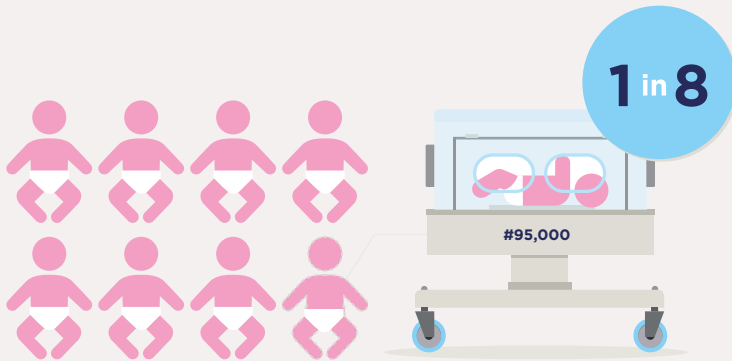


Your baby's care

Measuring standards and
improving neonatal care



A guide to the
**National Neonatal
Audit Programme**
2016 Annual Report



Neonatal unit admissions

Approximately 1 out of every 8 babies born in England, Scotland and Wales each year (or 95,000 out of 750,000) needs specialist neonatal care in hospital.

"We hope that the NNAP 2016 annual report on 2015 data, and this parent-focused leaflet, "Your Baby's Care", which accompanies it, will help parents and clinicians to work together to achieve the best outcomes for babies who require neonatal care.

By working with clinicians to improve care we, as parents, can help to improve things not just for our own babies, but for those babies who will require neonatal care in the future."

Ellen Hallsworth and Patrick Tully

Parent Representatives on the NNAP Project Board



Neonatal Care

One in eight babies born in the UK will spend at least a few days in hospital in a neonatal unit which specialises in looking after babies who are born early, with a low weight or who have a medical condition that requires specialised treatment.

Some babies may need breathing support or monitoring, or may be suffering from other medical conditions. Other babies may have an infection and need antibiotics. The length of a baby's stay may vary from days to weeks or months, depending on their needs.

What is the National Neonatal Audit Programme?

It is very important that the standards of care provided by neonatal units are monitored regularly. The Royal College of Paediatrics and Child Health (RCPCH) does this through the National Neonatal Audit Programme (NNAP).

Since it was set up in 2006, the NNAP has monitored and reported on neonatal care processes to help ensure that all babies admitted to neonatal units in England, Scotland and Wales have the best chance of survival and reaching their full potential. The NNAP looks for areas where the care of babies on neonatal units can be improved and makes recommendations on how those improvements could be made and by whom.

The NNAP currently covers neonatal units in England, Scotland and Wales and it is anticipated that units in Northern Ireland will join the audit in the near future.

The work of the NNAP is overseen by the members of a project board comprised of NNAP project staff based at the RCPCH, a lead clinician who is an experienced

consultant neonatologist, parents, healthcare professionals and representatives from a range of organisations including UK charity, **Bliss**.

Bliss
for babies born
premature or sick



What does the NNAP do for you and your baby?

The NNAP monitors whether the care that has been provided to babies and their families matches up to professionally agreed standards. By describing areas which are good, and those which could be better, the NNAP helps hospitals, neonatal networks, and those who plan healthcare, to improve neonatal care.

We hope that this booklet will help you to understand some of the standards that we measure neonatal care against. This might help you to discuss aspects of your baby's care with neonatal unit staff.



What aspects of care does the NNAP focus on?

The NNAP 2016 Annual Report on 2015 data looked at ten areas of care ('audit measures') for preterm and sick babies.

These ten areas were chosen by a group including parents and experts in neonatal care because they are particularly important for the development and well-being of babies and their families.

The audit measures for 2015 were:

- Antenatal steroids
- Temperature on admission
- Consultation with parents
- Recording of bloodstream and cerebrospinal fluid cultures
- Prevalence of central line associated blood stream infections
- Transfers of babies
- Bronchopulmonary dysplasia
- Retinopathy of prematurity (ROP) screening
- Mother's milk at discharge
- Clinical follow-up at two years of age

The 2016 report looks at data relating to how well these ten areas of care were provided for 95,325 babies who were admitted to 179 neonatal units across England, Scotland and Wales during 2015.

In the following pages, we give more detail about some of these measures, including the actual questions that the NNAP asks, and why it asks them.



