

OHCAO Privacy Statement – Information for the public

The OHCAO (Out-of-Hospital Cardiac Arrest Outcomes) registry is managed by Warwick Clinical Trials Unit at the University of Warwick medical School and is led by Professor Gavin Perkins. The study is funded by the British Heart Foundation and the Resuscitation Council UK and run in collaboration with the Association of Ambulance Chief Executives.

This page provides information about the OHCAO registry and describes how the OHCAO team will access and use your health and personal data if you were unfortunate to suffer a cardiac arrest and be treated by an NHS Ambulance Service in England or Wales. We refer to this as a “privacy notice” because it explains how we will use and look after your personal data. The University of Warwick is the sponsor and therefore data controller for the registry, which means it has overall responsibility for looking after your data. For more information on how the university processes your data and how you can exercise your rights in relation to this, please visit:

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

What is the OHCAO registry looking at?

The OHCAO registry collects data on out-of-hospital cardiac arrests (OHCA) in the UK. 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 promptly death will occur within a few minutes.

CPR involves chest compressions (pressing up and down on the person’s chest) and rescue breathing to maintain circulation until an ambulance arrives.

Each year about 40,000 people receive CPR for an OHCA in the UK. Approximately one in every ten people that have a cardiac arrest survive to hospital discharge.

A cardiac arrest is different from a heart attack. A heart attack is where the heart gets starved of oxygen-rich blood because of a blockage and it usually causes a lot of pain in the chest and/or arm(s). People suffering a heart attack can remain conscious and breathing, but some people having a heart attack can also have a cardiac arrest at the same time.

Why are we doing this?

Research and NHS Ambulance Service audit data show large differences in the number of people that survive an OHCA depending on where they live. The OHCAO registry aims to understand why survival rates vary and to help ambulance services improve the quality of care and treatment for patients who experience a cardiac arrest.

What information is being collected?

Information being collected has been carefully considered by the OHCAO registry team to ensure it will help to find out why survival rates of people who have an OHCA differ so widely across the UK.

Your data might be used and stored in the OHCAO registry if you meet the following criteria:

- Had an OHCA between 2013-present

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- You were attended to by an NHS Ambulance Service who participates and submit data to the OHCAO registry
- Resuscitation was attempted by an NHS ambulance service during your cardiac arrest

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

The registry receives Personal Identifiable Data (PID), e.g. NHS number, name, address, date of birth and personal health information which is considered to be “Special Category”. The data are collected for all eligible patients regardless of survival status. We collect the minimum amount of PID that we require and delete all PID that are not needed for the registry. We need PID in order to clarify other related data items and therefore improve data quality, or to follow up on survival status of patients. For example, we will use the home postcode of the patient to confirm OHCA location postcode, and the patient’s date of birth to confirm their age. We also keep PID for future confirmation of survival status by linkage to the Office for National Statistics (ONS), or to other datasets such as Hospital Episode Statistics (HES), or Myocardial Infarction National Audit Programme (MINAP) when it is required by specific projects. For details on the exact data items we collect, please visit this page: <https://warwick.ac.uk/fac/sci/med/research/ctu/trials/ohcao/health/data/> Our database has been running since 2013. Due to the success of the database and its role in research into OHCA we envisage that the database will not close. The database is also included in the NHS 10 year plan. However if it should close at some point, all information retained by the registry will be archived for at least ten years after closure of the database.

The OHCAO registry has permission to collect, hold and process the data for research without individual’s personal consent because it is in the public interest. We have this permission from the Confidentiality Advisory Group (CAG), which provides authorisation, on behalf of the Secretary of State, to lawfully hold identifiable data on patients without their consent under specific circumstances (CAG ref ECC 8-04 (C)/2013). You have the right to object to the processing of your personal data and the right to erasure of your data. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. For more information on your rights and how to exercise them, please visit <https://warwick.ac.uk/services/idc/dataprotection/privacynotices/researchprivacynotice>

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 normal working duties.

How is it collected?

The participating ambulance services provide the data to Warwick Clinical Trials Unit through a secure electronic database system. The security of the transfer and the systems is reviewed regularly.

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Who will have access to my data?

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

The OHCAO team also has a duty of confidentiality to research participants and all information is handled securely and in line with relevant data protection laws and the new General Data Protection Regulation (GDPR).

Specific personnel at participating ambulance services and certain members of the OHCAO registry research team have access to PID about you, in connection with working on the registry.

The PID about you may be shared with organisations mentioned above such as ONS, HES and MINAP, but only if appropriate approvals are in place.

If an external researcher wishes to use PID from the OHCAO registry, they must have a sound scientific reason for doing so and have approval from the Confidentiality Advisory Group (CAG). Anonymised data which does not identify you in anyway may be used by external researchers for research projects looking into cardiac arrests.

Whether they are intending to use personal identifiable or anonymised data, an external researcher who wishes to use OHCAO registry data for their project must have ethical approval for their study from a Research Ethics Committee (REC) and a data sharing agreement in place with the University of Warwick to comply with national and international governance rules and regulations.

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

Has the OHCAO registry received ethical approval?

Yes, the OHCAO registry has approval from:

- **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.
- **Confidentiality Advisory Group (CAG) Ethics and Confidentiality Committee (ECC 8-04(C)/2013)**, which provides authorisation, on behalf of the Secretary of State, to lawfully hold identifiable data on patients without their consent under specific circumstances. In this case it is not possible to obtain consent in the immediate emergency situation as resuscitation must be started without delay. It is not practical either to consult a relative or

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independent paramedic and/or doctor for consent without placing the potential risk of harm from delaying treatment.

Who do I contact if I have any further questions or concerns?

If you have any further questions about the registry, please contact the team at:

ohcao@warwick.ac.uk

If you wish to find out more about the University's privacy notice, please follow this link:

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