**The British Cardiovascular Intervention Society Out of Hospital Cardiac Arrest Registry (BCIS OHCA) Privacy Notice - Data Protection and Confidentiality**

**Version 1.2 27/10/2022**

**What is the BCIS OHCA registry?**

The BCIS OHCA registry is a research registry for patients whom have suffered an Out of Hospital Cardiac Arrest (OHCA) in the UK. The information captured within this pilot registry will be used to assess and improve the quality of services and outcomes in OHCA throughout hospitals in the South East, South West and South of the UK. It also provides real world data insights into how pathway and guideline changes effect outcomes.

**What information does it contain?**

Starting in 2022, healthcare researchers will input data about OHCA into the registry. The information includes details ranging from the cardiac arrest itself, the treatment provided by pre-hospital care providers, the initial cardiac/intensive care management and discharge details. Within this, information on the investigations performed, treatments provided and outcomes achieved will be gathered. All of this information is already collated in a patients inpatient hospital notes. The information gathered into the registry contains no directly patient identifiable information (anonymised).

**What is the legal basis for the BCIS OHCA Registry?**

Out of Hospital Cardiac Arrest data are collected for a “medical purpose”, as defined in the 2006 National Health Service Act Section 251, for the provision of care and treatment and the management of health and social care services.

The data are collected on patients diagnosed with OHCA, with the approval of the Secretary of State under Section 251. This approval is reviewed each year and approval sought for the following year.

The following article 6 (**Personal data**) conditions on personal data are applicable to the legal basis for the registry.

(e) Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

The following article 9 (**Special categories of personal data**) conditions on personal data are applicable to the legal basis for the registry.

(g) Reasons of substantial public interest (with a basis in law): (which shall be proportionate to the purpose and, respect the essence of the right to data protection)

(h) Health or social care (with a basis in law): (preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services)

(j) Archiving, research and statistics (with a basis in law): (archiving purposes in the public interest, scientific or historical research purposes or statistical purposes)

**Who manages the BCIS OHCA Registry ?**

The East of England Tertiary Network has funded the purchase of the registry from Dendrite Clinical systems, our technology partner. Dendrite developed the registry (as per specification provided by the Essex Cardiothoracic Centre) and they also host and manage the storage of data. The day to day running of the registry is done by a Cardiology Research Fellow at the Essex Cardiothoracic Centre in partnership with BCIS.

**What happens to the data and who can see it?**

The data are collected by the team treating and managing the patient. Hospital computers are used to collect the information, which is collated, checked and approved before being entered into the registry. The data is then stored on a Redcentric server located in Shoreditch, a tier 3 data storage facility. During the data transfer from the hospital to the server the information is encrypted (locked) to ensure it cannot be interfered with. Only an approved member of staff at the hospital can enter the data onto the BCIS OHCA Registry. Once the records have been entered they can be reviewed by authorised staff at the hospital using an approved user account with a secure password.

When the data have been checked and confirmed by the hospital or clinician, the software engineers and data analysts at Dendrite Clinical Systems will download the data to a secure server in Dendrite’s offices. They will produce an annual report under the guidance of the clinicians at the Essex Cardiothoracic Centre.

The information collected is valuable as it allows clinicians to understand the nature of OHCA, the profile of patients and the results that are being achieved by hospitals. The data will be analysed by the research team at the Essex Cardiothoracic centre and other participating hospitals and Dendrite Clinical Systems to produce annual reports. The reports do not contain the details of individual patients.

The reports are used to help commissioners, providers and doctors understand practice and outcomes. Non-technical versions of the reports are available for patients and members of the public. Information gathered from the BCIS OHCA registry will be formatted into research manuscripts, published in relevant journals and presented at scientific conferences.

The data will not be shared with anyone, or used for purposes other than those agreed within the ethics application supporting the BCIS OHCA registry. The ethics does permit NHS numbers to be shared with the participating centres to provide a means of re-identification if required, however this information is not held on the registry. At the end of the three-year contract period, the BCIS OHCA registry will be fully anonymised or undergo deletion of linkage file data.

**BCIS OHCA registry Database Server**

The server is hosted on a Redcentric server (Shoreditch, London). This is a tier three data centre which meets the highest levels of building security.

The service delivery and information governance provided complies with ISO 20000 & ISO 9001 accreditation and the security structure is aligned alongside ISO27001. The security arrangements are internally audited approximately every three months and externally audited every six months.

All servers have firewall and anti-virus software installed which is configured to use real-time scanning.

## Backup Resilience

The data is securely backed-up each day. All backed up data stored is compressed, de-duplicated and encrypted within a secure off-site vault.

There are two backup vaults, the primary one is hosted locally and is then backed up to a secure secondary off-site vault hosted within a separate datacentre located at Heathrow.

**Dendrite Security**

Dendrite Clinical Systems is assessed against NHS Information Governance standards, which includes both physical and organisational security measures. Dendrite’s toolkit assessment score is available on the DSP Toolkit website ( https://www.dsptoolkit.nhs.uk/OrganisationSearch?searchValue=8HJ38)

The computer software program created by Dendrite that holds the E-CAR data has been independently tested to ensure that it is not vulnerable to unauthorised access, or internal breaches of security.

**Can I ask to see the data that the BCIS OHCA Registry holds about me?**

Requests to see what data is held on the BCIS OHCA registry about you may be made via contact with the research fellow (https://e-dendrite.com/ecar/sar.htm)

**Further information**

Queries should be directed to the BCIS OHCA registry team @ The Essex Cardiothoracic Centre – please contact rupertsimpson@nhs.net or Thomas.keeble2@nhs.net