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Privacy Notice: CORECT-R

What is the purpose of this document?

This Privacy Notice describes how the UK Colorectal Cancer Intelligence Hub combine and use data within the COloRECTal cancer data Repository (otherwise known as CORECT-R) and is intended to demonstrate how we comply with the General Data Protection Regulation (GDPR). It describes how we create the CORECT-R dataset and use any personal data within it so you are aware of how and why we are using your information. The policy may be updated at any time.

Glossary

The term 'personal data' when used in this document means any recorded information that is about you and from which you can be identified. It does not include data where your identity has been removed. These are de-identified data.

The term 'processing' of your personal data means anything that is done with that information including collecting, use, storage, disclosure or retention.

What is the purpose of CORECT-R?

CORECT-R is a national dataset containing information on people with colorectal cancer (often known as bowel) or anal cancer. These health care data are generated along the care pathways people follow through the National Health Service (NHS) as they are diagnosed and treated for these diseases. The information is captured in lots of separate administrative or research datasets. The UK Colorectal Cancer Intelligence Hub seeks access to these different datasets, combines them within CORECT-R and then uses the combined information for research aimed at improving the care and outcome of people with colorectal and anal cancers.

What types of data does CORECT-R contain?

CORECT-R contains lots of information about the colorectal or anal cancer pathway. This includes details of any tumours (e.g. pathology, site and morphology) and the patient (e.g. age at diagnosis, and gender). Also, information about how the tumour was diagnosed (e.g. any diagnostic tests used and a person's route to diagnosis) and treated (e.g. any surgery, radiotherapy or chemotherapy). It also contains information about individuals at high risk of developing colorectal or anal cancer or undergoing tests aimed at diagnosing the illness. Any information in CORECT-R about individuals without a diagnosis of cancer is pseudonymised. Full details of all the data available in the resource are described http://www.ndph.ox.ac.uk/corectr/corectr

Is CORECT-R using your personal data?

Within CORECT-R there are lots of different datasets containing information about different aspects of care. To link these together direct patient identifiers (such as NHS or CHI (community health index) numbers) are used. This is to make sure that, for example, a person is linked to the correct diagnostic test or surgical procedure. Such personal data are, however, only needed for linking datasets and are not used for research. As such, researchers do not have access to any personal information.

How the University uses your data

CORECT-R data are gathered and processed (including your special category sensitive data) in this way for the purpose of performing scientific (medical) research being carried out in the public interest. This is known under data protection law as our "legal basis" for processing personal data. The UK Colorectal Cancer Intelligence Hub only process your personal data for these purposes under approval granted from the South West – Central Bristol Research Ethics Committee (18/SW/0134).

Please note that we may process your data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

The University of Oxford Policy on Data Protection can be accessed via the following link https://www.admin.ox.ac.uk/councilsec/compliance/gdpr/universitypolicyondataprotection/

Who has access to your data?

Access to your personal data is limited to a small team of people within the UK Colorectal Cancer Intelligence Hub within a strictly controlled data environment. All these individuals have undergone special training in handling confidential data and the data system they use is highly secure.

Researchers may access anonymised datasets created from the information inside CORECT-R. These researchers may be from the UK Colorectal Cancer Intelligence Hub team or other UK research organisations who work with us. Data may also be shared with external organisations providing services to us (including those who provide data) and with external NHS and regulatory bodies.

Transfer of CORECT-R data outside of the European Economic Area (EEA)

CORECT-R data is stored on secure servers within the UK. Researchers outside the UK can access the data in this 'Trusted Research Environment' if their project gains approval. No data will, however, be transferred outside of the EEA.

Retention period

The CORECT-R data resource has been created from a 5-year grant funded by Cancer Research UK and is due to end in March 2022. Further funding will be sought to keep it going beyond this but if

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these bids are not successful then the data will be retained until March 2026 to ensure all research using them is finished. At that point they will be destroyed.

Security

All CORECT-R data will be held securely in accordance with the University of Oxford's policies and procedures. Further information is available at the University's Information Security website http://www.infosec.ox.ac.uk.

Your rights

Under certain circumstances and by law you have certain rights with respect to your data. A summary of these rights is available here: https://compliance.admin.ox.ac.uk/individual-rights

If you want to exercise any of these rights or you are dissatisfied with the way you have used your data, please contact the University's Information Compliance Team at data.protection@admin.ox.ac.uk. The same address can be used to contact the University's Data Protection Officer. If you remain dissatisfied, you have the right to lodge a complaint with the Information Commissioners Office at https://ico.org.uk/concerns

Contact

If you wish to raise any queries or concerns about this privacy notice please contact crchub@leeds.ac.uk or write to Professor Eva Morris, UK Colorectal Cancer Intelligence Hub, Nuffield Department of Population Health, Big Data Institute, University of Oxford, Roosevelt Drive, Oxford OX3 7LF, or email her at eva.morris@ndph.ox.ac.uk.