Antenatal steroids

Question: *Are all mothers who deliver babies between 24 and 34 weeks gestation inclusive given any dose of antenatal steroids?*

Babies who are born at less than 34 weeks gestation sometimes have breathing difficulties in the few days after they are born.

When your baby is born the doctors and nurses will know to look out for this and will know how to treat it appropriately. Giving mothers who are about to give birth to a preterm baby antenatal steroids can help to reduce this breathing difficulty and also make other serious problems less likely.

Steroids do not work straight away and sometimes babies are born before they can be given.

The NNAP project board would like as many mothers as possible to be given antenatal steroids if they are about to deliver a baby at less than 34 weeks gestation.

For 2016 the NNAP has also started to measure how many mothers are given magnesium treatment, which reduces long term complications in the earliest babies. Future reports, starting with the 2017 report on 2016 data, will describe how often this is given.

85%
(2015)



Antenatal steroids

In 2015, **85%** of mothers who delivered babies born between 24 and 34 weeks of gestation received one or more doses of antenatal steroids prior to the birth of their baby.

Temperature on admission

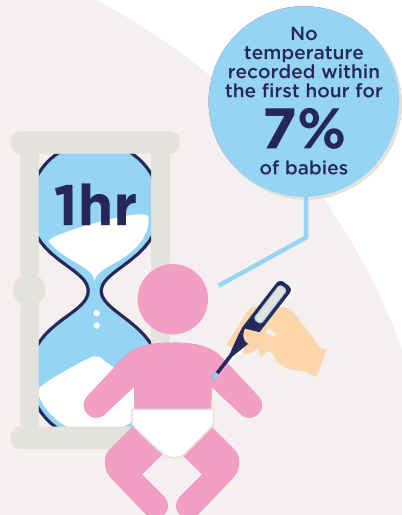
Question: *Do all babies born at less than 32 weeks gestation have their temperature taken within an hour after birth?*

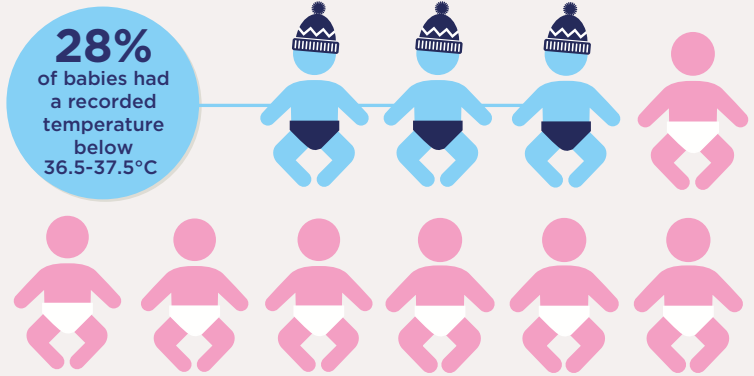
Babies who are colder on admission get more unwell and babies who are born very early (less than 32 weeks) get cold very easily after birth. It is extremely important that doctors and nurses measure babies' temperatures and use all available measures to prevent these babies from getting cold.

In 2015, 93% of babies born at less than 32 weeks gestation had their temperature recorded within an hour of birth. 62% of the babies who had their temperature recorded within an hour of birth had a temperature within the recommended range of 36.5°C to 37.5°C

Temperature on admission

In 2015, of the 7,864 babies born at a gestational age of less than 32 weeks, 7,351 (or **93%**) had their temperature recorded within the first hour of birth.





28% of babies born in 2015 at less than 32 weeks gestation who had their temperature recorded within an hour of birth had a temperature **below** the recommended range of 36.5°C to 37.5°C.



Consultation with parents

Question: *Is there a documented consultation with parents by a senior member of the neonatal team within 24 hours of admission?*

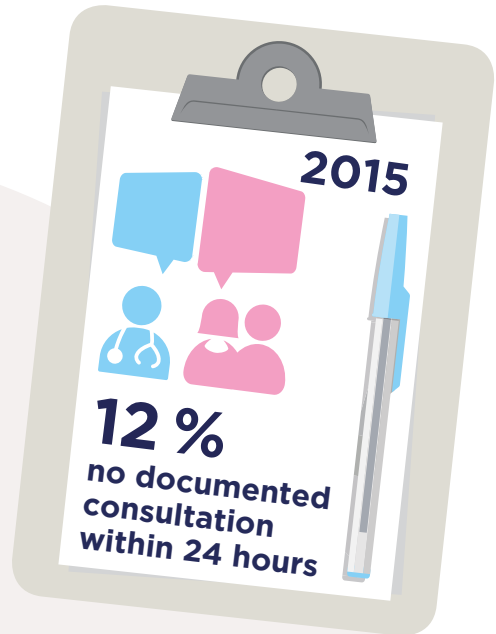
This measure of care looks at whether parents have been spoken to by a senior member of the neonatal team within the first 24 hours of their baby being admitted to the unit.

