

Privacy Notice: COVID RT

What is the purpose of this document?

This Privacy Notice describes how the COVID RT study is using patient data and is intended to demonstrate how we comply with the 2018 Data Protection Act. It describes how we create the COVID RT 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 the COVID RT study

The COVID-19 pandemic has had a significant impact on cancer patients and cancer services across the UK. During the peak of the pandemic, radiotherapy services across the UK continued to treat cancer patients in often challenging circumstances and implemented significant changes to standard practice in order to minimise the risks to patients of contracting COVID-19 and focus radiotherapy resources where they were most needed. The scale of these changes in radiotherapy practice, the clinical decision-making underpinning them and their impact on cancer patient outcomes is unknown. This study, called COVID RT, has, therefore been set up to understand the impact of COVID-19 on both people receiving radiotherapy and radiotherapy services patients. The study is being run by the National Cancer Research Institute Clinical and Translational Radiotherapy Research Working Group (NCRI CTRad) in partnership with the Royal College of Radiologists (RCR), Society and College of Radiographers (SCoR) and The Institute of Physics and Engineering in Medicine (IPeM).

What types of data will COVID RT use?

The COVID RT study uses data submitted about people treated with radiotherapy during the COVID-19 pandemic in 55 of the UK's Radiotherapy Centres during the time period 1 March 2020 to 28 February 2021. These data were collected by the clinical teams managing the care of these patients and they include a detailed description of clinical decisions. Each Centre's dataset is then sending their dataset into a secure central data store in either Scotland, England, Northern Ireland or Wales where it will be compiled into a national dataset and linked to other national datasets including cancer

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registration, hospital discharge datasets, chemotherapy and radiotherapy data. Once linked, all patient identifiable information is removed from the dataset and the resulting de-identified dataset will then be shared with the research team to investigate the impact of COVID-19 on patient outcomes and, critically, to inform the response to future waves of the COVID-19 pandemic and/or future pandemics.

Is COVID RT using your personal data?

The COVID RT dataset contains information on adult patients who received radical radiotherapy in one of the 55 participating radiotherapy centres during the pandemic. The data being used for the research study which is accessible to the research team does not contain any personal information.

How the University uses your data

The COVID RT data used by the research team does not contain any personal information and is being used 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 COVID RT team only process your personal data for these purposes under approval granted from the East of England – Cambridge East Research Ethics Committee (20/EE/0247).

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 Leeds Policy on Data Protection can be accessed via the following link

<https://dataprotection.leeds.ac.uk/>

Who has access to your data?

Access to your personal data is limited to the small COVID RT team and is accessed in a strictly controlled data environment. All the individuals who have access to the information have undergone special training in handling confidential data and the data system they use is highly secure.

Transfer of COVID RT data outside of the European Economic Area (EEA)

No COVID RT data will be transferred outside of the EEA.

Retention period

The COVID RT data resource has been created without direct funding, but support from Cancer Research UK, in response to the urgent need for intelligence to help inform the NHS response to COVID-19. The project will continue until the COVID-19 pandemic and cancer services have recovered and this is expected to be at least until March 2022. To ensure all research undertaking

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using the study data is completed and published it will be retained until March 2026. At that point they will be destroyed.

Security

All COVID RT data will be held securely in accordance with the University of Leeds's policies and procedures. Further information is available at the University's Information Security website https://it.leeds.ac.uk/it?id=kb_category&kb_category=7950ab68db7ffbc48b6583305b9619e0

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://ico.org.uk/your-data-matters/>

If you want to exercise any of these rights or you are dissatisfied with the way we have used your data, please contact the University's Information Compliance Team at dpo@leeds.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 Commissioner's Office at <https://ico.org.uk/make-a-complaint/>

Contact

If you wish to raise any queries or concerns about this privacy notice please write to Professor David Sebag-Montefiore, at CTRad, National Cancer Research Institute, 2 Redman Place, London E20 1JQ or email him at COVIDRT@ncri.org.uk