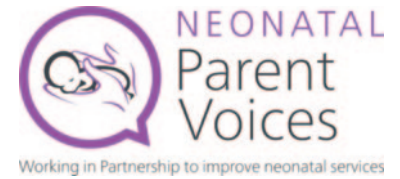


Lincolnshire listens – our ‘neonatal parent voice’



Lincolnshire’s Neonatal Parent Voices is a group of passionate parents that have helped shape and design services for the future. They are a pivotal part of the Maternity Transformation Programme and influence change and service improvement across the health and social care system. Learning from parents can improve the neonatal journey from the hospital to the community environment. Listening to parents gives us a greater understanding of their experiences and needs, including effective communication, empathy and an appreciation of what matters to them. By working in partnership with Neonatal Parent Voices, Lincolnshire’s neonatal pathway has flourished.

Claire Gartland

Maternity Transformation Neonatal Project Lead
claire.gartland3@nhs.net

Sue Jarvis

Maternity Transformation Project Manager
sue.jarvis1@nhs.net

Better Births Lincolnshire
Facebook: Better Births Lincolnshire
Twitter: @betterbirthlinc
www.betterbirthlincolnshire.co.uk

Keywords

neonatal staff education; Better Births; neonatal parent voice; family-integrated care; parent experience

Key points

Gartland C., Jarvis S. Lincolnshire listens – our ‘neonatal parent voice’. *Infant* 2020; 16(6): 239-42.

1. Involving neonatal families is at the heart of neonatal care.
2. Lincolnshire was the first LMNS to ensure the voice of neonatal parents was acted upon as part of the Maternity Transformation Programme.
3. Feedback from families within a structured framework enhances and addresses safety and quality.
4. Co-production and collaboration with professionals across the whole system is necessary for success of the neonatal pathway.

The publication of the report *Better Births: Improving Outcomes of Maternity Services in England* in 2016¹ and the subsequent ambition and vision of the national Maternity Transformation Programme (www.england.nhs.uk/mat-transformation) for a safer and more personalised care, is now embedded across England. From the outset, Lincolnshire has recognised the importance of an individualised neonatal pathway in its Better Births Maternity Transformation Programme and the contribution of families within this pathway, such that Lincolnshire was the first Local Maternity and Neonatal System (LMNS) to recruit a neonatal project lead and create a ‘neonatal parent voice’ working across the system.

Lincolnshire’s neonatal model is inextricably linked to maternity and obstetric services, community services and the children and young people’s pathway. This collaboration, together with Neonatal Parent Voices, facilitates a fully integrated seamless neonatal service across Lincolnshire from antenatal care, through birth, and on to home support.

Drivers for neonatal care

The current national neonatal agenda informs us of the need for families to be at the heart of neonatal care in terms of choice, access and continuity of care.¹ Furthermore, the concept of family-integrated care demonstrates that involving parents in the care of their baby is paramount.^{2,3} Certainly, empowering

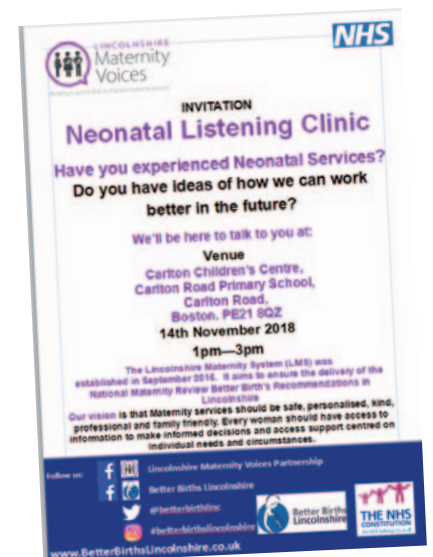


FIGURE 1 An example of a listening clinic poster.



