Public Health England

NHS

Newborn screening in neonatal units: survey findings

March 2018

Public Health England leads the NHS Screening Programme

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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About PHE Screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the 4 UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

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Summary

One in 9 babies in England (77,000 babies per year) is born needing neonatal care.

Delivery of newborn screening in non-maternity settings such as neonatal intensive care units (NICUs), paediatric intensive care units (PICUs) and children's hospitals can be challenging. The complex and serious clinical needs of these babies may mean more 'routine' aspects of care like newborn screening can be missed or delayed. The climate in which services operate is changing due to the maternity transformation programme and this may provide opportunities for improving the screening pathway.

PHE screening and immunisation leads (SILs) developed and conducted a survey in February 2017 covering the 3 newborn screening programmes- newborn hearing, newborn blood spot and newborn and infant physical examination.

Thirty five NICUs responded, which is just over one fifth of the NICUs in England. Respondents were from NICUs only. The findings may not be transferable to PICUs and standalone children's hospitals.

Around three quarters of NICUs said they had a named person responsible for newborn screening. In trusts with good links between the NICU and the local antenatal and newborn screening coordinator this created additional benefits in:

- joint working with education and training
- management of screening safety incidents
- attendance/ representation at local screening programme boards

Admission and discharge information flows are complex for babies needing neonatal care. They are different for babies admitted immediately following delivery to those transferred at a later stage.

Newborn screening results, if recorded, are in multiple places, including:

- on screening IT systems (NIPE SMART)
- NICU clinical systems (Badgernet)
- provider IT systems (mainly Cerner)
- written clinical notes
- the baby's personal child health record (red book)

Badgernet is widely used, and the ability for Badgernet to communicate with newborn screening IT systems could reduce duplication of data recording. Few units described failsafe arrangements for identifying eligible babies.

Newborn hearing screening staff appear to take full responsibility for making sure newborn hearing screening is completed for babies on NICUs.

Some NICUs use the newborn blood spot failsafe system (NBSFS). It is worth noting that some units use the NBSFS to manage repeat sample requests while in others he need for a repeat sample is communicated by the local antenatal and newborn screening coordinator.

Neonatal staff, mainly nurses, have some form of training in undertaking blood spot sampling that is either included in induction or mandatory education. Some NICUs have also developed competency-based training.

Some NICUs reported that the newborn physical examination would be delayed if the baby was too unwell or premature. In a handful of NICUs this appeared to be a blanket policy using a gestational age cut- off. In cases where babies were screen positive and referred there was little evidence that referrals were tracked.

Recommendations

NICUs, PICUs and children's hospitals should:

- have a named lead with responsibility for oversight of the 3 newborn screening programmes
- give all parents the PHE screening leaflet 'Babies in special care units: screening tests for you and your baby'
- have regular contact with their closest antenatal and newborn local screening coordinator(s); this could be achieved by attending local screening programme boards
- inform their closest antenatal and newborn local screening coordinator(s) if a baby dies so that it can be recorded on the screening IT systems (NBSFS, NIPE SMART, S4H)
- review admission and discharge processes to make sure newborn screening checks are included and relevant information transferred on discharge
- perform newborn hearing screening as per national protocol (in NHSP community models NICU staff are responsible for performing the newborn hearing screen)
- provide NHSP screening teams with medical information about the baby to make sure screening is undertaken within national guidance (for example risk factors, bacterial meningitis)
- inform the local newborn hearing screening programme where the baby is resident in cases where the baby is being discharged home and screening was not completed
- use NBSFS to help identify the eligible population, manage failsafes and repeat requests
- use NIPE SMART to help identify the eligible population, manage failsafes and keep track of babies who are referred. This includes having clear roles and responsibilities for making referrals and tracking of the referral outcomes; this requires two way communication between the NICU and the referral units to enable outcomes to be recorded and monitored on NIPE SMART
- follow NIPE guidance on eligibility for the newborn examination, there should not be a blanket policy that applies a gestational age cut-off

Screening and immunisation teams should continue:

- work to strengthen their relationships with NICUs, PICUs and children's hospitals in their area to make links with local maternity systems to influence pathways and communication flows that maximise timely screening of newborn babies

- to promote the use of NBSFS and NIPE SMART

PHE Screening should:

- continue to work with NHS Digital and other stakeholders on achieving interoperability between national screening IT systems and other IT systems used in clinical practice

- explore whether any aspect of newborn screening can be included in the national neonatal audit programme as this has demonstrated improvements in timely screening of preterm infants for retinopathy

- continue work to consider guidance regarding eligibility for NIPE newborn screening based on gestational age

Background and context

There are 157 NICUs across England (see appendix 1). Babies born needing neonatal care have a higher chance of having some of the conditions we screen newborns for.

