

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

### Linked de-identified research database for congenital anomaly outcomes (mortality and health)

#### 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 (mortality and health)

### 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 of these 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 and nationally in Wales. 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, Public Health England took over the registration of congenital anomalies nationally and data collection ceased in the regional registries.

This study aims to enhance this historically collected data of congenital anomalies in England, by performing linkages to administrative and healthcare databases, including Office for National Statistics (ONS) death registrations and Hospital Episode Statistics (HES). The linked datasets would be anonymised (i.e. not contain any personal identifiable information) and available for approved research projects aiming to evaluate the long-term survival and health 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 consist of clinical data of liveborn babies with a major congenital anomaly collected by the following regional congenital anomaly registers in England 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 NHS Digital for cases to be matched to their hospital admissions and civil registration records, 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: DARS-NIC-64474-V4B2D

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 - DPA Registration Number Z5770328

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 (sensitive) personal data which includes data concerning health and ethnicity for scientific research purposes.

Data Sources:

Extracts from Hospital Episode Statistics (HES) and civil registrations data are provided by NHS Digital. Public Health England are the source of the historical congenital anomaly register data from the Northern Congenital Abnormality Survey (NorCAS) and South West Congenital Anomaly Register (SWCAR).

### Who we share your information with

Personal identifiers including name, sex, date of birth, address and NHS numbers will be shared with NHS Digital for the purpose of record-matching only; congenital anomaly and other clinical data will not be shared. NHS Digital will securely return requested HES/ONS data extracts of successfully matched cases to SGUL, to be merged with the congenital anomaly data. Once the linked dataset has been created, SGUL and NHS Digital will delete all personal identifiers; thereafter the de-identified dataset will be securely stored at the Population Health Research Institute within SGUL.

St George's University of London, Oxford University, Leicester University, Newcastle University, University Hospitals Bristol NHS Foundation Trust and University Hospital Southampton NHS Foundation Trust are joint data processors of the de-identified research data; researchers employed by these institutions will be granted access to the dataset for approved future research projects but no personal data will be processed.

Your information will not be used for any form of automated-decision making or profiling.

### How long we keep your information for

Personal identifiers are kept to effect the afore-mentioned linkages only and will be deleted once linkages have been completed.

The de-identified linked research database will be accessed for current and future research projects for a period to be agreed with NHS Digital. As this is a one-time linkage of historically collected records with no prospect of future linkages, it is proposed to retain the linked database for 15 years to allow future studies to be designed and conducted to ensure that maximum benefit is derived from this unique resource.

Permission to retain and use the database for research will be sought from a NHS Research Ethics Committee (REC) every 5 years. The database will be destroyed upon expiry of REC approval or when the BINOCAR Management Committee judge it to no longer have scientific value.

## What your rights are

The linked database of congenital anomaly outcomes is a research project carried out in the public interest. Therefore 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 do not wish to have your data used for research, you can register a national data opt-out at any time by using the online service at [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters) or by calling 0300 3035678. By registering an opt-out, NHS Digital and Public Health England will not share any data they hold about you with us. However, 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/>