

STATEMENT OF INFORMATION PRACTICES

OHCAR processes data from the Statutory Emergency Medical Services (EMS), including the National Ambulance Service (NAS), Dublin Fire Brigade (DFB), in the form of Patient Care Reports (PCRs). OHCAR also receives data from the participating acute admitting Hospitals.

What information is collected?

OHCAR includes data on patients who suffer a witnessed or un-witnessed out-of-hospital cardiac arrest in Ireland which is confirmed and attended by the EMS and resuscitation attempted. A comprehensive list of the data collected is included in the accompanying Data Dictionary.

How the information is collected, recorded and stored

Data from NAS: Data is extracted from ambulance PCRs which are completed by attending practitioners during or immediately after attending the OHCAR event. PCRs are collected from all ambulance stations on a monthly basis, scanned electronically and sent to OHCAR from IMSCAN (Ireland) LTD. PCRs for OHCA incidents are prioritised by NAS staff and fast-tracked in order to facilitate OHCAR. IMSCAN enter OHCAR data variables onto a preliminary database and forward this and copies of the electronic PCRs to OHCAR.

The information on the PCRs is entered onto a preliminary database and forward with a copy of the PCR to OHCAR. NAS dispatch data is sent separately to OHCAR and this is added to the PCR data. The information is sent in encrypted, password protected and is stored securely on the HSE server in the North West.

Data from DFB: PCRs are obtained by DFB's EMS Support Unit and data is provided to OHCAR on a quarterly basis in a summarised electronic format. These records are integrated with data from the DFB East Region Command Centre in Townsend Street. Electronic copies of DFB PCRs are also sent to OHCAR to enable validation to be carried out. The information is sent in encrypted, password protected format and is stored securely on a HSE server.

Hospital Data: OHCAR also has a data sharing agreement with all participating Hospitals. Collection of data from hospitals is facilitated by a range of hospital staff, including administrators, resuscitation officers, clinical nurse managers and consultants. Data from hospitals is collected electronically.

The participating hospitals provide information on survival status and Cerebral Performance Category (CPC) score. The information is password protected and is stored securely on the HSE server in the North West.

How the information is used

OHCAR data is used to provide regular feedback to service providers, for quality improvement purposes. OHCAR provide NAS with monthly and quarterly reports, and DFB quarterly reports. OHCAR publishes an Annual Report on OHCA survival rates, geographical incidence, aetiology, bystander participation and trends in EMS actions, e.g. drug administration and use of Mechanical CPR.

Overview of the consent process

OHCAR does not seek individual patient consent for data processing. Unfortunately approximately 92% of patients die as a result of their OHCA event. Seeking individual consent would compromise the validity of results reported due to the risk of consent bias^{1,2}. Patients who survive OHCA may not be in a position to provide informed consent for a considerable time after the event. It would not be possible for OHCAR staff to judge how soon patients might be in a position to provide consent as OHCAR does not have access to data on patient status at any stage after discharge. Due to the proportion of surviving patients, if even a small percentage were unable to provide consent, this could bias outcome results. A proportion of surviving patients sustain neurological damage as a result of their event, and obtaining informed consent in this situation is likely to be more difficult. This would create the additional risk that the degree of neurological compromise among survivors may be underrepresented by OHCAR. While OHCAR holds patient-identifiable data, OHCAR staff do not contact individual patients nor share identifiable patient data. Any requests for data are directed to the data controllers who must provide express permission for any data sharing.

OHCAR operates under 'implied consent'. OHCAR does not contact patients, hospitals are advised to inform patients that they are on OHCAR and what their rights in this regard are.

Information sharing and for what purpose

OHCAR receives data requests from academics, students or those interested in exploring the data that is held. Each data request is considered by the OHCAR steering Group and its merits or otherwise is discussed, and if needed the NAS Research Committee, only then is a decision made to allow data sharing. If data is shared, it is only ever in an anonymised format, i.e. patient identifiers

are never provided, and ethical approval is essential before research proposals are considered, and the permission of NAS/DFB is required for data release.

[Protection of the privacy of personal information](#)

All data held by OHCAR is stored securely, electronically on the HSE server in the North West and is password protected. OHCAR never divulges information without permission from NAS/DFB to any third party, unless it is agreed by the data owners (NAS / DFB) and sanctioned by the OHCAR Steering Group.

[Information on people's rights and personal information access](#)

Patients whose data is held are freely available to request a copy of their data held, or to have it removed from the Registry. The General Data Protection Regulations 2018³, provide a specific statutory framework to protect patients information and to obtain access to it. Patients have the right to have any information erased or to have factual inaccuracies corrected.

[Procedure for making a personal information access request](#)

Discharging Hospitals are advised to inform patients that their information will be forwarded to OHCAR. The Hospitals are advised to inform patients of the contact details of OHCAR, both email and telephone numbers. As OHCAR are data processors, the data providers (NAS, DFB and the Hospital involved) are advised that a request has been made, and the once the authenticity of the requester is verified, the information held by OHCAR is then released directly to the patient.

[How to obtain further details on Information handling practices](#)

OHCAR can be contacted at;

Email: OHCAR@hse.ie

Telephone: 074-9104636

Mobile: 087-7089807

Procedure for making a complaint or raising a concern about the information handling practices

Contact details for HSE National Office:

National Lead Office -

Freedom of Information, Data Protection & Record Management

Block 4, Central Business Park,

Clonminch,

Tullamore,

Co. Offaly

Tel: (057) 935 7879

References

1. Al-Shahi R, Vousden C, Warlow C, Committee SIVMSSS. Bias from requiring explicit consent from all participants in observational research: prospective, population based study. *BMJ* 2005; **331**(7522): 942.
2. Buckley B, Murphy AW, Byrne M, Glynn L. Selection bias resulting from the requirement for prior consent in observational research: a community cohort of people with ischaemic heart disease. *Heart* 2007; **93**(9): 1116-20.
3. General Data Protection Regulations 2018.
<https://gdpr-info.eu/> (accessed 16th May 2018).