FIGURE 2 Families and healthcare professionals at a listening clinic.

parents and placing families at the centre of care is supported by various reports, standards and studies.⁴⁻¹⁰ Alongside this and most recently, the Neonatal Critical Care Review in 2019 is clear in its demand

for the delivery of a high quality, family-centred neonatal care service.¹⁰ The Neonatal Critical Care Review emphasises the need that parents are not bystanders in the care of their child, but part of the solution; outcomes are better for babies whose parents are able to play an active role. Indeed, the British Association of

Perinatal Medicine (BAPM) reminds us to listen, hear and respond to what is being said by the parents/carers.¹¹

The development of a neonatal parent voice

It is important to mention that co-production is one of the seven themes and

recommendations of the Better Births report:

‘Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered.’¹²

Parents said...	What we did...
“Separation from our baby and not knowing how they are is the most distressing experience. We were totally unprepared and unaware that our baby may be transferred from the local unit.”	<ul style="list-style-type: none"> • Targeted education of mothers during the antenatal period • Created a neonatal section of the Lincolnshire Better Births website to provide information to mothers regarding neonatal care • Set up a neonatal voice collaboration with the EMNODN • Secured additional support from the FaB service and the community outreach project • A neonatal parent voice attends the East Midlands multi-professional working group addressing criteria for Saving Babies Lives (element 5) and the transfer of babies in and out of the county¹⁴
“Once we were discharged home we found little community support for premature or sick babies.”	<ul style="list-style-type: none"> • Community neonatal support groups have been established by Neonatal Parent Voices • There is now a link with parents on the neonatal unit to signpost to community support • Establish contact with the health visitor and children’s centre on the unit before discharge home
“While in hospital, I didn’t have time to focus on myself. It was once home and at nine months that having her so premature hit me and I struggled with my mental health.”	<ul style="list-style-type: none"> • Neonatal Parent Voices links closely with the Perinatal Mental Health Team and Mental Health Services to improve services for our families • The perinatal mental health team attends the neonatal community support groups

FIGURE 3 Some examples of actions from the neonatal listening clinics. FaB=Family and Baby support service – a point of contact throughout a family’s journey. Key: EMNODN=East Midlands Neonatal Operational Delivery network.



FIGURE 4 Some members of the Neonatal Parent Voices group.

Certainly, our neonatal strategy has been built on extensive engagement with women and their families who have a premature baby, sick baby, or baby with special considerations. We respect and understand that each locality will have their unique requirements and due to the specialist nature of neonatal services, specialist units can be located many miles from the baby's home. Furthermore, Lincolnshire covers a large rural area and a significant number of families will have experienced intensive neonatal care outside of the county for at least part of their neonatal journey. Therefore, concerns such as travelling and separation from their baby become apparent. Within our neonatal pathway we wanted to ensure we reached out locally to our neonatal families to hear their views, stories, concerns and thoughts. So as a start, and with support from our Early Years Team, we organised 'listening clinics' in local children's centres within Lincolnshire County Council in 2018, to hear the voice of our neonatal families (FIGURE 1).

The listening clinics

The listening clinics were supported and attended by the lead nurse for the East Midlands Neonatal Operational Delivery network (EMNODN)¹⁵ and other professionals within the system, which gave us a platform and framework to address any needs and concerns (FIGURE 2). By speaking to families, we were able to consider how it might feel to be the parent of a premature or sick baby within Lincolnshire; working with them should improve the parental experience and their involvement, leading to improved care and outcomes for babies. All listening clinics were documented (with the families' consent) and the actions highlighted were included in our neonatal work-stream plans. FIGURE 3 shows some examples of actions from the neonatal listening clinics.



FIGURE 5 Support in hospital. Due to the COVID-19 pandemic, plans are currently evolving for virtual Neonatal Parent Voices support groups.

