

OHCAO Privacy Notice – Information for the public

The Out-of-Hospital Cardiac Arrest Outcomes (OHCAO) registry is managed by Warwick Clinical Trials Unit at the University of Warwick Medical School and is led by Professor Gavin Perkins. It is funded by the British Heart Foundation and the Resuscitation Council UK with support from the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) West Midlands. It is run in collaboration with the Association of Ambulance Chief Executives (AACE).

This document provides information about the registry and describes how the team will access and use your health and personal data if you sustain a cardiac arrest and receive treatment from an NHS Ambulance Service in England and Wales.

The University of Warwick is the sponsor and “data controller” for the registry. This means it has overall responsibility for looking after your data. For more information on how the university processes your data please visit:

<https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice>

What is a cardiac arrest?

Cardiac arrest is the term used to describe when the heart stops beating, and the person stops breathing and becomes unconscious. Unless cardiopulmonary resuscitation (CPR) is started straight away, death will happen within a few minutes. CPR involves chest compressions (pressing up and down on the person’s chest) and rescue breathing to maintain blood flow until an ambulance arrives.

About 40,000 people receive CPR for an out-of-hospital cardiac arrest in the UK every year. Around one in every ten people that have a cardiac arrest will survive to leave hospital.

Why are we doing this?

We want to save more lives and reduce the devastating consequence of cardiac arrest for patients and their families.

We are doing this through helping charities and the NHS to ensure that patients and their families have access to resuscitation training and that public access defibrillators are placed where they are most needed.

We are finding out which treatments are most effective for cardiac arrest and helping NHS Ambulance Services to improve outcomes from cardiac arrest.

Whose information is being collected?

People who sustained an out-of-hospital cardiac arrest and received treatment by NHS Ambulance Services from 2013 onwards.

What information is being collected?

Data collected includes patient information (such as age, sex), location of the cardiac arrest and response and treatments given for the cardiac arrest by the ambulance service.

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The registry receives Personal Identifiable Data, e.g. NHS number, name, address, date of birth and personal health information. The data are collected for all eligible patients regardless of survival status. We need this information to clarify other related data items and to improve data quality, or to follow up on the survival status of patients with organisations such as NHS Digital and the Office for National Statistics (ONS).

Who is collecting it?

The ambulance services will collect information about you for the registry in accordance with our instructions. The data are already collected routinely by the ambulance services on patient records as part of their everyday working duties.

How is it collected?

The participating ambulance services provide the data to Warwick Clinical Trials Unit through a secure electronic database system.

Who will have access to my data?

All information that is collected and stored in the database is kept strictly confidential and is only seen by authorised staff involved in the registry and by the participating ambulance services who provide the data. All members working on the project have completed all relevant training to follow the University of Warwick's policy on data protection and the Data Protection Act 2018.

Sometimes we receive requests to share information held in the registry for example from the NHS or from researchers. When this occurs the request is reviewed by a committee which includes patient and public representatives to check there is a valid and important reason to share the data. In most circumstances only anonymised data are shared (i.e. information that does not allow someone to identify who the person is the data relates to). In exceptional circumstances and subject to approval by a Research Ethics Committee (REC) and the Confidentiality Advisory Group (CAG), we may share identifiable information with another organisation. All data sharing activities are covered by a legally binding data sharing agreement.

No information that can identify you will be used in any published reports or papers that use the registry data.

Has long will my data be retained?

As long-term outcomes are important to patients, the public and the NHS, the registry will continue to hold data for as long as it is funded and approved to do so. If the registry is closed in the future, then an anonymised data set will be retained for 10 years in alignment with the University's audit and governance requirements.

Has the registry received ethical approval?

Yes, the registry has approval from:

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- **South Central – Oxford C Research Ethics Committee (reference 13/SC/0361).** All research studies run in the NHS are conducted in accordance with the Research Governance Framework and relevant legislation. The Health Research Authority provides robust, ethical review of proposed research via independent Research Ethics Committees (RECs) who scrutinise applications and put the rights, safety, dignity and well-being of research participants at the centre of their decision making.
- **Health Research Authority (HRA) on advice from the Confidentiality Advisory Group (CAG) (22/CAG/0072 & 22/CAG/0087)** The OHCAO registry has permission to collect, hold and process the data for research and non-research purposes without an individual's personal consent because it is in the public interest. The Confidentiality Advisory Group have recommended that support under Regulation 5 of the Health Service (control of patient information) Regulations 2002 ('section 251 support') is given for the processing of confidential patient information.

How is the National Data Opt out (NDO) applied?

Given the importance of receiving complete information for monitoring NHS performance and planning the delivery of health services (i.e. non-research purposes), the national data opt out is not applied to the registry where information is being used for non-research purposes.

How do I request to remove my data from the registry?

If you wish to see your data or request for your data to be removed, please get in touch using the details below:

Email: ohcao@warwick.ac.uk

Tel: 02476 572725

Postal address:

OHCAO, Warwick Clinical Trials Unit, University of Warwick, Gibbet Hill Road,
Coventry, CV4 7AL

A member of the team will then contact you to complete a validation process to help identify you and action your request accordingly.