Privacy Notice for General Health & Hospital Admissions in Children Born after ART: A Population Based Linkage Study

Who are we?

The [University College London Great Ormond Street Institute of Child Health](link) (UCL ICH), together with its clinical partner Great Ormond Street Hospital for Children (GOSH), forms the largest concentration of children's health research in Europe. Our mission is to "improve the health and well-being of children, and the adults they will become, through world-class research, education and public engagement".

Why do we need to process your personal data?

UCL (Great Ormond Street Institute of Child Health) wish to establish if children born after assisted conception (including IVF and related techniques) are at an increased risk of specific diagnoses compared to spontaneously conceived siblings and unrelated spontaneously conceived controls. Access to patient data is vital for this, and we implement high security and governance standards to ensure patient confidentiality within our research studies. In addition to obtaining ethical and legal approvals for all research, UCL also ensures that the use of personal information is strictly in the public interest by complying with the UK Policy Framework for Health and Social Care Research.

What personal data do we require?

To safeguard your rights, we will use the minimum personal information (which includes information about your health and treatment), and this will be collected from a third party source with relevant approval from the [Health Research Authority.](link)

The data required and their sources have been listed below:

- Personal information (such as name, date of birth, postcode and NHS number etc) of women who were treated with assisted reproductive technologies (ART) (source: [NHS Digital)](link).
- Personal information (such as name, date of birth, birth weight, sex, NHS number etc) of ART children and their non-ART siblings and controls (source: [Human Fertilization & Embryology Authority)](link).
- Records of hospital episodes (admitted patient care, critical care, outpatient care, and accident and emergency care) (source: [Hospital Episode Statistics - NHS Digital)](link).

Linkage and de-identification of these data extracts will be carried out by NHS Digital, and we (UCL) will receive a pseudo-anonymised dataset where each individual has been assigned a unique ID.

How will we handle your personal data?

The data will be pseudo-anonymised (key-coded) and, although this information is linked to you as an individual, UCL have no requirement and will not attempt to re-identify the data. For example, if we receive a unique ID number, no efforts will be made to determine your name, address or any other demographic details from other sources. Safeguards will be placed in all of our processes to protect your identity.

Who will have access to the data and will it be shared with any third parties?

The data will be held securely using UCL's data safe haven, and only individuals working under appropriate supervision on behalf of the data controller / processor who are subject to the same policies, procedures and sanctions as substantive employees will have access to the data and only for the purposes described in this document. The data will not be released to any other individual(s) or organisation(s) not directly connected with the work specified without prior approval, except in the form of non-disclosive statistical tables or conclusions.

What is the legal basis for processing the personal data?

Under the EU General Data Protection Regulation, the legal basis for processing this information is for the performance of a task carried out in the public interest. UCL processes health information for the purposes of scientific research with appropriate safeguards in place to protect personal information, as required by the EU General Data Protection Regulation.

How will the data be processed?

Data processing for this project has been designed to ensure that identifiable data are seen by the fewest number of people at secure locations in secure methods, in accordance with the Data Protection Act. The expected outputs, which will contain only aggregate level data with small numbers suppressed, include a number of scientific papers which will be submitted to broad medical peer-reviewed journals directed towards a scientific/ clinical audience. Further dissemination of results will be carried out through medical conferences and the Human Fertilisation and Embryology Authority website and their associated networks (the fertility clinics, clinicians and directly to patients via these clinics and their website). All of this will be carried out in accordance with the ONS (Office for National Statistics) Disclosure Control Guidance for Birth and Death Statistics.

How long will the data be stored for?

The data will be stored in the UCL data safe haven until the end of 2019, following which it will be securely destroyed. Only information believed to be factually correct, relevant to our work and not excessive for the purpose it was collected for will be stored and used.

Your rights

You have rights over your personal information by law and these apply to information processed for research purposes. However, as the data collected for this study is pseudo-anonymised and considered to be compliant with the ICO's "Anonymization: managing data protection risk" code of practice, there are some specific exemptions and your rights to access, change or move your information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you have any queries, need further assistance or have a complaint about how your data has been used, please contact Professor Alastair Sutcliffe at a.sutcliffe@ucl.ac.uk or the University Data Protection Officer at data-protection@ucl.ac.uk.