

ICNARC Privacy Notice – OPTIC-19

This Privacy Notice is intended to provide information for participants in our research study whose information may be used for the OPTIC-19 Research study. It explains what type of information we collect, why we collect it and what we do with it.

This privacy policy was last updated on the 16/3/2023. We will update this privacy policy whenever we change the type of processing we carry out. Please regularly come back to here and check this policy for any changes.

Who are we?

We are the Intensive Care National Audit and Research Centre (ICNARC), an independent registered charity (charity number: 1039417).

Contact details

Intensive Care National Audit & Research Centre (ICNARC)
Napier House
24 High Holborn
London
WC1V 6AZ
Tel: 020 7831 6878
Email: icnarc@icnarc.org

Data Protection Officer

The Data Protection Officer at ICNARC is Scott Carnegie. Further information is available by emailing DPO@icnarc.org or by contacting the office on 0207 7831 6878.

What personal information do we collect?

We collect your Case Mix Programme admission number (a number assigned to each patient admitted to an Intensive Care Unit (ICU) which allows us to identify them within the Case Mix Programme national clinical audit which is also held by ICNARC) and your date of admission to the ICU.

This personal information is then used to combine with demographic information about you (age, sex and dependency prior to ICU admission) and your critical care admission (illness severity, treatment received in critical care, length of stay in critical care and critical care outcome).

This will be used to identify patients who were admitted to intensive care for treatment of COVID-19 and a group of similar patients who were admitted prior to the pandemic with non-COVID-19 related diseases.

How is the personal information provided?

Personal data about the patient, provided by the participating ICU and obtained from the Case Mix Programme national clinical audit includes:

- Demographics information (age, sex and dependency prior to ICU admission)
- Information about the patients ICU stay (illness severity, treatment received, length of stay and ICU outcome)

Information about you will also be collected from the following bodies:

- NHS Digital – Hospital Episode Statistic (HES)
- NHS Digital – Civil Registration (deaths)
- Patient Episode Database for Wales (PEDW)
- UK Renal Registry (UKRR)
- National Institute for Cardiovascular Outcomes Research (NICOR)
- Stroke Sentinel National Audit Programme (SSNAP)

Our purposes for processing your data

The purpose of processing data for the OPTIC-19 Study is to understand longer term risks to patients who have been critically ill with COVID-19, which may help to make sure they receive suitable care from their GP and other NHS services after they leave hospital.

We will use data collected by us as part of the Case Mix Programme to identify patients who were treated on an ICU. We will then create a unique (pseudonymous) study ID for the collected data. We will then transfer the direct identifiers and unique study ID to NHS Digital and national audit databases to obtain follow-up data. NHS digital will then pass this data onto our joint controller, the University of Oxford, who will use NHS data to see whether these patients were readmitted to hospital and why. By linking different sources of patient data, they will be able to estimate the health risks faced by survivors of severe COVID-19.

Further information regarding how your data is processed as part of this research study can be found here:

<https://www.ndcn.ox.ac.uk/research/critical-care-research-group-kadoorie-centre/research-themes/improving-monitoring-and-follow-up-of-patients-after-critical-illness/six-month-outcomes-after-surviving-treatment-for-covid-19-disease-on-an-intensive-care-unit-in-england-optic-19>

Further information on the Case Mix Programme can be found here:

<https://www.icnarc.org/Our-Audit/Audits/Cmp/About>

Sharing your personal data

We will share your personal information with the following third parties during the course of our activities:

NHS Digital
University of Oxford

Our legal basis for collecting your information

The legal bases for collecting and using personal data are:

ICNARC processes your personal data for the purposes of the research study under our legitimate interest of supporting improvements of standards in intensive care as part of our purposes as a charity and under our articles of association. Namely, the advancement of education about the organisation and practice of critical care, in particular through the promotion of audit and research into critical care and the publication of the useful results of such audit and research.

We process your special category data under the basis of processing being necessary for scientific research purposes and statistical purposes.

The special categories of personal data we collect includes:

- Ethnicity
- Health data

In order to carry out this work we have been given permission to collect and use this information under very strict conditions of confidentiality and data security by the Confidentiality Advisory Group in England and Wales.

How we store your personal information

Electronic patient and organisational information (such as databases, questionnaires or health records etc.) are kept on secure servers and only authorised ICNARC staff have access to patient identifiable data. Access to your personal data is password-protected and our servers are regularly monitored for possible vulnerabilities and attacks.

ICNARC holds all records that are supplied by NHS organisations in the strictest confidence. All staff adhere to our internal policies and procedures and are regularly trained in data protection.

Retention period

At the end of the study, ICNARC will keep identifiable information about you for no longer than one year after the study has finished. The information will be then anonymised so that study participants can no longer be identified (unless agreed otherwise).

Your rights as a data subject

Subject to certain conditions, you have the following rights in relation to your personal data:

- Right of access – you have the right to request a copy of the information that we hold about you.
- Right of rectification – you have a right to correct data that we hold about you that is inaccurate or incomplete.
- Right to erasure – in certain circumstances you can ask for the data we hold about you to be erased from our records.
- Right to restriction of processing – where certain conditions apply to have a right to restrict the processing.
- Right of portability – you have the right to have the data we hold about you transferred to another organisation.
- Right to object – you have the right to object to certain types of processing such as direct marketing.
- Right to object to automated processing, including profiling – you also have the right to be subject to the legal effects of automated processing or profiling.

- Right to judicial review: in the event that *ICNARC* refuses your request under rights of access, we will provide you with a reason as to why. You have the right to complain as outlined in below.

Complaints

In the event that you wish to make a complaint about how your personal data is being processed by ICNARC, or how your complaint has been handled, you have the right to lodge a complaint directly with the supervisory authority and ICNARC's Data Protection Officer.

The details for each of these contacts are:

Data Protection Officer (DPO) / GDPR Owner contact details

Scott Carnegie
24 High Holborn
London
WC1V 6AZ
DPO@icnarc.org
020 7831 6878

Supervisory authority contact details

ICO – Information Commissioner's Office

Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
<https://ico.org.uk/global/contact-us/>
Tel: 0303 123 1113