

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

### Clinical outcomes of a PPS program undertaken in a large UK cohort

#### 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

#### Can you object from your personal information being shared with NHS Digital and NHS Scotland?

**Yes, you can.** You have the right to dissent from participation in this research study. If you think you may be affected by this research project (screened by Cardiac Risk in the Young between 2007 and 2018) and have any questions or wish for your information not to be provided to NHS Digital and NHS Scotland, please contact us via email at [azra@c-r-y.org.uk](mailto:azra@c-r-y.org.uk). Alternatively, please ring 01737 363222 or write to: Cardiac Risk in the Young, Unit 1140B, The Axis Centre, Cleeve Road, Leatherhead, Surrey KT22 7RD.

We will keep the information about you that we have already obtained from NHS Digital 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/>

## 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: Clinical outcomes of a PPS program undertaken in a large UK cohort

### Project Details:

Around 400 young people die from sudden cardiac death (SCD) each year in the UK. The majority of these events are due to inherited abnormalities of the heart muscle or electrical systems and are often silent until they present with a cardiac arrest.

A government-sponsored preparticipation cardiac screening (PPS) program, mandated by Italian law, has demonstrated a fall in rates of SCD by 89%. Currently no equivalent UK state sponsored program exists. Concerns in part relate to the perceived low incidence rate of sudden cardiac death in young individuals.

The reported incidence of SCD in young individuals varies widely. It is challenging to compare studies with heterogeneous case identification methods that originate from different geographical locations. Passive collection methods using retrospective review of media reports and insurance claims are limited by ascertainment and selection bias which will likely underestimate calculations of incidence.

This study will provide the most reliable estimate for incidence of SCD and sudden cardiac arrest in the existing literature. Only once a reliable estimate is agreed, can the screening community gauge the effectiveness of preventative strategies such as PPS.

Category of personal data collected relates to:

Cardiac Risk in the Young (CRY) is a charitable organisation that offers subsidised cardiac screening to

individuals aged between 14 and 35 years. Individuals voluntarily undergo evaluation with a health questionnaire and an ECG. Completion of the medical questionnaire and acquisition of the ECG is performed by CRY at various sites throughout England and Wales at the time of cardiac screening events. All participants gave written informed consent for their data to be stored and used for research purposes by CRY. Primary source data (i.e. medical questionnaire responses and ECG) were used to construct two databases. The first containing the participants demographic details and the second containing data from the medical questionnaire and ECG.

Using mortality data, NHS Digital and NHS Scotland will then identify any relevant individuals held in their records to the CRY research team. The research team will use this information to look for links between the risk of sudden cardiac death and the early repolarisation pattern. This work will then provide vital insight into assessing the risk of sudden cardiac death through heart screening.

Contract Reference: CON-341863-LOX2Y

Project Reference: DARS-NIC-190086-F5Z7B-v0.6

Funding: Cardiac Risk in the Young

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

Data Source: Data will be sourced from the ONS database through a data sharing agreement with NHS Digital and NHS Scotland.

Legal basis: General Data Protection Regulation – Chapter 9 (Article 89) - "necessary for archiving purposes in the public interest, scientific or historical research purposes..."

#### [Who we share your information with](#)

The demographics of screened individuals will be shared with the ONS through a data sharing agreement with NHS Digital. Transfer of data will be done securely to remove any risk of personal information. All data will be processed and stored securely at St George's University of London.

#### [How long we keep your information for](#)

The data sharing agreement will end on the 10<sup>th</sup> of July 2021.