategies: exchange of ideas and learning between units about gathering and measuring parent feedback is a pillar of 'good practice', both in relation to mechanisms for measuring experience and initiatives for improving experience.

These good practice strategies can lead to capturing parents' stories and journeys – i.e. 'how it felt' and 'what it meant' – as much as capturing 'data' per se, and to a powerful learning experience for both parents and unit staff.

Turning priorities into recommendations

For Commissioners to reach the ambitions for people's experience of care as set out in Domain 4 of the NHS Outcomes Framework (i.e. well-integrated care that patients would commend to friends and family), the uniquely difficult journey of parents' with babies in neonatal care needs to be measured, and their feedback acted upon.

"Working in neonatal services for over 30 years, I've always felt I was the patient's advocate – but who better to advocate for the baby than the parents? It is our responsibility to support the parents to empower them to be the best advocate for their baby. Accurate information within health is important and a useful tool to identify where change needs to occur. Nothing is more powerful than the parents' reflection on their journey through our services."

The nurse's view: Denise Evans, lead nurse, Yorkshire Neonatal Network

Recommendations

To ensure parents' insight and feedback is effectively incorporated into decision-making and planning throughout the commissioning and delivery of neonatal care, we recommend:

- NHS England to centrally commission a written retrospective survey of parents' experience of neonatal care in which all units in England are required to participate⁴. The need is to carry out the survey on a regular basis (every three years).
- The Clinical Reference Group for specialised neonatal care to continue to prioritise parent experience with specific reference to capturing and responding to feedback in both the neonatal service specification and the neonatal dashboard.
- The Clinical Reference Group to make recommendations about how to use appropriate mechanisms (eg CQUIN, QOF) as incentives to providers who can evidence improvements in parent experience.
- NHS England Area Teams to hold to account Operational Delivery Networks (ODNs) and all providers of neonatal care, requiring evidence that parent experience and insight is regularly captured, acted on and communicated to families and clinical teams. For example, neonatal ODNs to include specific and explicit information in their annual reports about how parent feedback is captured and used.
- NHS England Area Teams to hold to account ODNs and all providers of neonatal care to ensure strong parent representation within network governance structure, and to demonstrate that the patient voice is at heart of service improvements. Good practice in this area would include⁵:
 - o specific roles for parent representatives
 - o appropriate training and support provided to parent representatives and staff
 - o network reports to reflect the impact/contribution of parent representation.
- NHS England Area Teams to hold to account ODNs and all providers of neonatal care to ensure parents have access to a plurality of mechanisms to give real-time feedback at all points of key transition on their journey. This should include more than one of the following:
 - o parent focus groups and/or parent-to-parent feedback fora
 - o named member of staff to receive feedback
 - o 'you said, we did' approaches
 - o exit questionnaires
 - o surveys (including local surveys and the Neonatal Audit Programme parent experience questionnaire)

(See box on page 6 for examples of good practice.)

References

¹ NHS. High Quality Care for All – NHS Next Stage Review. London, Department of Health, 2008.

² Mid Staffordshire NHS Foundation Trust. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Executive summary). London, Crown Copyright, 2013.

³ NHS Toolkit for High-quality Neonatal Services, Principle 3 audit indicators include “parent feedback” and “independent national parent surveys”. NICE Specialist Neonatal Care Quality Standard Statement 5: Quality measure c) “Evidence of regular surveys on parent experience.” Process: “Parents’ experience is monitored through satisfaction surveys and the evidence used to inform learning and change for improvement.”

⁴ Relevant examples of good practice from other services include:

(i) NPEU, 2010. Delivered with care: a national survey of women’s experience of maternity care [pdf]. Available at <https://www.npeu.ox.ac.uk/files/downloads/reports/Maternity-Survey-Report-2010.pdf> [accessed 20 May 2013]

(ii) Picker Institute Europe, 2012. Highly Specialised Services Patient Experience Survey 2012 [pdf]. Available at http://www.specialisedservices.nhs.uk/library/22/Highly_Specialised_Services_Patient_Experience_Survey_2012.pdf [accessed 20 May 2013]

⁵ For relevant examples from other NHS services see for example NHS National Cancer Care Team (2010). Service User Involvement in Cancer Care – Policy, Principles, Practice

"It is vitally important that the experiences of parents whose babies have received care on neonatal units are measured, reported and acted upon in order to improve neonatal services for babies and their families. Parents are an integral part of care provided to babies in neonatal units and their experiences reflect a user's perspective which only they can give. Health care professionals think they are providing services which are best for babies and their families, but parents can also help by identifying areas that need to be improved from their unique perspective which will be different from the healthcare professional's view of the service."

Ruth Moore, Manager/Lead Nurse, Staffordshire, Shropshire and Black Country Newborn and Maternity Network

Bliss is the UK charity working to provide the best possible care and support for all premature and sick babies and their families.

We ensure that all babies have the best chance of survival and of reaching their full potential. We give parents of the sickest and tiniest babies somewhere to turn to for help, advice and support.

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