It also looks at whether details of that discussion are documented, and applies to ALL babies who require care on a neonatal unit.

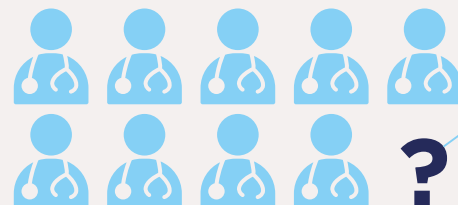
It is important that families understand and are involved in the care of their baby. Doctors and nurses should take the time to explain to families how their baby is being cared for and to answer any questions that parents may have.

Consultation with parents

In **88%** of cases there was a documented conversation with a senior member* of the neonatal team within 24 hours of the baby's admission to the unit.



*The NNAP regards a senior member of the neonatal team as being a consultant or second tier medical trainee, or a nurse practitioner operating in such a role.



1 in 10

This means that in more than **1 in 10** cases parents may not have had a timely explanation of their baby's illness and treatment. Involving parents in their baby's care is crucial for achieving the best long-term outcomes; engaging them in the first 24 hours is an essential part of doing this. It is therefore vital that neonatal unit staff take the time to explain to parents how their baby is being cared for and also listen to parents, try to understand how they are feeling and respond to any questions that they may have.

Neonatal unit transfers

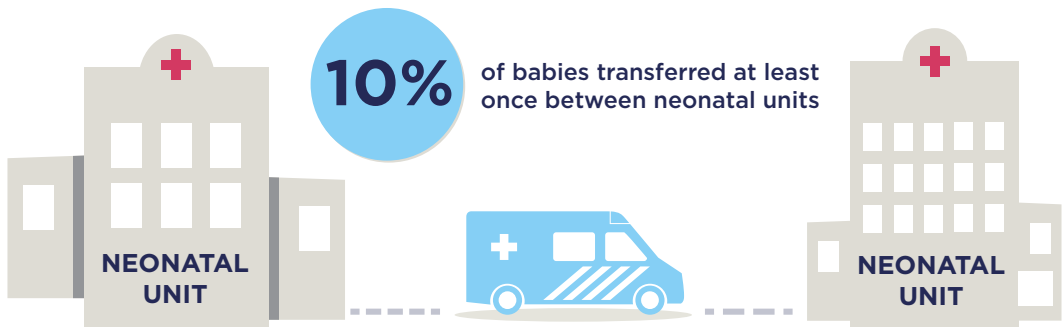
Question: *Are all babies accessing neonatal services treated in their own network (except where clinical reasons dictate)?*

In the UK, neonatal care is provided by three different levels of unit (Special Care Unit, Local Neonatal Unit and Neonatal Intensive Care Unit) which have different levels of skills and specialties.

These neonatal units are grouped together within a geographical location, known as a 'network'. The hospitals in each network aim to work together to provide a safe and high quality service for babies who require specialist neonatal care.

There are occasions when a baby may need to be transferred to another unit that provides the level of care that is more appropriate to his or her needs at the time. In 2015, 10% of babies experienced at least one transfer during their time in neonatal care.

At times it may not be possible to do this within the network where the baby's parents live and this may require transferring the baby to a hospital further away from home.



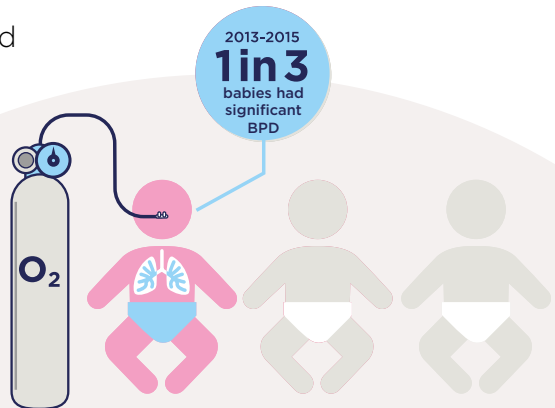
Bronchopulmonary dysplasia (BPD)

Question: *What is the proportion of babies born at less than 32 weeks who develop Bronchopulmonary dysplasia (BPD)?*

When babies are born very early their lungs often haven't fully developed. This means that they need support with their breathing from a ventilator.

