

Information collected about your baby

Dear parent or guardian

When your baby is admitted to a neonatal unit for care, certain information and records recording your baby's details and information about your baby's treatment and stay are collected. If your baby needs to be transferred to another neonatal unit for specialist care or further care this information will be transferred with your baby. This will allow the neonatal unit looking after your baby to have a full history of the treatment, condition and episode of care prior to transfer.

This information is collected and stored both on paper and electronically on a secure data system. Neonatal services across the country are working together to provide the highest and most consistent levels of care and to ensure that your baby's stay with us is communicated to those people who need to know including your GP, Midwife and Health Visitor. This information is stored in the same way as your own medical records and shared with those practitioners who need to know about your medical care to continue caring for you.

Sometimes this information is shared to enable local, regional and national audit and secondary analysis to ensure that this unit is conforming to national standards and providing the best care available for your baby. When this happens the information shared is not identifiable to one particular baby and is totally anonymous.

Your neonatal unit stores this information on The South England Neonatal Database (SEND) system. This system is in place in all the neonatal units across London and SE England. It is a secure web based system which collects and stores clinical information regarding your baby.

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, as described in this letter, then you do not need to do anything.

If however you do not want 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 and stored in your baby's notes.

We hope that you will feel able to raise any concerns or queries with a member of the neonatal staff. Further information is available in the 'Information sharing leaflet' attached to this letter. Please do feel free to ask for any further information that you feel you need.

Thank you

The Neonatal Unit Staff

I am aware that clinical information about my child is held by
NHS Trust.

I do not consent for this clinical information about my child to be transferred between neonatal units

I am the mother/father/legal guardian of:-

Child's name

NHS Number

Date of Birth

Signature

Name

I do not consent for anonymised clinical information about my child to be used for secondary
analysis such as, clinical audit, research, evaluation and health service planning.

I am the mother/father/legal guardian of:-

Child's name

NHS Number

Date of Birth

Signature

Name

These issues have been explained to me by:-

Name of staff member.....

Post

Signature

Name

Date