eLIXIR, Born in South London Project Privacy Policy

Our contact details

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The type of personal information we collect

The eLIXIR project brings together information from different healthcare organisations on women presenting to maternity services, and on their children after birth. The purpose of eLIXIR is to support research into the health of mothers and their children. We currently collect and process the following information:

- Personal identifiers: your name, date of birth, NHS number, and address
- Physical, social and health situation of condition: your medical history, treatments, test results, care plans, medication, medical opinions and other relevant support you are receiving
- Protected characteristics: your ethnicity, religion, sexual orientation, and gender, as recorded in clinical services.

How we get the personal information and why we have it

We assemble the information first from maternity and neonatal records at Guys and St Thomas Trust and King's College Hospital Trust, and from mental healthcare records at the South London and Maudsley Trust. We also incorporate information from Lambeth DataNet – i.e., records from general practices in the borough of Lambeth. Personal identifiers are used to bring this information together (to ensure that information from different sources refers to the same individual) but is not made available to any researcher. Instead, the individuals on the databases used by researchers are given a unique identifier number which cannot be linked back by researchers to any source information.

The information from maternity, neonatal and mental healthcare is joined with other information from hospital records (for example, on blood tests or care from other services) and from general practice.

We use this information to support research into health outcomes, sharing this with researchers on approved projects who have either a substantive or honorary contract with one of the three participating Trusts.

Under the General Data Protection Regulation (GDPR), the lawful bases we rely on for processing this information are:
- General Data Protection Regulation Article 9 (2) (j) – processing is necessary for scientific research purposes,
- General Data Protection Regulation Article 6 (1) (e) – processing is necessary for the performance of a task carried out in the public interest

How we store your personal information
Your information is securely stored at the South London and Maudsley NHS Foundation Trust. Please see the [South London and Maudsley privacy policy](#).
The eLIXIR project is seeking to continue accumulating information on mothers and their children so long as funding is available to support this.

Your data protection rights
Under data protection law, you have rights including:
Your right of access – You have the right to ask us for copies of your personal information.
Your right to erasure – You have the right to ask us to erase your personal information.
Your right to restriction of processing – You have the right to ask us to restrict the processing of your personal information.
Your right to object to processing – You have the the right to object to the processing of your personal information for this project.
You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.
Please contact us at dataprotectionrequests@slam.nhs.uk if you wish to make a request.

How to complain
If you have any concerns about our use of your personal information, you can make a complaint to us at Informationgovernance@slam.nhs.uk
You can also complain to the ICO if you are unhappy with how we have used your data.
The ICO's address:
Information Commissioner's Office
Wycliffe House

Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline number: 0303 123 1113
Visit the ICO website