

Data information



HOW

How will we use information about you?

We will need to use information from you, your GP, your medical records, and national datasets for this research project.

This information will include your:

- Initials
- Name
- NHS number (or equivalent in Scotland known as Community Health Index/Northern Ireland known as Health & Care Number)
- Date of birth
- Contact details (address, telephone number, and email address).

People will use this information to do the research or to check your records to make sure that the research is being done properly



People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Warwick is the study Sponsor and is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- The chief investigators and research partners at other universities or NHS organisations including Queen's University Belfast, University of Manchester, Guy's and St. Thomas' NHS Foundation Trust, King's College London and King's College Hospital NHS Foundation Trust
- A third-party company to send you study updates and follow-up questionnaires
- NHS England (participants only in England), Patient Episode Database Wales (participants only in Wales), Information Services Division Scotland (participants in Scotland only)
- Scottish Intensive Care Society Audit Group
- Intensive Care National Audit and Research Centre



We will keep all information about you safe and secure by:

- Ensuring paper data is held in secure, locked filing cabinets within a restricted area.
- Electronic data will be held on a secure, password-protected database accessible only to relevant people.
- We have put in place strict legal agreements with the other organisations and have conducted a strict information security assessment.



The University of Warwick is currently running several studies looking at how we care for patients with respiratory failure who are currently on a breathing machine (ventilator) or at risk of needing to go on a ventilator.

This group of studies is called the 'Confederation of Respiratory Critical Care Trials' or 'CoReCCT'. These studies are working closely together, so that if someone takes part in more than one of these studies, we will share data between the studies so that we only ask you for your contact information once.



International transfers

We may share or provide access to data about you outside the UK for research related purposes to:

- notify you via text message when questionnaires are ready to complete.

If this happens, we will only share the data that is needed, this will include your first name and telephone number.

If your data is shared outside the UK, it will be with the following sorts of organisations:

- Twilio is a cloud communications company that provides tools for sending automated text messages, phone calls, and other digital communications.

We will make sure your data is protected. Anyone who accesses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- we use specific contracts approved for use in the UK which give personal data the same level of protection it has in the UK. For further details visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/>
- we do not allow those who access your data outside the UK to use it for anything other than what our written contract with them says
- we need other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
- we have procedures in place to deal with any suspected personal data breach. We will tell you and applicable regulators when there has been a breach of your personal data when this is legally required. For further details about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>



How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will publish the findings in medical journals and present at medical conferences.

We will make a copy of the study results and a lay summary available on the study website: www.warwick.ac.uk/confederation. We will keep your study data for a maximum of 5 years. The study data will then be fully anonymised and securely archived or destroyed.



What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have

If you choose to stop taking part in the study, we would like to continue collecting information about your health from central NHS records, your hospital, your GP and national databases. If you do not want this to happen, tell us and we will stop.

You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information, including the specific mechanism used by us when transferring your personal data out of the UK:

- our leaflet www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to infocompliance@warwick.ac.uk

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



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