Newborn screening in non-maternity settings such as NICUs, PICUs and children's hospitals can be challenging. The complex and serious clinical needs of these babies may mean more 'routine' aspects of care like newborn screening can be missed or delayed.

The way these services are currently configured is also changing due to ongoing work around the maternity transformation programme. In a recent survey, half of all trusts in England reported their neonatal service configuration was under review or that changes were planned. 92% of trusts were engaged in both a maternity and a neonatal network, an increase from 74% in 2013. One further trust reported involvement in a neonatal, but not a maternity, network. All trusts reported some referral of women between hospitals, for example for more specialist care. These changes are likely to impact on the delivery of newborn screening programmes but there may be opportunities to improve the arrangements for screening with good engagement with local maternity systems.

Methodology

PHE screening and immunisation leads (SILs) developed and conducted a survey in February 2017. This built on work in Surrey and Sussex in 2016 that found gaps in information flows, particularly in areas where babies crossed geographical boundaries. SILs distributed the audit tool to all non-maternity unit settings in their areas where newborn screening may be carried out (NICUs, PICUs, and children's hospitals). Responses were returned to the local SIL and optionally forwarded to the London antenatal and newborn SIL for collation and analysis. Responses were returned between February and May 2017.

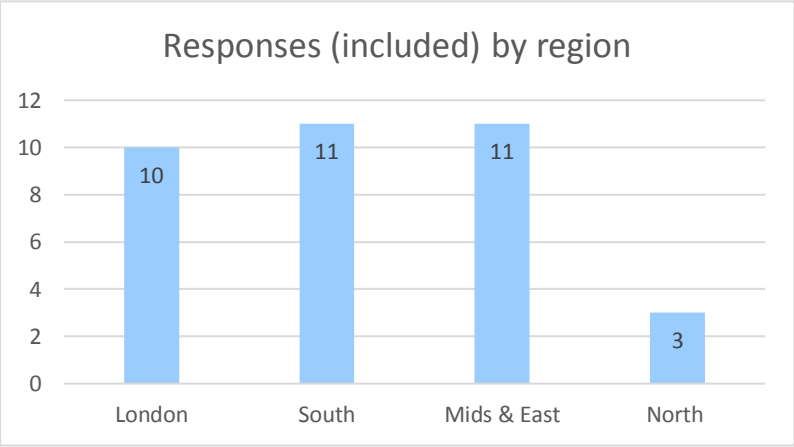
The newborn screening programmes covered in this audit were:

- Newborn hearing (NHSP)
- Newborn blood spot (NBS)
- Newborn and infant physical examination (NIPE)

Findings

Responses

Thirty five NICU providers responded to this audit (see appendix 2). Disappointingly, no standalone children's hospitals responded. One response was received from a London maternity unit and was excluded from the analysis. Responses were received from each region, ranging from small to large NICUs (the number of admissions ranged from 275 to approximately 1600).



Responsibility

Three quarters of NICUs said they had a named person responsible for newborn screening. This was sometimes the local antenatal and newborn screening coordinator (LCO). Responsibility in the other providers included:

- having someone to cover newborn blood spot but not the other screening programmes
- the shift coordinator taking responsibility but there being no oversight
- linking with hearing screeners
- having a consultant who led NIPE
- having a newborn blood spot champion

In 4 NICUs there was no one with assigned responsibility for newborn screening.

About one third of the providers reported good links with the local antenatal and newborn (ANNB) screening coordinator. Links were also evident in some NICUs with the hearing screening team. In cases where good links were reported, this resulted in joint working with education and training, management of screening safety incidents and attendance/ representation at the local screening programme boards.

Admission to the neonatal unit

Admission varied across the units. Some units mainly received babies immediately following delivery before any screening. Others received babies who were a bit older as they came from another NICU. Communication streams used by units included:

- IT systems (maternity system, Badgernet, NIPE SMART)
- personal child health records (PCHR) ‘red books‘
- handover notes

Two units noted that communication was better from their internal/local referrers compared to external units. One unit reported an internal failsafe for babies transferred internally. Overall results of newborn screening are often not recorded on admission.