- Attending the neonatal work-stream meetings; communicating closely with the MVP chair
- Presenting at national neonatal conferences
- Visiting neonatal units to speak to families, listen to stories and signpost to community support
- Collaborating with users, stakeholders and providers across the system
- Linking closely with professionals (health visitors, perinatal mental health team) and children's centres
- Being the voice to feed back family experiences through the MVP Chair and LMNS (listening, signposting and advising)
- Setting up specific neonatal support sessions in the community for those parents discharged home
- Providing links with parents through social media and online support groups
- Connecting with families via interviews on local radio stations
- Helping to identify, signpost and repatriate a UK mother and her NICU baby returning from Singapore
- Helping to develop and support the Better Births Neonatal online presence
- Providing a resource and opinion for parent information and new developments in neonatal care
- Advocating for parents and parent stories
- Acting as a parent representative for the Royal College Of Paediatrics and Child Health National Neonatal Audit Programme
- Acting as a parent representative for the East Midlands working group for preterm labour and Saving Babies Lives Element 5
- Linking closely with the EMNODN and attending the network parent advisory group
- Providing congratulatory Harrison Hampers (www.lincsdownsyndrome.org.uk/harrisons-hampers), which are filled with treats and important support information for those families with a baby with Down's Syndrome
- Connecting with our 'stork project' initiative. All neonatal families are offered storks that contain contact information for Better Births, the neonatal network, health visiting services and children's centres, along with mental health support links and our neonatal/MVP group
- Developing video stories for professional training purposes

FIGURE 6 Neonatal Parent Voices achievements.

Neonatal Parent Voices

An amazing group of passionate parents took part in the listening clinics and from this the Neonatal Parent Voices emerged (FIGURE 4). The group was created in January 2019 under the umbrella of the Maternity Voice Partnership (MVP) and the MVP chairperson.

We know that being the parent of a premature or sick infant requires advocacy, endurance and persistence and the neonatal parent voice is at the heart of our transformation programme. These parents have been a huge resource and are central to our neonatal work-stream. Shared visions have been formed, strategies identified and a plan has evolved. Our parents find families on social media, listen to stories, signpost and provide support both in hospital (FIGURE 5) and in the

community. They are able to influence change within a safe, structured framework that feeds into the LMNS. Representatives from Neonatal Parent Voices have presented at national conferences and represent parents at national and local meetings. A neonatal logo, identity badges and a banner have been produced to complement their professional ethos (FIGURE 6).

Developing our neonatal pathway with Neonatal Parent Voices

As part of co-production within the system, we have developed operational neonatal work-stream plans that have brought a focus and systematic approach to the neonatal pathway. Stakeholders within perinatal mental health, primary care and providers are working together with their

own active neonatal plans, including Lincolnshire County Council, Lincolnshire Clinical Commissioning Group, United Lincolnshire Hospitals NHS Trust, and Lincolnshire Partnership NHS Foundation Trust. The neonatal work-stream plans address the criteria required for neonatal care within the Maternity Transformation System¹ and, importantly, the Neonatal Critical Care Review.⁷ A representative from Neonatal Parent Voices attends the neonatal work-stream meetings and has developed a work-stream plan; they are a key influence in networking and participating within all eight plans (FIGURE 7).

Working in collaboration with the EMNODN

The EMNODN is one of 11 clinically-managed operational delivery networks for neonatal services in England. Its purpose is to make certain that babies who require neonatal care and their families/carers receive the best care as close to home as possible.¹³ Furthermore, the EMNODN demands assurance from neonatal services that care is of a high standard and meets national recommendations. As part of the assurance programme the EMNODN carries out service reviews of each unit within the network. The Neonatal Parent Voices in Lincolnshire has participated in local reviews and attends the Network Parent Advisory Group meetings. Central to the success of the Neonatal Parent Voices are these strong communication links with the EMNODN.

Summary

We recognise that neonatal families have a unique and often very difficult journey and that their voice is pivotal to care. Family-integrated care is fast becoming the standard of care across neonatal units in the UK and certainly the current agenda for neonatal care paves the way for a neonatal parent voice. The Neonatal Parent Voices within our Better Births programme has given us the inspiration to drive forward with our neonatal pathway, crossing cultures and multi-professional boundaries and overcoming demographic challenges. Lincolnshire has put families first, heard their voices and been proactive in multi-professional collaboration. A culture has been created that gives parents 'permission' within the system to make decisions, and a voice to demand a safe, seamless, high quality neonatal service.

