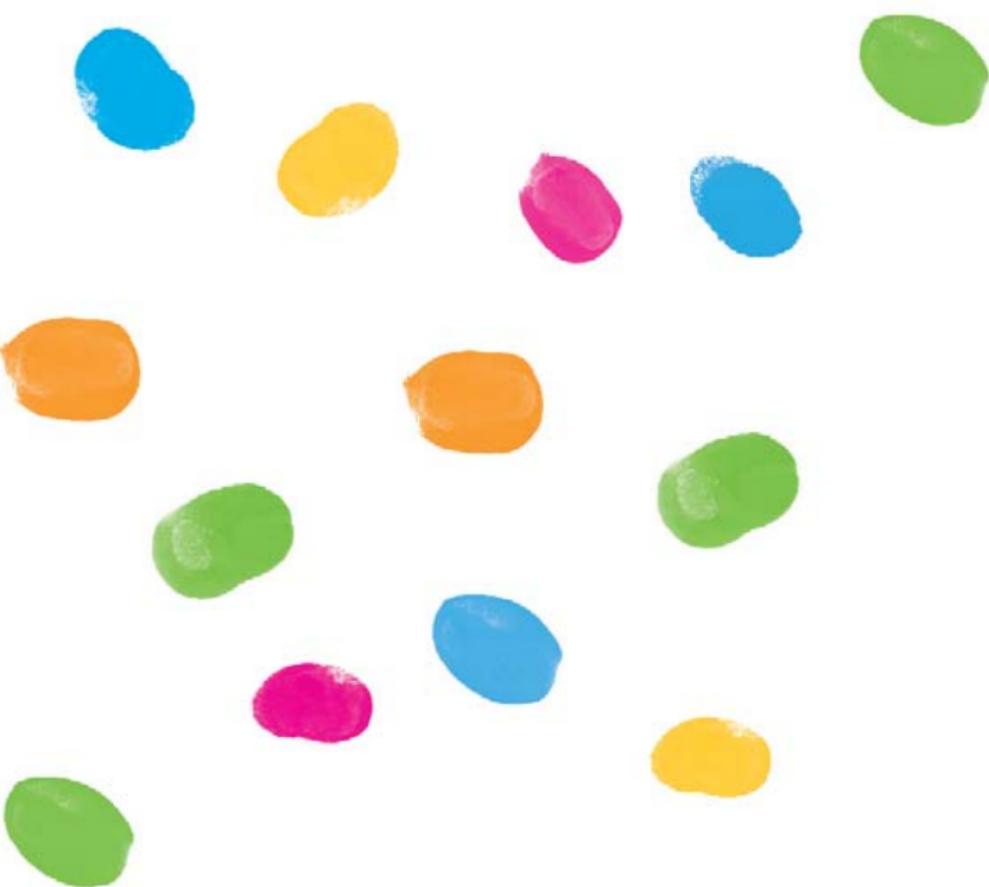


Neonatal research

Information for
parents/guardians about
supporting clinical research





Working to give babies the best chance

Welcome to the Neonatal Unit. We understand that this may be a confusing and stressful time for you and your family. Your baby is receiving 24 hour care by a dedicated expert neonatal team. Our aim is to continually improve this.

We believe that combining high quality clinical care with ongoing research is key to providing the best possible outcome for your baby.

By reading this leaflet, we hope you will understand why we may approach you and ask you to consider research opportunities for you or your baby.



Clinical research

Research is a way of gaining knowledge and improving our understanding of diseases, treatments and the effects of current practice. It is an important tool for improving the quality of care we provide.

By choosing to take part in clinical research, you may help improve the health and future of babies who are born sick or premature.



A better future - examples

Surfactant: This treatment was identified and tested in research studies and is now used as standard for breathing problems in newborn babies. It helps save babies' lives

and has been proven to improve how they do in the long term.

Kangaroo care: Research on the benefits of kangaroo care led neonatal units to encourage skin-to-skin contact and has helped to get parents more involved in the care of babies whilst on the neonatal unit.



Types of research

There are different kinds of research studies which involve different procedures. Some research projects gather data about diseases and treatments, or measure the quality of care provided. Other studies may test a new medicine or treatment, and involve procedures like blood tests or having a scan.

Our Evelina Newborn Imaging Centre, based within the Neonatal Unit, is a major neonatal research facility in partnership with King's College London. Its specialist neonatal research team use MRI scans to understand how the brain is growing and developing in babies, how it can be affected by certain conditions, and test new therapies.



Safety and quality

Research studies are reviewed and approved by the appropriate and applicable regulatory authorities such as NHS Research Ethics Committees and the Health Research Authority. Within the Trust, the safety and quality is also reviewed by the Research and Development Department, and the Evelina London research teams. This ensures

studies are unlikely to pose any increased risk for babies, compared to the standard care they would otherwise receive.

Your participation

There are many different research projects taking place and we believe every family should be offered the opportunity to take part in research.

Some research studies require you to sign a consent form in order to participate. You will be approached by a member of staff, be given detailed verbal and written information about the study, and time to think. You can ask as many questions as you wish, and if you choose to take part you will then be asked to sign the consent form. This is a legal requirement and states that you agree to participate and understand what it involves.

For other studies you will be provided with an approved parent information leaflet. After reading it if you choose not to take part, you have the option to opt out.

Your rights

Participation is totally voluntary and free. If you decide you do not wish to take part in a study or if you change your mind during a study, please speak to a member of the research team. You do not have to share your reasons and your baby's care will not be affected.



More information

People can contribute to research without taking part in a trial. If you would like to get involved in the development of neonatal research, or if you have any questions, comments or suggestions, please talk to a member of the neonatal research team or one of the healthcare professionals involved in the care of your baby.

For information relating to a specific study, please see the contacts listed in the study leaflet you have been provided with.



Useful sources of information

Bliss

A UK charity working to support all premature and sick babies and their families. **w:** www.bliss.org.uk

Evelina London Research

Find out more about the research we do at Evelina London and how you can get involved.

w: www.evelinalondon.nhs.uk/research

National Institute for Health Research

The National Institute for Health Research funds health and care research and translate discoveries into practical products, treatments, devices and procedures, involving patients and the public in all its work. **w:** www.nihr.ac.uk

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline. **t:** 020 7188 3003, Monday to Friday, 10am to 5pm
e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS).

To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS)

e: pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815

e: languagesupport@gstt.nhs.uk

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