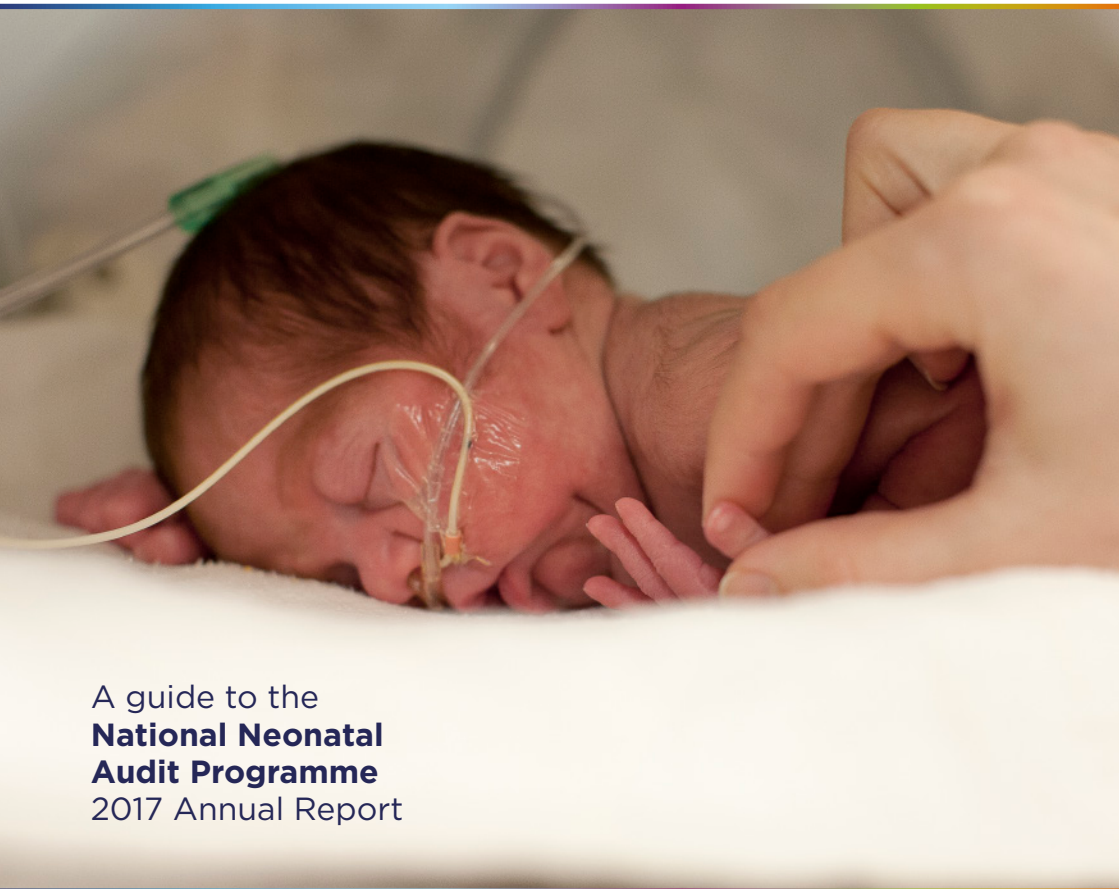
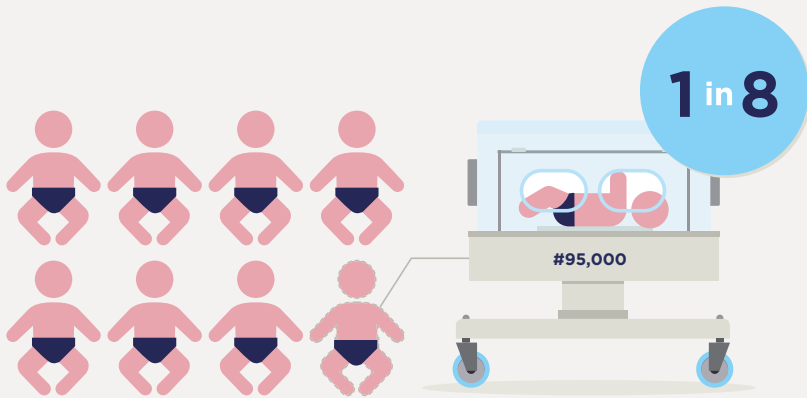


Your baby's care

Measuring standards and
improving neonatal care



A guide to the
**National Neonatal
Audit Programme**
2017 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.