Being on a ventilator for some time can cause damage to the lungs and mean that babies have more breathing problems later and are at more at risk from chest infections. This is known as Bronchopulmonary dysplasia (BPD). It is also sometimes called Chronic Lung Disease (CLD).

Some babies will require extra oxygen for a while after they go home from hospital. When babies are in still oxygen at 36 weeks gestation after very early birth this is known as significant BPD. BPD sometimes causes problems in the longer term, but the good news is that babies' lungs continue to grow and develop as they get older and most babies do very well.



Babies affected by BPD

Just under **one in three** babies born at less than 32 weeks gestation who were admitted for neonatal care between 2013 and 2015 were affected by significant BPD.

Recording of bloodstream and cerebrospinal fluid cultures

Question: *What percentage of babies admitted to a neonatal unit had a recording of bloodstream and cerebrospinal fluid (CSF) cultures?*

Bacteria that usually live on the skin, and within the bowel, of healthy adults can cause serious infections in sick and premature babies.

To look for infection in infants, doctors and nurses commonly take blood cultures to check

whether bacteria are present in the blood. Doctors may sometimes want to take a small sample of cerebrospinal fluid (CSF) from the spine instead of a blood vessel. Sampling of CSF is essential for the accurate diagnosis of meningitis.

In 2015 there was no important increase in the number of blood cultures recorded compared to 2014 (64,798 from 95,325 babies in 2015 and 55,388 from 86,287 babies in 2014).



Central line associated blood stream infections

Question: *How many bloodstream infections are there on a NNU per 1000 days of central line care?*

Many babies will need thin plastic tubes, or 'central lines' that go into their veins to give them medication and nutrition. There are many types of central lines, but they all generally do the same thing and are essential for providing premature and sick babies with the vital treatments that they need. They do, however

increase the possibility of infection by providing a point of entry for infection through a baby's skin.

The NNAP monitors infection rates in neonatal units in order to provide important information and feedback to neonatal units which can help them in their efforts to reduce infection.

By reviewing results for 2015, the NNAP has identified that neonatal units must improve their recording of blood culture data so that infection rates can be accurately identified and acted upon.

Retinopathy of prematurity screening

Question: *Are all babies with a gestational age at birth of less than 32 weeks, or with a birth weight of less than 1501g (whatever their gestational age), undergoing first Retinopathy of Prematurity (ROP) screening in accordance with the current national guideline recommendations?*

From looking after babies born prematurely for many years, doctors and specialists have learnt that babies that are born early at less than 32 weeks gestation,

or with a birth weight of less than 1501g (whatever their gestational age), are at risk of a condition that affects the eyes called Retinopathy of Prematurity (ROP). With this

condition the blood vessels in the back of the eye do not develop normally and this can lead to loss of vision. If doctors and specialists look for ROP in those babies at risk of having it they can monitor them and treat the ROP, if treatment is needed.

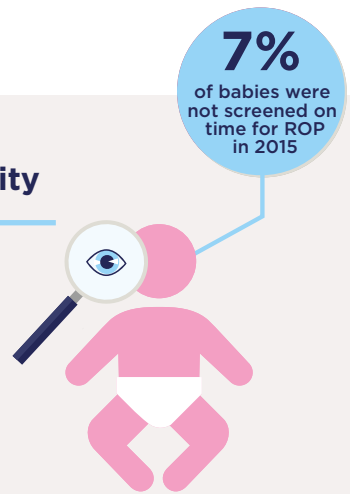
The only way to find out which babies have ROP is through an eye screening examination. A clear national guideline says when this should be done, depending on the gestational age and weight of a baby.

The NNAP project board would like every baby who is well enough to do so to have their eye examinations on time.

In this year's annual report the NNAP project board recommends that parents should be given individualised written information by the neonatal unit that explains the need for ROP screening and gives the anticipated date of the first ROP screening for their baby.

Screening for Retinopathy of Prematurity

In 2015, more than **one in 20** babies did not receive ROP screening within the recommended time frame - a figure unchanged from 2014.



