

**Privacy Notice for the Respiratory Health in Childhood (RHIO) Study
Long-term follow-up questionnaire for Baby Biome Study participants**

Baby Biome Study (BBS) is a research study that aims to find out how microbes, such as bacteria and viruses, interact with our immune system in early life. Using this information, we want to find out why we stay healthy, and why we sometimes get sick. The BBS is trying to build a picture of how our experiences as babies shape our lives.

BBS is a UK birth cohort study and biobank which enrolled 3,476 mother-baby pairs in three UK hospitals between 2016 and 2017. This study has been funded by the Wellcome Trust and University of Birmingham.

Respiratory Health in Childhood (RHIO) is a follow-up study of children enrolled in BBS to understand their respiratory health in the first 4-6 years of life, and to explore whether early gut microbiota composition might be associated with childhood respiratory diseases. This is a self-administered electronic follow-up questionnaire.

The electronic questionnaire was designed using RedCap and is stored within the UCL secure network Data Safe Haven (DSH). During October and November 2022, a postal letter or a text message will be sent to mothers who were enrolled in BBS and who consented to follow-up to ask them to take part in RHIO. They will receive a personalized QR code and link to access the questionnaire, which takes about 10 minutes to complete.

Data Controller: University College London (UCL)

Data Protection Officer: data-protection@ucl.ac.uk

Data Processor: University College London (UCL), Page One (Janetxt provider)- data will be securely stored in their servers to allow sending text messages but data will only be accessible to those with account password (RHIO researchers).

If you would like to discuss anything else relating RHIO please contact:

Professor Nigel Field
UCL, Centre for Molecular Epidemiology and Translational Research,
nigel.field@ucl.ac.uk,
Telephone: 020 3108 2092

Supervisory Authority:
University College London (UCL)

Lawful Basis:

The Data Controller for RHIO is UCL. The lawful basis UCL relies on to process your data performance of a task in the public interest. The lawful basis for processing special category data is for the purpose of archiving, research and statistics.

The study was approved by the NHS Proportionate Review Sub-committee of the Wales REC 6 (REC reference 22/WA/0287).

Where we collect information about patients

The link/QR code will take participants to an electronic Participant Information Sheet and consent form to be completed before accessing the questionnaire, which takes about 10 minutes to complete. Responses will be automatically stored in RedCap and will be de-identified before any analyses are conducted. All data storage and analyses will be conducted within UCL's central data warehouses the "Data Safe Haven", which is a "walled garden" protected site that is certified to the ISO27001 information security standard and conforms to NHS Digital's Information Governance Toolkit.

Only mothers and babies who consented to participate in BBS and to being followed-up, who have not withdrawn from BBS, will be contacted.

What personal data will be collected and how will it be used?

The questionnaire is divided into the following sections:

- 1) Demographic information (7 questions)
- 2) General questions about your child (5 questions)
- 3) Your child's Health (6 questions)
- 4) Family history and general questions (5 questions)

When we receive participant's answers, personal identifiers (name and date of birth) will be replaced with a unique study number to identify questionnaire responses before any analyses are undertaken.

Personal identifiers will be kept separately and securely. All analyses of the data and dissemination of the findings will be anonymous. Nothing that will be published or disseminated will identify study participants.

All the information we collect will automatically be stored and held securely at UCL in accordance with data protection laws General Data Protection Regulation (GDPR 2018).

How long will we keep your information for?

We will store data in a pseudo-anonymized way for at least ten years, so that researchers can use them in the future.

How can patients opt out of the study?

If you do not want to take part in the follow up study, you don't need to do anything. If you don't want to be contacted by us about this study or any other follow ups, please let us know by contacting us.

If you decide to take part, and then change your mind and would like to withdraw, please let us know [cristina.alcazar.19@ucl.ac.uk or nigel.field@ucl.ac.uk]. This means we will not use any of the data you have given us from the date you decide to withdraw. If you have any complaints, you can email research-incidents@ucl.ac.uk.

What if there is a problem?

If you have a concern about any aspect of this study, there are a number of contacts you can speak to, including the Director of BBS and RHIO - Professor Nigel Field, nigel.field@ucl.ac.uk, 020 3108 2092 or by post:

Centre for Molecular Epidemiology and Translational Research,
Institute for Global Health
Mortimer Market Centre
Off Tottenham Court Road UCL
WC1E 6JB

Link to UCL privacy notice

<https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-careresearch-studies>