"On many of the National Neonatal Audit Programme's measures, making progress depends on parents and clinical staff working together. We hope staff will use these data to spread innovation and improvement."

Ellen Hallsworth & Patrick Tully,
Parent Representatives



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 2017 Annual Report on 2016 data looked at nine areas of care (covered by 12 audit measures) for premature and sick babies.

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

The focused areas of care for 2016 were:

- Antenatal steroids
- Magnesium sulphate
- Bronchopulmonary dysplasia (BPD)
- Temperature on admission
- Consultation with parents
- Measuring rates of infection on neonatal units
- Retinopathy of prematurity (ROP) screening
- Mother's milk at discharge
- Clinical follow-up at two years of age

The 2017 report looks at data relating to how well these ten areas of care were provided for 99,849 babies who were admitted to 181 neonatal units across England, Scotland and Wales during 2016.

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.



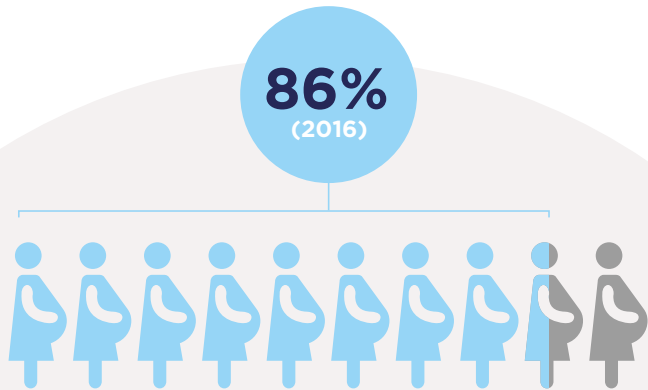
Antenatal steroids

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 premature 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.

We would like as many mothers as possible to be given antenatal steroids if they are about to deliver a baby early.



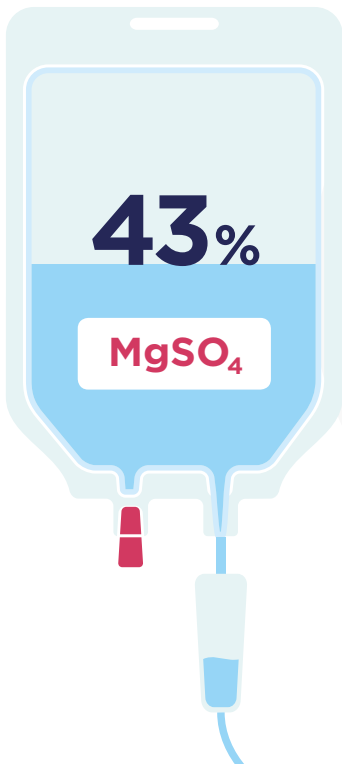
Antenatal steroids

86% of mothers of premature babies were given antenatal steroids in 2016. This figure has risen by 1% since 2015.

Magnesium sulphate

Question: *Are mothers who deliver babies below 30 weeks gestation given magnesium sulphate in the 24 hours prior to delivery?*

Giving women who are at risk of having a premature baby magnesium sulphate through their veins reduces the chance that their baby will later develop cerebral palsy by 30%. It is recommended that all women who may give birth before 30 weeks of pregnancy should be offered this treatment.



Mothers who were given magnesium sulphate

Magnesium sulphate was given to **43%** of women who gave birth before 30 weeks of pregnancy.