Twenty-six units use Badgernet. Two described other systems and did not mention Badgernet, and 6 did not mention any IT systems. Twenty-three units had systems for flagging screening, including one unit that had prompts on their local system in addition to using Badgernet. Admission prompts described were mainly either locally developed checklists or blood spot cards on arrival.

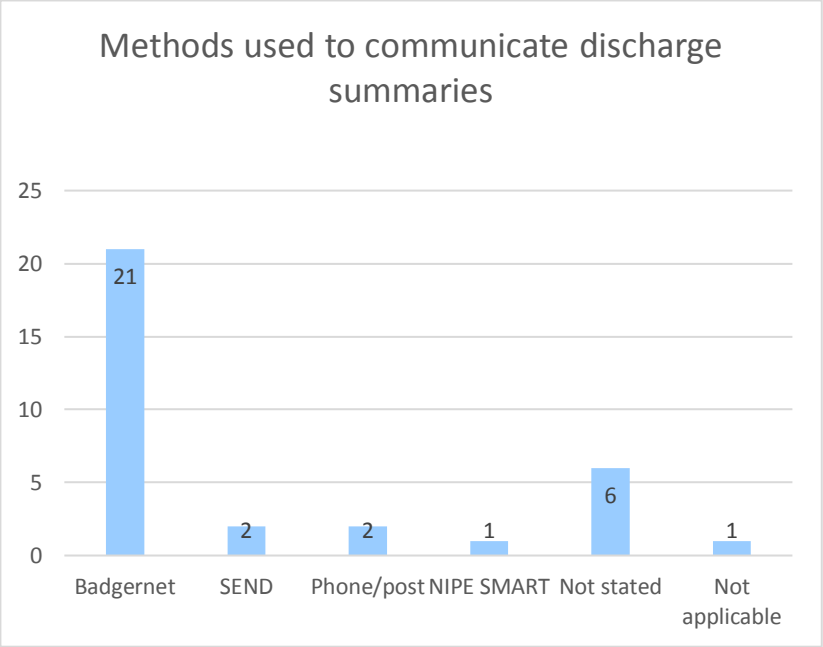
Most units use the leaflet ‘Babies in special care units: screening tests for you and your baby’. Three units stated the leaflet was not always given and 2 use the leaflet provided by the charity Bliss instead. Three did not describe alternative arrangements.

Several methods were described for identifying eligible babies. Several units stated that all babies were eligible and/or mentioned national screening standards. Eight units described specific checks/failsafes for each programme (mainly NIPE SMART).

Discharge from the neonatal unit

The number of discharges in a year ranged from 109 to 905. Most of these babies were discharged from NICU to home. Most units transferred very few babies back to the referring maternity unit. Transfers to other hospital units ranged from very few to 450, but most units transferred either 20 to 50 or around 150 to 200.

Units used a variety of methods to transfer discharge information. Following screening safety incidents where some babies missed screening, one unit now uses electronic systems in addition to written information. However, most units do not always transfer screening results. Several commented that blood spot results may not be available, but NIPE and hearing screening results were often not mentioned in responses.



Newborn hearing survey responses

Babies cared for in a NICU setting are more at risk of a permanent childhood hearing impairment (PCHI) than a well-baby. The incidence is 1 per 100 compared to 1 per 1000 for a well-baby. There is a specific newborn hearing screening pathway for NICU babies.

What arrangements are in place for newborn hearing screening to be carried out?

Respondents mentioned specific hearing screening staff visiting the unit daily, checks for all babies admitted and for babies due for discharge. Four units also mentioned electronic failsafe lists to check for eligible babies.

How are newborn hearing screening results recorded?

Results are recorded in 4 main places – in the PCHR (red book), clinical notes, Badgernet and Smart4Hearing (S4H). Sixteen units mentioned recording in S4H.

How are referrals managed for babies who are screen positive?

In most cases NICUs answering this question said referrals were made by the hearing screeners. One unit said referrals were made by the doctors. Additionally 4 units did not say who made the referral.