What you can do

Talk to staff on your unit and find out whether this might be relevant and when your baby's screening might be due. If your baby is due to be screened after being discharged from the unit make sure that this happens..

Mother's milk at discharge

Question: *What proportion of babies born at less than 33 weeks gestation are receiving any of their mother's milk when discharged from a neonatal unit?*

We know that receiving breastmilk makes a huge difference to premature babies and helps to prevent infection. While premature or sick babies may not be ready to feed from their mother's breast straightaway, mothers can still provide babies with milk by expressing. It can be difficult and stressful feeding a premature baby, so it's vital that unit staff provide positive and practical support to help you with expressing for

your baby and to get feeding established for going home.

Due to all of the advantages of breast milk, the NNAP project board would like as many very premature babies as possible to receive their own mother's breast milk (whether by breast feeding directly or with expressed milk) and go home from neonatal units feeding with breast milk.

Mother's milk at discharge

In 2015, at a national level, **60%** of eligible babies were receiving their mother's breastmilk, either exclusively or with another form of feeding, at the time of their discharge from neonatal care.

At a neonatal network level, breastmilk feeding rates varied considerably, ranging from **43%** to **85%**.



Clinical follow-up at 2 years of age

Question: Was a clinical follow up consultation conducted at 2 years of age for babies born at a gestational age of less than 30 weeks?

This audit measure looks at whether there are any significant problems with movement, the senses, delays in development, or other health problems 2 years on from the due date for babies who were born more than ten weeks early.

Babies that are born very early encounter these type of problems more often than those born at full term and it is important for those involved in the care of premature babies to know how the babies are developing as they get older.

Your baby's development should be regularly assessed and monitored by their healthcare professional. This will help to reassure you if your baby is doing

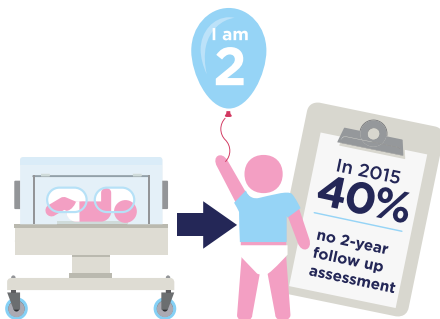
well, and enable any difficulties to be acted on early and also provide an opportunity to address any concerns that you may have.

The NNAP found that in 2015 there was no 2 year follow up data recorded for 40% of babies born more than 10 weeks early in 2012 and 2013.

This suggests that, either neonatal units are not doing the 2 year follow up consultations, or that they are recording the findings somewhere other than the system used to record the data for the NNAP.

What you can do

Stay in touch with the neonatal unit you're discharged from. Making sure that you go along to all follow up appointments means you're able to get reassurance about how your baby is developing, and get any support your baby might need for their future development.



Would you like to know more?

You can find out more about the NNAP, and download a copy of the full NNAP 2016 Annual Report, including all of the key findings and recommendations, from the NNAP website at:

www.rcpch.ac.uk/nnap

At the same site, you will also find a link to NNAP Online which enables you to view and compare NNAP audit results across neonatal units and networks.

If you would like to receive updates about the work of the NNAP, or if you have any queries about the work of the audit, please contact the project team at:

nnap@rcpch.ac.uk

The RCPCH would like to give special thanks to the parent representatives on the NNAP project board for their input and guidance in the development of this report and for their kind permission to use images of their own babies within it.

If you would like to discuss how any of the NNAP findings relate to your baby's care, please ask your baby's nurse or speak to one of the medical staff.

Bliss is the UK charity working to ensure that every baby born premature or sick in the UK has the best chance of survival and quality of life.

For more information on Bliss please visit: www.bliss.org.uk

Parents,
Carers & Us[®]

& Us is the RCPCH's platform for children, young people and families to help improve child health and healthcare for young patients.

Join **& Us** and help make the NHS a better place:

www.rcpch.ac.uk/and_us

Information for parents and carers:

Written consent is not required for submission of patient data to the NNAP, however parents should be aware that data on their baby's neonatal care is being utilised, and that they can choose to opt out of having their baby's data submitted to the audit. The data that the NNAP collects and analyses is encrypted and stored securely. For further information on how to opt out contact the NNAP team at: nnap@rcpch.ac.uk

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The National Neonatal Audit Programme is commissioned and sponsored by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit Programme.

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