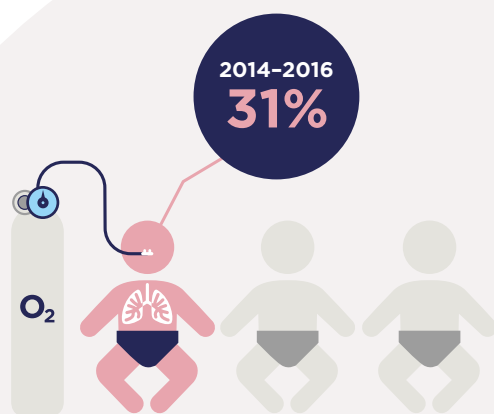
Bronchopulmonary dysplasia (BPD)

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 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.

Some babies will require extra oxygen for a while after they go home from hospital. When babies are still receiving extra 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

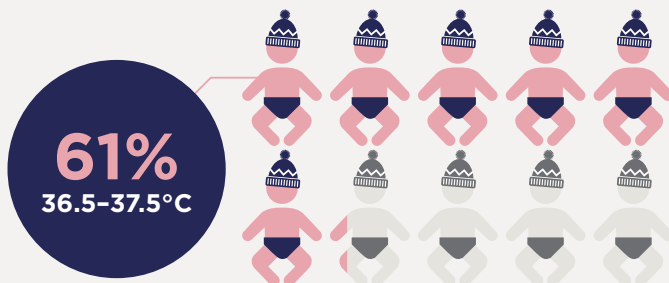
31% of all babies born before 32 weeks developed significant BPD.

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 born before 32 weeks get cold very easily after birth, and being cold on admission to a neonatal unit can make babies more sick. It is extremely important that doctors and nurses measure babies' temperatures and use all available measures to prevent these babies from getting cold.

In 2016, 96% of babies born before 32 weeks had their temperature recorded within an hour of birth. 61% 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 2016, **61%** of babies born before 32 weeks were admitted onto a neonatal unit with a temperature in the recommended range.



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 applies to the parents of all babies who require care on a neonatal unit and 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.

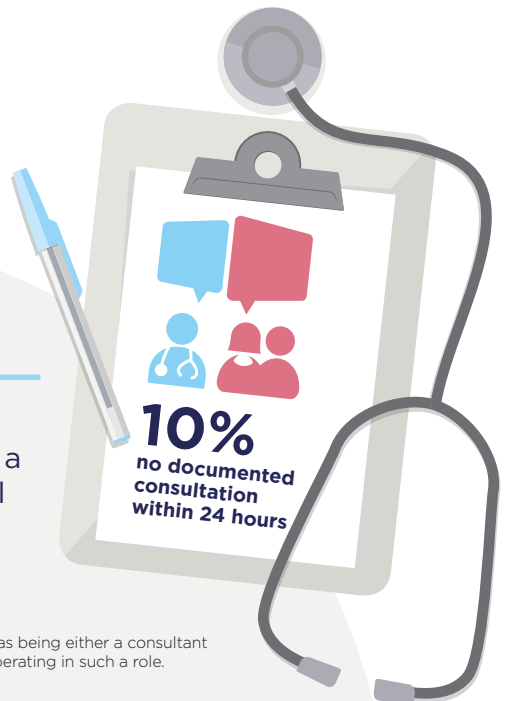
It is important that families understand and are involved in the care of their baby. Doctors and nurses should take the time to explain to families how their baby is being cared for and to answer any questions that parents may have.

For 2017, the NNAP has also started measuring whether at least one of the parents of babies with admissions of greater than 24 hours attended any consultant ward round, at any time, during the baby's stay on the neonatal unit. Future reports from 2018 will describe whether parents are present on all ward rounds.

Consultation with parents

In **90%** 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 either a consultant or senior speciality trainee doctor, or a nurse practitioner operating in such a role.



What you can do

Parents who feel they haven't had an early consultation should ask their baby's nurse to arrange one and use such meetings to discuss how they can work in partnership with the neonatal unit staff in their baby's care.

