



As part of Cardiac Risk in the Young 's (CRY) ongoing commitment to research we are looking at novel features on a person's ECG that could be used to identify those who may be at higher risk of sudden cardiac death. In order to evaluate the importance of such novel ECG features, it is important to be able to check health outcomes of individuals who participate in heart screening. To do this, through our research partner St. George's, University of London (Data Controller) we work with the UK governmental agencies: previously the office for National Statistics (ONS), and more recently NHS Digital and NHS Scotland who co-ordinate clinical research for the National Health Service in the United Kingdom.

Approximately 100,000 people who underwent voluntary cardiac screening between 2008 and 2018 will be included in this project. Identifiable personal details including name, sex, date of birth and postcode (at time of screening test) will be stored on secure databases at St. George's, University of London and, from there, provided to NHS Digital. This information will be transferred securely to remove any risk to personal information. NHS Digital and NHS Scotland will use this information to identify any relevant individuals held in their records to the CRY research team.

The research team based at St. George's, University of London will use this information to look for links between the risk of sudden cardiac death and a range of ECG features. No information will not be released to anyone else. Any research publications will not mention specific individuals and all information presented will be completely anonymous. This work will then provide vital insight into assessing the risk of sudden cardiac death through heart screening.

Can I object to my personal information being shared with NHS Digital and NHS Scotland?

Yes, you can. If you think you may be affected by this research project and have any questions or wish for your information not to be provided to NHS Digital, please contact us via email at 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

Please note that opting-out of this study will have no impact on any other aspect of your screening process.