

## Privacy Notice - St George's University of London - Health and Social Care Research - Research Project:

### **Linked de-identified research database for congenital anomaly outcomes (education)**

#### Who we are

St George's, University of London (SGUL) is the 'Data Controller' of personal data provided directly or indirectly to us and are registered with the Information Commissioner's Office (ICO) for the purposes of UK data protection legislation, registration number Z5770328.

#### How to contact us

The University has a Data Protection Officer who can be contacted at:

Email: [dataprotection@sgul.ac.uk](mailto:dataprotection@sgul.ac.uk)  
Tel: 020 8725 0668  
Address: Data Protection Officer, Information Services, St George's University of London,  
Cranmer Terrace, LONDON SW17 0RE

#### What research information we collect from you and why

As an active healthcare university with research at the core of our activity we use personally-identifiable information to conduct health and social care research with the aim of improving healthcare and related services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use the personally-identifiable information of people who have agreed to take part in one of our research projects, either provided directly by those individuals or from a 3<sup>rd</sup> party source such as NHS Digital or ONS. This means that when you agree to take part in a research study we are leading or collaborating in, we will use your data in the ways needed to conduct and analyse the research study.

Health and social care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research. For SGUL general research privacy notice please see:

[https://www.sgul.ac.uk/images/about/Policies/Privacy\\_Notice\\_Research\\_SGUL.pdf](https://www.sgul.ac.uk/images/about/Policies/Privacy_Notice_Research_SGUL.pdf)

## Research Project specific information we collect and why

Project Name: Linked de-identified research database for congenital anomaly outcomes (education)

### Project Details:

It is estimated that around 3% of babies born will have a major congenital anomaly, which equates to almost 30,000 births in England and Wales annually. Congenital anomalies are a major cause of infant mortality, childhood morbidity and long-term disability. However little is known about the longer term outcomes in terms of survival, health and education attainment of affected children, particularly for those with rare anomalies.

The UK has a long history of conducting surveillance and research into the causes and consequences of congenital anomalies. Regional Congenital Anomaly Registers (CARs) were established at different times in different areas across England. The British Isles Network of Congenital Anomaly Registers (BINOCAR) was established as a self-governing collaboration in the late 1990s to bring together the register leads, staff and others with a clinical/research interest in congenital anomalies. This enabled standardisation of registers' operations and data collection, as well as training and knowledge exchange, ensuring that anomaly coding was performed expertly and consistently throughout. In March 2015, the individual regional CARs ceased data collection as the registration of congenital anomalies came under the remit of Public Health England.

This study aims to enhance this historically collected data of congenital anomalies in England by performing a linkage of case data to the National Pupil Database (NPD). The linked dataset would be anonymised (i.e. not contain any personal identifiable information) and available for approved research projects aiming to evaluate the long-term educational outcomes of children affected by congenital anomalies, and how these may be influenced by geographical, socio-economic and other risk factors.

### Category of personal data collected relates to:

The data to be linked relate to liveborn babies with a major congenital anomaly reported to the following regional congenital anomaly registers in England (by hospital teams within their catchment areas) from their inception up until 31 March 2015:

1. Congenital Anomaly Register for Oxfordshire, Berkshire and Buckinghamshire (CAROBB) – 1991
2. East Midlands and South Yorkshire Congenital Anomaly Register (EMSYCAR) –1997
3. Northern Congenital Abnormality Survey (NorCAS) – 1985
4. South West Congenital Anomaly Register (SWCAR) – 2002
5. Wessex Antenatally Detected Anomalies Register (WANDA) –1994

The data contain personal identifiers (names, dates of birth, addresses and NHS numbers) as well as clinical diagnoses and patient/pregnancy characteristics (e.g. birthweight, weeks of gestation, maternal age, prenatal screening results).

Personal identifiers will be submitted to the Department for Education (DfE) for cases to be matched to their educational records in NPD, whereupon all identifiers will be deleted.

Individuals (or parents of individuals in the case of children) who had been registered by the historical congenital anomaly registers listed above should contact Professor Joan Morris at SGUL, by email ([jmorris@sgul.ac.uk](mailto:jmorris@sgul.ac.uk)) or telephone (02087251324), with any queries/requests in the first instance.

Contract Reference: *pending*

Project Reference: 16/EM/0440 (NHS Research Ethics Committee reference)

Funding: European Commission Horizon2020 programme grant (Ref: 733001)

Data Controller(s): St George's, University of London

Legal Basis:

- a. Article 6(1)(e) of the General Data Protection Regulation (GDPR) provides the legal basis for public authorities (e.g. universities and NHS organisations) to process personal data for research purposes.
- b. Additionally, article 9(2)(j) of the GDPR provides the legal basis for processing special categories of personal data which includes data concerning health and ethnicity for scientific research purposes.

### Who we share your information with

Data will be shared in two stages with DfE through a data sharing agreement between SGUL and DfE. Personal identifiers will be shared for the purpose of record-matching only; these will be deleted once all linkages have been completed and verified. Secondly patients' clinical data on congenital anomalies (without identifiers) will be shared to enable DfE to create a linked research dataset within the ONS secure research service for analysis by SGUL researchers only, as NPD data extracts cannot be transferred outside of the ONS environment.

### How long we keep your information for

*To be agreed with data provider*

As this is a one-time linkage of historically collected records with no prospect of future linkages, it is proposed to retain the de-identified linked dataset for 15 years to allow future studies to be designed and conducted to ensure that maximum benefit is derived from this unique resource.

### What your rights are

Your rights to access, change or move your information are limited, as we need to manage the data in specific ways in order for the research to be reliable and accurate. If you withdraw your consent to participate in a research project, this will not mean we will have to remove all data as well. We will keep the information about you that we have already obtained to ensure research integrity is maintained in the public's interest. To safeguard your rights, we will strive to use the minimum personally-identifiable information possible.

### How to make a complaint

If you are unhappy with the way in which your personal data is being processed you may, in the first instance, lodge a complaint with the University Data Protection Officer using the contact details above.

If you continue to have concerns thereafter you have the right to contact the Information Commissioner for a decision. The Information Commissioner can be contacted as below

Helpline: 0303 123 1113

Website: <https://ico.org.uk/for-the-public/raising-concerns/>