

Privacy notice - mapping from depression outcomes to generic measures (NIHR ARC project)

Sebastian Hinde, Gerry Richardson, Laura Bojke

This privacy notice sets out the ways in which data gathered as part of the CASPER, CASPER PLUS, REEACH, and REEACH2 trials, conducted by the University of York will be used, stored, and shared by the Universities of York and Sheffield as part of a secondary analysis. It also sets out how long we keep your data and what rights you have in relation to your data under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

1) Who is responsible for the data

For the purposes of this privacy notice, University of York is a Data Controller as defined in the GDPR.

We are registered with the Information Commissioner's Office and our entry can be found [here](#). Our registration number is: Z4855807.

We have an appointed Data Protection Officer who can be contacted as follows: Data Protection Officer, University of York, University of York, Heslington, York, YO10 5DD, UK.
dataprotection@york.ac.uk.

We will place any updates to this privacy notice on this web page (<https://www.york.ac.uk/che/privacy-notices/>).

2) Who is conducting the research?

The research is conducted by researchers at the University of York in collaboration with the University of Sheffield.

3) What are the objectives of the research and the purpose of using your data?

The University of York's charter is for the advancement of learning and knowledge through teaching and research.

We will use the data collected to understand the links between different patient completed health outcome measures collected as part of the four completed trials (the CASPER, CASPER PLUS, REEACH, and REEACH2). This will allow us to better understand how measures which focus on patient mental health, such as the PHQ-9 and GAD-7, can be compared to generic measures, such as the EQ-5D, and therefore the health of patients suffering from different illnesses compared.

4) Where do we get your data from and what data do we have?

For this research we will use data from a number of trials, all conducted by the York Trials Unit at the University of York. All data is stripped of any personal identifiers (e.g. names, NHS numbers, postcodes, date of birth) before being shared with us.

We have received data from the York Trials Unit containing minimal patient information, e.g. gender and age, alongside responses to the patient completed health outcome measures from the CASPER, CASPER PLUS, REEACH, and REEACH2 trials.

5) What is our legal basis for processing the data?

The GDPR requires us to establish a legal basis for processing your information. For the purpose of this privacy notice the processing is necessary for the performance of a task carried out in the public interest. Our public task functions are as set out in our University charter.

6) Who do we share your data with?

Permitted employees and agents of the Universities working on the research project will use the data. Although we do not anticipate the requirement to share the data with third parties, should this be required disclosures would be made only in full accordance with data protection legislation and only where necessary. You will be advised of such disclosures through this privacy notice unless exceptional circumstances apply.

7) How do we keep your data secure?

The University of York takes information security extremely seriously and has implemented appropriate technical and organisational measures to protect personal data and special category data. Access to information is restricted on a need-to-know basis and security arrangements are regularly reviewed to ensure their continued suitability. For further information see, <https://www.york.ac.uk/it-services/security/>.

8) Will we transfer your data internationally?

No, we will not transfer any data out of the UK.

9) How long will we keep your data for?

Data will be retained for the duration of the funding of the projects and until outputs from the research have been published. Data will be destroyed safely, in accordance with the Data Protection Laws and in line with our agreement with NHS Digital governing secure data deletion methods.

10) What rights do you have in relation to your data?

Under the General Data Protection Regulation, you have a right of access to your data (accepting that we are not able to personally identify data given the anonymous nature of the data we hold), a right to rectification, erasure (in certain circumstances), restriction, objection or portability (in certain circumstances).

11) Questions or concerns

If you have any questions about this privacy notice or concerns about how your data is being processed, please contact the University's Data Protection Officer at dataprotection@york.ac.uk.

12) Right to complain

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.