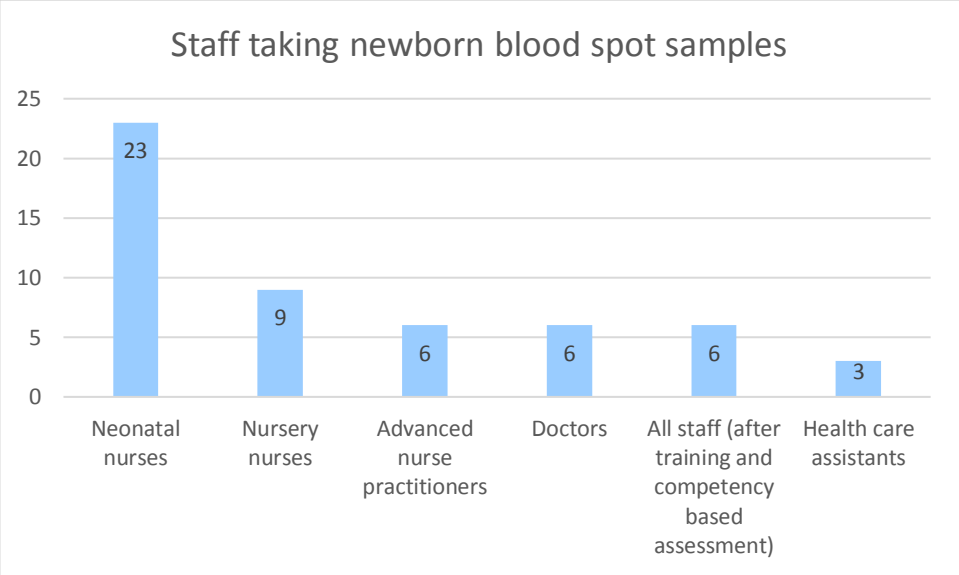
Newborn blood spot survey responses

What arrangements are in place for newborn blood spot screening to be carried out?

Respondents talked about having checks in place at certain critical points. The most common point was on admission mentioned by 11 NICUs. Four of the 11 mentioned that they used the newborn blood spot failsafe system (NBSFS) to do these checks. Other touch points mentioned were at handover and on discharge. Two NICUs mentioned the use of checklists which includes NBS.

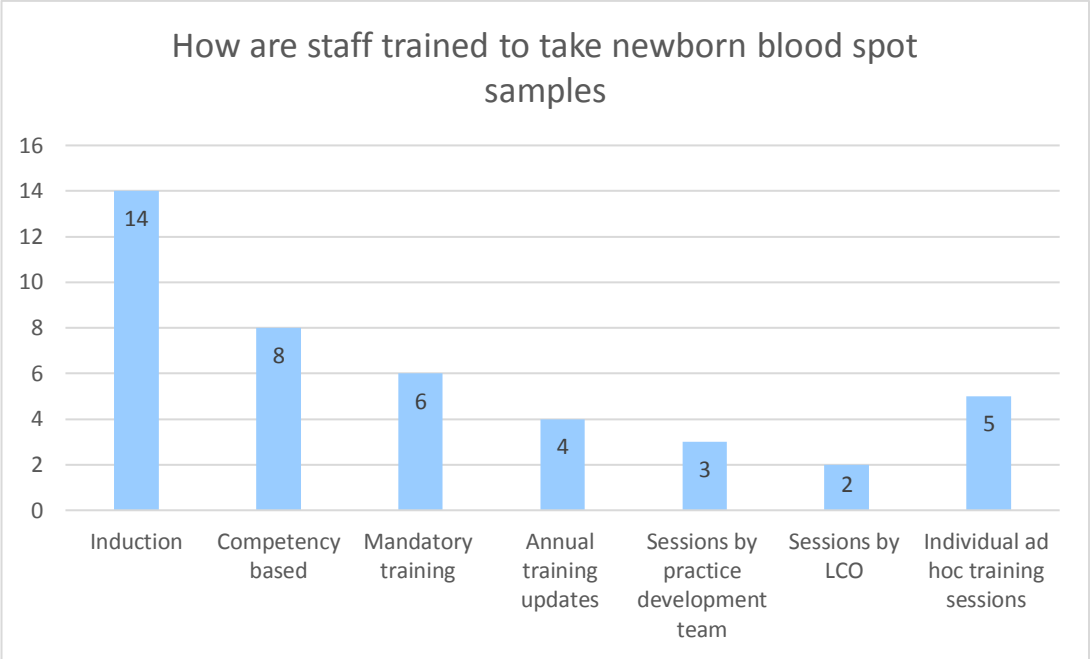
Which staff carry out newborn bloodspot screening?

