



eLIXIR, Born in South London: The early life cross-linkage in research

Background

We know that nutrition in pregnancy, stress, illness and the environment can influence the health of the baby and the development and growth of the child. Also when the baby is born, ill health can affect health later in life. Investigation of health in pregnancy and early life needs information from large numbers of people to identify problems and develop treatments to improve health in the future. As part of your maternity care at Kings Health Partners (Guy's and St Thomas' Hospital and Kings College Hospital) doctors, midwives and other health care professionals record information about you and your health in your health records. Some of these are in your handheld maternity notes but many more are kept in NHS computer systems. Records from you and your baby are held separately in several different computer systems.

What is eLIXIR?

A system has been developed that enables us to link these health records from the different computer systems and to carry out research using information from King's College Hospital, Guys and St Thomas' and South London and Maudsley NHS Trusts, which would help us follow health across pregnancy and childhood in large numbers of women and children in South London. This system is called eLIXIR. This information has been linked with other health care data from your GP records and national hospital data, along with data from national immunisation, and from national fertility treatment records. In future, we also plan to link this information with

other data sources including national school pupil's data. All information is kept securely, and no one will be able to identify you or your child.

The aim of eLIXIR is to provide information about health in pregnancy and across the life span in a large number of people to help us work out when and how health problems begin and what treatments work in some people and not others.

Here are some of the things we hope to look at:

- How mothers' physical or mental health in pregnancy may affect their babies.
- How to improve the health of babies who are born too early.
- Some mothers can get diabetes in pregnancy. Our research may help us find ways of making sure this does not affect the baby.
- How being unwell in early life might affect children's mental and physical development.
- Which treatments of common conditions in pregnancy are best for mother and baby.
- Maternal mental health following fertility treatments
- Understanding and improving vaccination trends in pregnant women

What happens to information about me and my child?

Researchers wanting to look at specific health issues will develop a plan (protocol). This will be approved by a committee including scientists and members of the public before relevant information from the database is released to the researcher to answer that particular question.

How are your personal details protected?

We will use limited identifiable data, such as your NHS number and date of birth to link your data with your baby's, and to combine the information about your pregnancy and your baby's health from different computer systems. eLIXIR will then transform information so it becomes totally anonymous. This means that your clinical data can be used in research but your personal details cannot. The

computer removes or covers up any information that can identify you. Your name and baby's name and address will be removed and your full date of birth and baby's date of birth and postcode are made shorter. All data will be stored in accordance with the Data Protection Act 2018, at the National Institute for Health Research (NIHR) Biomedical Research Centre Clinical Data Linkage Service at South London and Maudsley NHS Foundation Trust. For specific projects, in order to compare health outcomes in this group, to others across the UK, a stripped down version of the data may be transferred to a secure data environment at King's College London. These projects will be reviewed and granted approval on a need basis only by the eLIXIR Oversight Committee.

Who can access eLIXIR data?

eLIXIR data is available only to researchers who have a contract with Guy's and St Thomas' NHS Trust, King's College NHS Trust or the South London and Maudsley NHS Trust. These researchers might work in collaboration with other organisations (both 'not-for-profit' and 'for-profit'). The information in eLIXIR is protected by strict trust information security. It cannot be accessed or taken outside the Trust in any form, unless completely anonymised and cannot be traced back to you in any way, even by the eLIXIR team.

The eLIXIR team

Many people are involved including researchers, doctors, midwives and nurses from maternity and child health care.

Who is funding this research?

This research is supported by the Medical Research Council (MRC). None of the doctors, midwives or other health care professionals looking after you or your baby have received any payment because you are taking part.

Who has approved this study?

Oxford C research ethics committee has reviewed and agreed this research.

How can I find out more about eLIXIR?

We are keen to share information about eLIXIR and are holding regular open sessions.

Information about these can be found on the eLIXIR website, **w:** <https://www.kcl.ac.uk/research/elixir-1>

We want to know if you have any concerns or do not want your information included in eLIXIR

If you have any questions or would want to have you or your baby's health records removed, please contact, **e:** elixir@gstt.nhs.uk or write to: eLIXIR team, Department of Women and Children's Health, 10th Floor, North Wing, St Thomas Hospital, London SE1 7EH

You may also choose to do so via the National Data Opt Out process: <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/>

Contact us

If you have any concerns about this research and want to discuss it further, or for independent advice, please contact: Patient Advisory and Liaison Services (PALS)

t: 020 7188 8801, **e:** pals@gstt.nhs.uk,

w: www.guysandstthomas.nhs.uk/patients-and-visitors/patients/your-care/pals.aspx

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

NHS website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk