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A list of sources is available on request
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Why do we need your help with our research?
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What is the purpose of the research? eLIXIR will create a sample collection that can be used in studying a range of questions about women and babies’ health. We may look at how the mother’s health influences the health of her child. For example, if the mother had diabetes in pregnancy, or was taking medicine. We might also want to know how the health of the baby would be affected by being born too early or having difficulties at the time of birth which may affect the health of the child in later life. Mothers’ and baby genes might play a role too, and so could environmental pollution. This might influence the baby’s health but we don’t know exactly how. Sometimes we might want to know about particular genes that were switched on or off when your baby was born.

Does my child have to take part? No. It is up to you to decide whether or not your child takes part. If you decide your child can participate, we will ask you to sign a consent form to show you have agreed for your child to take part. You are free to withdraw from the research at any point without giving us a reason.

Your decision about taking part will not affect the treatment you or your child receives.

What will happen to your baby if you agree to him/her taking part? Your baby needs care in the neonatal intensive care unit and a small blood sample will be needed as part of clinical care. Often, a small amount of blood is left over after the clinical tests are finished. We would like to keep these left-over samples and store them in the eLIXIR Research Tissue Bank. Usually these excess samples are discarded.

All babies have a heel-prick test to check for certain metabolic problems when they are a few days old. The heel prick test involves making a small prick and collecting four spots of blood on a paper card. With your permission, when this test is done we will collect up to 4 extra spots on a separate card to store in the eLIXIR Research Tissue Bank. All of the samples collected will be anonymised (they will not have your child’s name on them) and identified only by a sample number. We will store the sample number in a secure research database. The blood samples will be stored in the eLIXIR Research Tissue Bank licensed under the Human Tissue Act. The eLIXIR Research Tissue Bank will be housed at the National Biosample Centre.

Will the samples be tested for genetic disorders? As part of future research projects, using biobank samples, including your baby’s sample, tests may be undertaken for specific genetic disorders or a range of genetic abnormalities by testing your baby’s whole genetic profile (genome wide sequencing). In the unlikely circumstance that any disorder of clinical significance is found, your GP will be informed.

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What will happen to the samples my child donated? If you decide to donate your child’s sample, we will arrange for it to be stored securely in the eLIXIR Research Tissue Bank. Research groups in academic institutions, the NHS and commercial companies in the UK and abroad will be able to apply to use samples stored in the eLIXIR Research Tissue Bank. In all cases, before they are given access to your stored sample and data, the quality of the application will be judged by a group of expert scientists and doctors who work in the same field. Only high-quality applications will be approved.

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