Most respondents listed nursing staff (neonatal nurses, special care baby unit nurses) as the staff group carrying out most newborn blood spot sampling but other staff were also involved. Other staff groups mentioned were practice educators and midwives.



What arrangements are in place for training?

A variety of training methods are used. Where induction was used many units mentioned use of PHE e-learning.



Eight units had a competency-based training in place. Two of these (Derby and Brighton) mentioned the use of competency work books. Individual ad hoc training sessions were also used to discuss individual practice issues. One unit (Brighton), in addition to induction and competency based training also talked about sharing lessons learnt from screening safety incidents. These are shared at training sessions, meetings and handovers.

How are NBS results recorded?

Most NICUs said they did not receive NBS results. A few mentioned they would get abnormal results if the baby was still an in-patient. If results were received they were recorded in the baby's paper medical notes and on Badgernet where available. Some NICUs mentioned that results were available on NBSFS and on child health information systems (CHIS).

How are referrals managed for babies who are screen positive?

These are usually managed centrally and instigated by the newborn screening laboratory. Contact is made directly with the consultant neonatologist or specialist team for example the endocrine team.

How are requests for repeat samples managed?

Two methods were reported. Repeats were either flagged by NICU admin staff/ staff with responsibility for checking NBSFS (n=8) or flagged to NICU by the screening midwife/ team (n=8).

Newborn and infant physical examination survey responses

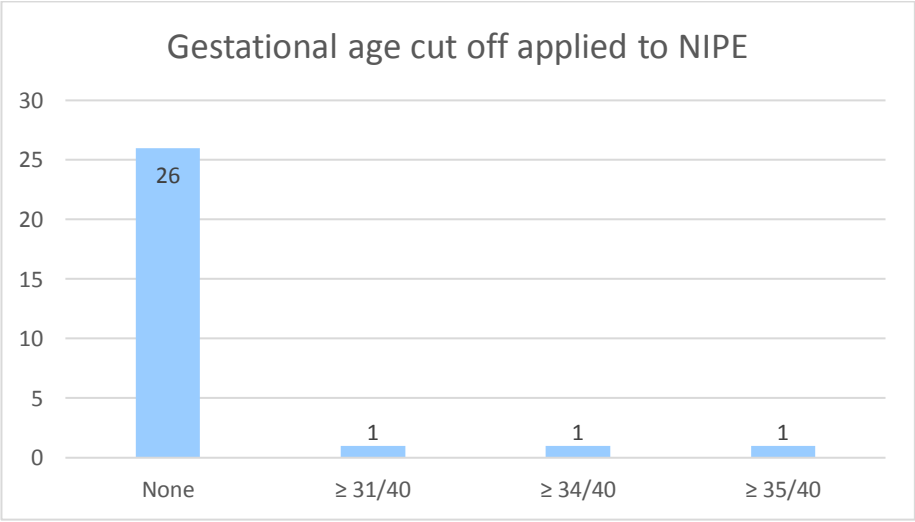
What arrangements are in place for newborn physical examination to be carried out?

The majority of respondents reported that the process to make sure the newborn examination was carried out was linked to the admission process. In some cases there was a further check at discharge. A few units mentioned running a daily list either from NIPE SMART or another IT system to make sure no babies are missed. They also reported that the examination would be delayed if the baby was too unwell or premature.

Do you use a gestational age cut-off for NIPE screening?

Most units did not apply a gestational age eligibility cut-off and, in the few that did, the gestational age differed.

The national screening programme recommends eligibility for NIPE screen is based on the baby's condition. Babies should only have screening delayed if they are too unwell (it is acknowledged that some babies in neonatal units may be too ill at the time the examination is due and the NIPE screen is not appropriate). If possible all screening elements should be undertaken but if not, each element of the NIPE screen should be completed as soon as it is practical to do so.



Additional comments provided were as follows:

- it is clearly not appropriate to carry out a NIPE examination on extremely preterm infants – not least because the Barlow and Ortolani's tests are not validated for preterm infants
- hips and eyes are examined at a later date near term

- preterm infants, while they will receive an admission examination (<6hrs of age), hips and eyes are not routinely checked – hips due to prematurity, there is no consensus as to when hips will be formed/stable/no longer immature and so no defined gestation cut-off, so checked on discharge

Which staff carry out NIPE screening?