Better Births Lincolnshire neonatal plans	Ownership
1. Staffing of neonatal services, training and multiprofessional collaboration Neonatal dashboard Improved patient experience and family-integrated care Keeping mother and baby together: transitional care and neonatal outreach service	Local hospital provider
2. Continuity of support from hospital to home	Children's centres, health visitors
3. Perinatal mental health	Perinatal Mental Health Team, Steps2Change, mental health midwife
4. Reducing mortality Improving safety and quality Avoiding term admissions	Local hospital provider
5. Supporting bereavement and palliative care	Bereavement midwife
6. Neonatal parent voice	Neonatal Parent Voices
7. Keeping mother and baby together – transitional care and outreach	Local hospital provider
8. Neonatal feeding strategy – 'Latch-on Lincolnshire'	Better Births working group
Data requirements	Across the system

FIGURE 7 The eight neonatal work-stream operational plans and ownership within the system.

Acknowledgements

Thank you to Tracy Pilcher (SRO LMNS Lincolnshire), Linda Hunn (Director/Lead Nurse at EMNODN), our MVP Chair Amanda Pike and Neonatal Parent Voices: Jo Vickers, Alison Marriott, Isobel Pollitt, Katherine Etoria, Tilly McGill, Emma Hall, Tyla Clancy, Heather Ind and Layla Moore. Thank you also to Clare Brumby (Maternity Transformation Lead Midwife) and Tracy Clinkscales (Maternity Transformation Project Support Officer).

References

1. **NHS England.** Better births: improving outcomes of maternity services in England. 2016, online at: www.england.nhs.uk/publication/better-births-improving-outcomes-of-maternity-services-in-england-a-five-year-forward-view-for-maternity-care/
2. **O'Brien K, Robson K, Bracht M, et al.** Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes. *Lancet Child Adolesc Health* 2018;2:245-54.
3. **Patel N, Ballantyne A, Bowker G, et al.** Family integrated care: changing the culture in the neonatal unit. *Arch Dis Child* 2018;103:415-19.
4. **Department of Health.** Maternity matters. Choice, access and continuity of care in a safe service. 2007, online at: https://dera.ioe.ac.uk/9429/7/dh_074199_Redacted.pdf
5. **Staniszewska S, Brett J, Redshaw M, et al.** The POPPY study: developing a model of family-centred care for neonatal units. *Worldviews Evid Based Nurs* 2012;9:243-55.
6. **Bliss.** Bliss Baby Charter. 2007 online at:

www.bliss.org.uk/health-professionals/bliss-baby-charter

7. **NICE.** Neonatal specialist care. Quality standard [Q54]. Quality statement 5. 2010 online at: www.nice.org.uk/guidance/qs4/chapter/Quality-statement-5-Encouraging-parental-involvement-in-care
8. **BAPM.** Neonatal transitional care - a framework for practice. 2017 online at: www.bapm.org/resources/24-neonatal-transitional-care-a-framework-for-practice-2017
9. **Picker Institute Europe, Sarah-Ann Burger.** Parents' experiences of neonatal care: findings from neonatal survey. 2014, final report, online at: www.picker.org/wp-content/uploads/2014/12/P2725_Neonatal-Survey-2014_Online-Version_Final1.pdf
10. **NHS England and NHS Improvement.** Implementing the recommendations of the neonatal critical care transformation review. 2019 online at: www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the-Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf
11. **BAPM.** Enhancing shared decision making in neonatal care: a framework for practice. 2019, online at: https://hubble-live-assets.s3.amazonaws.com/bapm/attachment/file/180/Shared_Decision_Making_in_Neonatal_Care.pdf
12. **The Care Act 2014.** Parliament of the United Kingdom.
13. **EMNODN.** What is a neonatal network? Online at: www.emnodn.nhs.uk/about-us/what-is-a-neonatal-network/
14. **NHS England.** Saving Babies' Lives. A care bundle for reducing perinatal mortality. 2019 online at: www.england.nhs.uk/wp-content/uploads/2019/07/saving-babies-lives-care-bundle-version-two-v5.pdf