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**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.
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