Staff groups who did the newborn examination included:

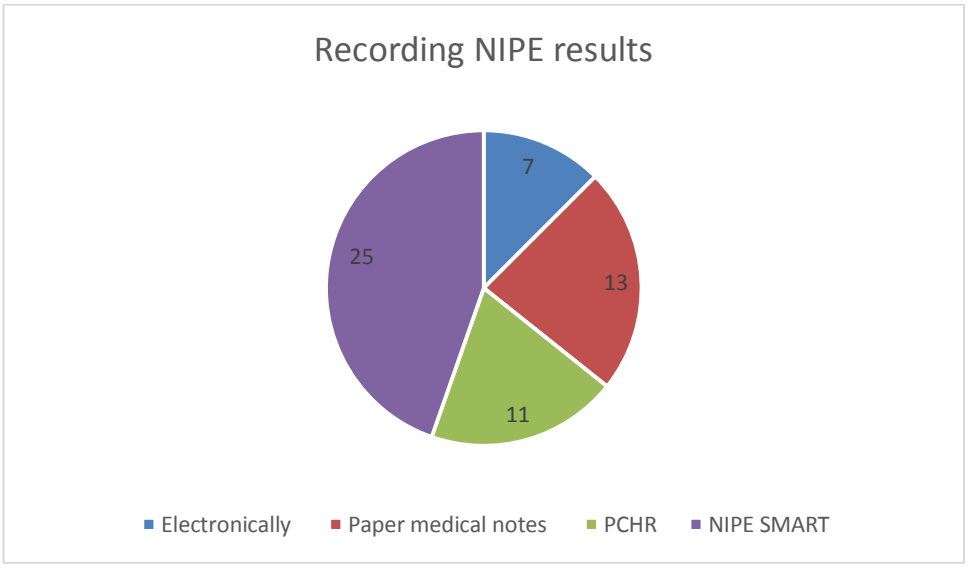
- medical staff – SHOs, registrars, consultants
- advanced neonatal nurse practitioners
- neonatal nursing staff who have undertaken specific training
- midwives

What arrangements are in place for training?

- SHOs are trained as part of their induction with a few completing the e-learning as well
- Nursing and midwifery staff are required to complete a university accredited examination of the newborn training course

How are NIPE results recorded?

In most cases the result was recorded in more than one place. For the majority of respondents using NIPE SMART, a paper print out was also filed in the baby's medical notes and/or to place a copy in the PCHR (red book). Five respondents did not use NIPE SMART. Where results were recorded electronically not using NIPE SMART, various systems were in use, namely Badgernet, Cerner, Eclipse, Meditech V6 and Athena.



How are referrals managed for babies who are screen positive?

There is wide variation on how referrals are managed from paper based referral processes to more automated ones using NIPE SMART. In some cases the consultant paediatrician or their secretary manages these, in other cases the doctor completing the examination is responsible for making the referral. It was evident from the responses that referrals were not always tracked; we are aware that this has resulted in screening safety incidents.