This could include asking whether you might be able to attend ward rounds for your baby, or discussing other ways in which you can become involved in aspects of day-to-day care.



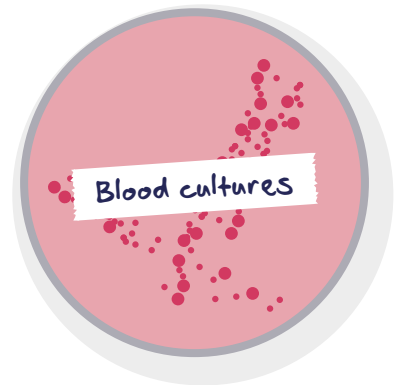
Measuring rates of infection on neonatal units

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 babies, doctors and nurses usually take blood cultures to check whether bacteria are present in the blood. Doctors may 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.

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 chance of infection by providing a point of entry for replace infection with bacteria.

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.



In 2016 there was no important increase in the number of blood cultures recorded compared to 2015 (64,798 cultures from 95,325 babies in 2015; 71,627 from 99,849 babies in 2016).

By reviewing results for 2016, 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 (ROP) 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?*

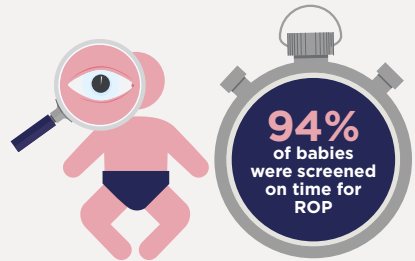
From looking after babies born prematurely for many years, doctors and specialists have learnt that babies that are born early at less than 32 weeks gestation, or with a birth weight of less than 1501g (whatever their gestational age), are at risk of a condition that affects the eyes called retinopathy 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 2016, **98.4%** of babies had documented screening for retinopathy of prematurity at any time in their course, an increase from 97.5% in 2015.



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 you should make every effort to attend the appointment.

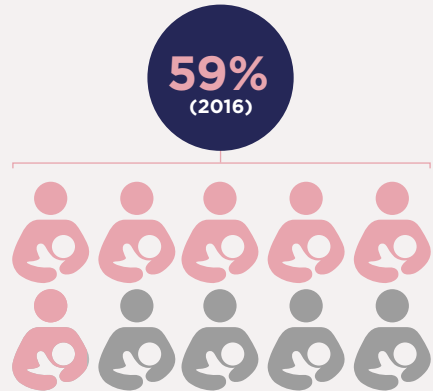


Mother's milk at discharge

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 2016, at a national level, **59%** 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.

What you can do

Ask staff on your unit about what support is available for expressing and breastfeeding.

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.

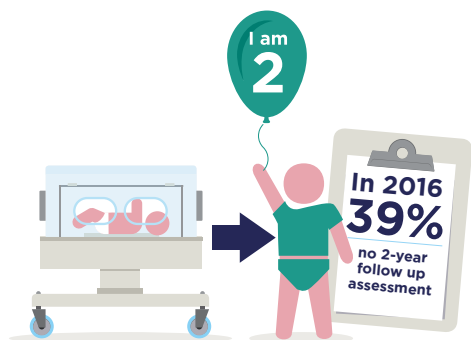
Babies that are born very early encounter these type of problems more often than those born at full term and it is important for those involved in the care of premature babies to know how the babies are developing as they get older.

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 difficulty to be acted on early and also provide an opportunity to address any concerns that you may have.

The NNAP found that in 2016 there was no 2 year follow up data recorded for 39% of babies born more than 10 weeks early in 2013 and 2014.

