

The EXTEND study

Early Intervention in Psychosis (EIP) care is currently recommended to everyone experiencing a first episode of psychosis for up to 3 years. This study is looking at how different durations of EIP care impact service users.

We are planning to link existing research datasets from two sources, the National Clinical Audit of Psychosis (NCAP) and NHS Digital. This will create a new dataset of the EIP care received by service users, and the outcomes they experienced (such as relapse or hospitalisation).

The EXTEND study is a team of researchers from universities across the UK, led by Professor Belinda Lennox from the University of Oxford and Professor Paul French from Manchester Metropolitan University. It is funded in full by the National Institute for Health Research (NIHR).

How is your data used in the NHS now?

The NHS records routine medical information from your consultations, for example:

Patient X referred to EIP service on 3/6, seen by Dr. Z on 12/6, presented with symptoms of psychosis, offered therapy and medication. 5.11.2022 13:14:14

This routine medical information might be used for research or planning, and is organised within the NHS into datasets like this:

Patient ID	Referral date	Waiting time	Diagnosis code
X	03/06	9 days	F20
Y	14/07	20 days	F20

These datasets are never published, but might be used for research and planning

How will your data be used in the EXTEND study?

If you received Early Intervention in Psychosis care in England between September 2018 and September 2020, your data may be used in the following way:

- Stage 1: NHS Digital will match individual service users to its own records using identifying information (such as your NHS Number) shared from the NCAP
- Stage 2: Healthcare data from the NCAP and NHS Digital (such as hospital admissions) with the identifying information from matching removed will be sent to a secure environment, where it will be used for research

No one outside NHS Digital will identify individuals within the data. Only approved researchers will be able to access your healthcare data. No information about individual care or outcomes will be published at any point, only statistical summaries.

How to opt out

You can opt out if you would prefer that your data not be used in this study. To do so, email the Royal College of Psychiatrists (who store the NCAP data) at: NCAP@rcpsych.ac.uk

You will be asked to provide an NHS Number so that your data can be identified and excluded. You can ask your carer or GP to help with the opt out process, in which case they will be asked to provide your NHS Number. If you request to opt out after the data has been transferred, we will not be able to identify and exclude your data. If you have opted out of all NHS data sharing, NHS Digital will not share your data as part of this study (for more information see <https://www.nhs.uk/your-nhs-data-matters>). No transfers will take place before **16th December 2022**.

Find out more

For more information on how your data will be used, the legal and organisational safeguards in place and why service user data is important to the study, visit: <https://www.psych.ox.ac.uk/research/extend>

Get involved

Data from the NHS will help us understand and improve psychosis care, but so will the voices and experiences of service users. To hear about events you can attend or to get in touch, visit the "Contact us" section of the study website.

Legal and data protection information

You can contact the EXTEND study team via <https://www.psych.ox.ac.uk/research/extend/contact-us>, or by emailing extend@psych.ox.ac.uk. Alternatively you can contact the study sponsor on 01865 616480 or ctrg@admin.ox.ac.uk. You have the right to lodge a complaint with the Information Commissioner's Office (0303 123 1113) or www.ico.org.uk.

The University of Oxford, based in the United Kingdom, as sponsor, is the data controller. This means that we, as University of Oxford researchers, are responsible for looking after the information received and using it properly. Research is a task that we perform in the public interest. We will use the minimum information possible. Data protection regulation provides you with control over your personal data and how it is used. Further information about your rights with respect to your personal is available at <https://compliance.admin.ox.ac.uk/individual-rights>.

The legal basis for the processing and storage of personal data in this study is 'a task in the public interest' **Article 6(1)(e) UK GDPR**. The legal basis for processing special category data is 'public interest, scientific or historical research purposes or statistical purposes' **Article 9(2)(j) UK GDPR**, in accordance with **Article 89(1) UK GDPR** (as supplemented by **section 19 Data Protection Act 2018**).