References

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Acknowledgements

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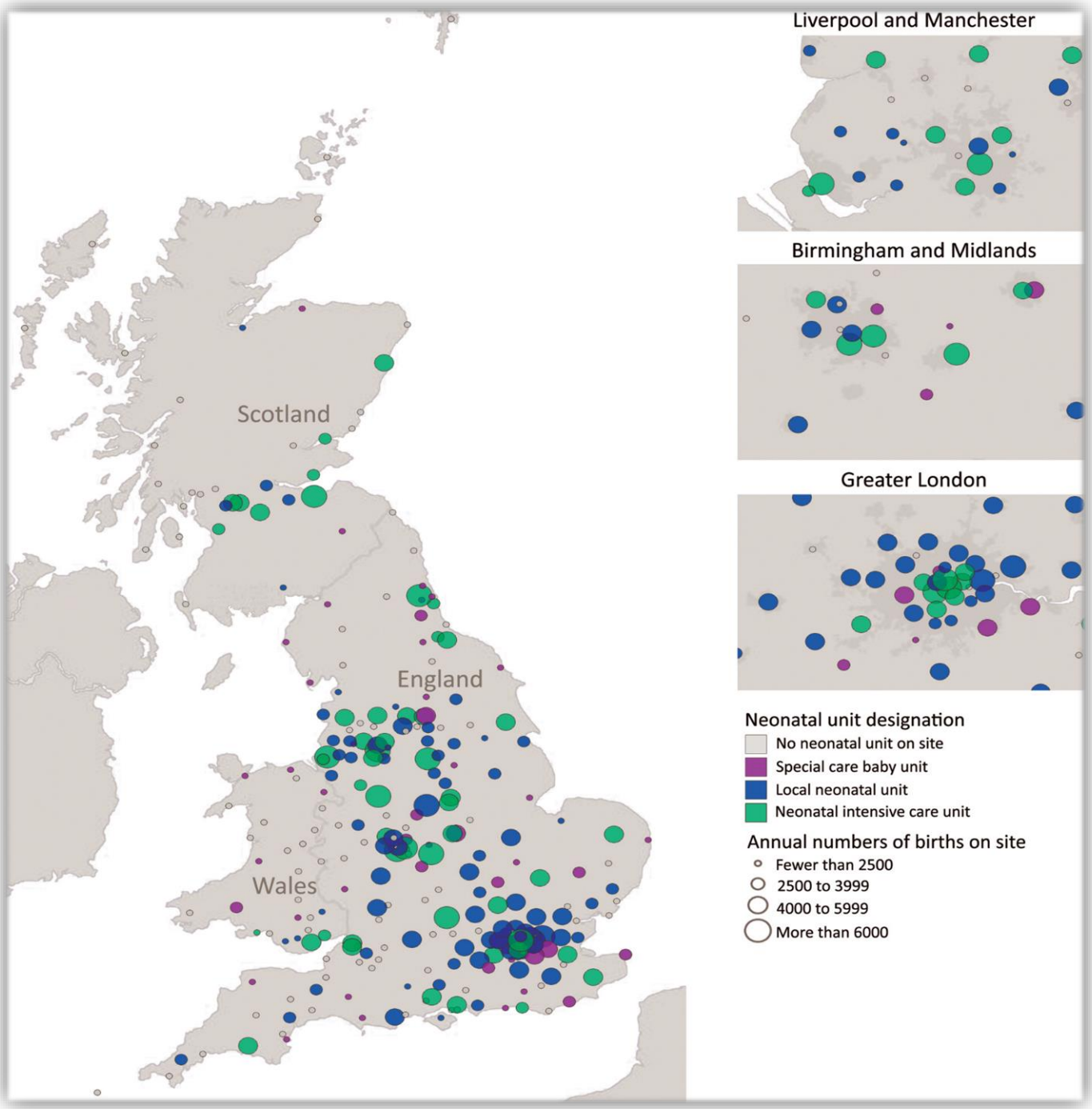
Comments incorporated where possible from Mike Harris, Julie Wilcox, Jane Hibbert and Jill Walker.

Appendix 1: neonatal units across England



Reference: NMPA project team. National Maternity and Perinatal Audit: organisational report 2017.RCOG London, 2017
http://www.maternityaudit.org.uk/downloads/NMPA%20organisational%20report%202017.pdf

Appendix 2: list of responders

Hospital	Unit
Basildon Hospital	Neonatal Unit
Bradford Teaching Hospitals NHS Trust	
Brighton Hospital	
Calderdale Royal Hospital, Halifax	Neonatal Unit
Chesterfield Hospital	Neonatal Unit
Colchester Hospital	Neonatal Unit
Darent Valley Hospital	Special Care Baby Unit
Derby Teaching Hospitals NHS Foundation Trust.	
East Kent Hospitals University Foundation Trust	Neonatal Unit
East Sussex Hospital	
Epsom Hospital	Special Care Baby Unit
Evelina London Children's Hospital	Neonatal Unit
Frimley Park Hospital	
King's College Hospital	Fred Still NICU
King's Mill Hospital	Neonatal Unit
Kingston NHS Foundation Trust	Neonatal Unit
Medway Hospital NHS Foundation Trust	Oliver Fisher Neonatal Unit
Mid Essex Hospital Trust	Neonatal Unit
Mid Yorkshire Hospitals NHS Trust	
Milton Keynes University Hospital	Neonatal Unit
Newham Hospital	Neonatal Unit
Nottingham University Hospital NHS Trust	QMC and City Neonatal Units
Queen's Hospital, Burton Upon Trent	
Royal Free Hospital	
Royal Surrey County Hospital	
St George's Hospital	Neonatal Unit
St Helier Hospital	Neonatal Unit
St Peter's Hospital, Chertsey	
Southend Hospital	Neonatal Unit
Surrey and Sussex Healthcare Trust	
Tunbridge Wells Hospital	Neonatal Unit
University College Hospital London	Neonatal Unit
University Hospitals of North Midlands	
West Sussex Hospital	