Privacy Notice for Educational Outcomes in Children Born after ART: <u>A Population Based Linkage Study</u>

Who are we?

The <u>University College London Great Ormond Street Institute of Child Health</u> (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".

For the purposes of data protection UCL will be the controller for this study.

What information does this Privacy Notice provide?

This Privacy Notice describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider UCL privacy notice:

www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice

Why do we need to process your personal data?

UCL Institute of Child Health wish to establish if children born after assisted conception (including IVF and related techniques) have comparable educational outcomes to children who are naturally conceived. 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 <u>UK Policy Framework for Health</u> and Social Care Research.

What personal data do we require?

To safeguard your rights, we will use the minimum personal information and this will be collected from a third-party source with relevant approval from the

- Information regarding fertility treatments received by mothers of the ART conceived children (source: <u>Human Fertilization & Embryology Authority</u>).
- Educational information (test scores for national 'Key Stage' pupil assessments, special educational needs status, school exclusion status, and eligibility for free school meals) (source: National Pupil Database -<u>Department for Education</u>).

Linkage and de-identification of these data extracts will be carried out by the Department for Education (DfE) and the Office for National Statistics (ONS), 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-

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 Data Protection Legislation. The expected outputs, which will contain only aggregate level data with small numbers suppressed, will include scientific papers which will be submitted to peer-reviewed journals directed towards a scientific / medical audience. Further dissemination of results will be carried out through medical conferences,ill