

access to personal information like your baby's NHS number and date of birth. By law, everyone who works for the NHS must keep all personal information confidential and the Trust has strict confidentiality and security procedures in line with the Data Protection Act (1998).

What is the consent procedure?

If you are happy for your baby's details to be used for clinical care purposes, secondary analysis such as audits and for clinical information to be transferred between units should the need arise then you do not need to do anything.

If however you do not want to your baby's clinical information to be available for such purposes please ask a member of staff for an opt-out consent form.

A signed copy of the opt-out consent form will be given to you for your information.

Can I see the records on the database?

Yes, you can see a copy of the information we have about you and your baby. To do this please talk to the nurse in charge.

How can I find out more?

Please talk to member of staff if you:

- Need more information
- Have any questions or concerns
- Want us to remove any information from the database

A guide to recording information on your baby's care in the neonatal unit

South England Neonatal Database
(SEND) system

Your baby needs the expert care of the medical and nursing team on the neonatal unit. To help deliver the best care possible we collect information about all the babies we look after.

The South England Neonatal Database (SEND) system is being implemented within all the neonatal units across London and SE England. It is a web based system which collects clinical information regarding your baby.

Why do you need this information?

We use the information we collect to help us:

- Collect accurate details about the care of sick or premature babies in the neonatal unit
- Monitor neonatal care and make sure it is always up to date
- Plan and develop services for you and your baby within your area
- Produce reports that highlight areas of good practice that we can share across the region

Clinical information necessary to those staff directly involved in your baby's day to day care will be identifiable data. Clinical data required for all other purposes will be anonymised.

What information do you collect?

We record:

- the NHS number for you and your baby

- personal detail such as your contact details
- your baby's condition and treatment on a daily basis
- GP details
- your baby's medication and follow up information
- where your baby was born
- how many babies you had
- your baby's birth weight
- how many weeks pregnant you were when your baby was born

Who collects the information?

The staff on the neonatal unit – usually this is a neonatal nurse, doctor or ward clerk. All information will be stored on a secure system and password protected.

When will you collect the information?

Information is updated regularly throughout your baby's stay in the neonatal unit

How will you collect the information?

We collect the information from the medical notes and nursing records. We enter it directly into the SEND system.

Who will see the information?

Only the people who care for your baby see all the details. There are very strict regulations controlling