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

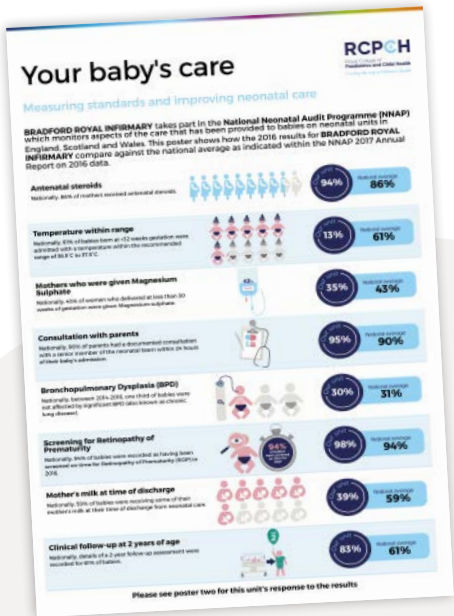
Stay in touch with the neonatal unit you're discharged from. Making sure that you go along to all follow up appointments means you're able to get reassurance about how your baby is developing, and get any support your baby might need for their future development.

Your unit's NNAP results

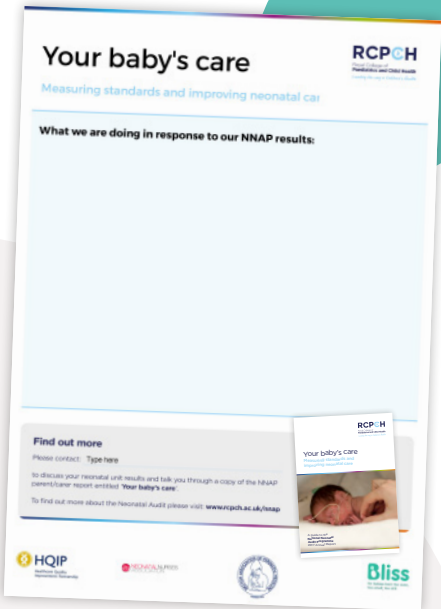
Helping units to share their NNAP results with parents, carers and families.

The aim of the NNAP is to drive up national standards of neonatal care. We realised that there was more that most neonatal units could do to communicate the NNAP's results to parents. We believe that parents can help us to make care better in unit's across the UK. We worked with parents of premature babies and nurses to develop a poster to help with this.

You may already have seen the poster on your unit. Part of the poster shows your unit's results compared to the national average, and the other part allows units to say what they're doing to make care better.



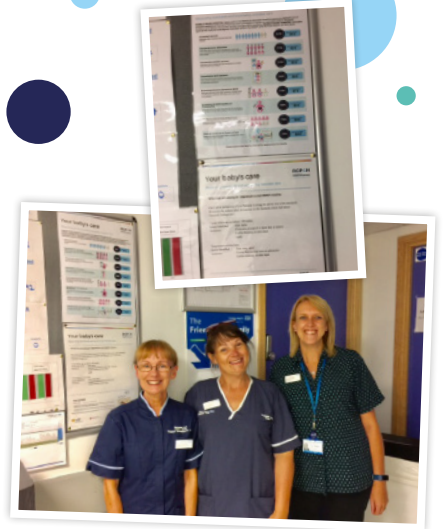
NNAP Infographic Poster



NNAP Response Poster



Royal Hospital for Children, Glasgow displaying their posters.



Frimley Park Hospital unit staff displaying their posters.



Royal Berkshire Hospital displaying their posters alongside copies of 'Your baby's care'.



Poole Hospital displaying their poster.



New Cross Hospital displaying their posters alongside copies of 'Your baby's care'.

The NNAP project board would particularly like to thank the members of the working group who developed the posters and the neonatal unit staff members and parents who helped to pilot them.

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 (**www.nnap.rcpch.ac.uk**) which enables you to view and compare NNAP audit results across neonatal units.

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:

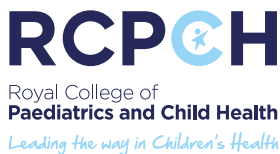
Written consent is not required for submission of patient data to the NNAP, however parents should be aware that data on their baby's neonatal care is being utilised, and that they can choose to opt out of having their baby's data submitted to the audit. The data that the NNAP collects and analyses is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

A guide to the National Neonatal Audit Programme 2017 Annual Report



Commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

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