

National Clinical Audit of Psychosis Early Intervention in Psychosis audit 2020/2021 privacy notice – version for younger people

Summary version:

We collect information which includes personal details from NHS services to help us to report on the quality of care these services provide.

We make a special application to ensure that we can legally collect the personal information (NHS number, date of birth, postcode). This means we must show that we are able to hold these details securely in accordance with national and international regulations

We make sure that all our reporting is anonymised – we publish nothing about individuals or any detail that can identify you in any way.

We do **not** allow any unauthorised access to the data or share information for marketing purposes.

We do **not** collect any information we do not need.

We do **not** keep the information for any longer than is necessary. This is specified in our permit to collect the data.

If you would prefer that we do not look at your information to report on care quality you can use the [opt out process](#) (patients in England only)

Full version:

What is NCAP?

NCAP is the [National Clinical Audit of Psychosis](#). In 2020/21 this audit programme is collecting **information on the care received by people with first episode psychosis** in **Early Intervention in Psychosis Teams** (EIP services) and **Children and Young People's Mental Health** (CYPMH) services. We **report on the quality of care and treatment** they provided and **make recommendations for how to improve**.

What information is collected?

NCAP collects information about **the different treatments and interventions delivered** to people with first episode psychosis. This means therapies or medications, advice or help offered with physical health, e.g. to stop smoking, and other advice or help like work or education programmes.

We also collect **some personal information** about the people using the services.

What is this notice about?

This notice **explains what personal information we hold** about you, **what it is used for** and **how it is kept safe**. It also tells you **what to do if you don't want us to hold this information**.

In this notice, you will see different names or terms used that you may not be familiar with such as:

Clinical audit, or audit programme: This means collecting and reporting on data from healthcare organisations to demonstrate how well they are performing and to identify ways that they can improve

Data Controller: The organisation in charge of the information we collect. This is NHS England together with the Healthcare Quality Improvement Partnership who commission and manage audit programmes in healthcare services.

Data processor: This organisation processes information for the data controller. The Royal College of Psychiatrists is the data processor for this audit programme. We also work with other organisations to process and keep the data secure:

The data processors we use are:

- Software providers/hosts for databases which hold the data (Formic);
- Hosting partner which provides the secure virtual datacentre (Microsoft);
- Statisticians who may carry out detailed analysis of sections of data, from which all personal information has been removed

These processors cannot do anything with the information unless we have instructed them to do it, nor can they share your data with any other organisation.

Data protection officer (DPO): This person makes sure we do everything the law says.

The Royal College of Psychiatrists DPO can be contacted at DataProtection@rcpsych.ac.uk

Personal data: This means any information that can be used to identify someone. The personal data collected for this audit is NHS number, date of birth, and postcode.

What is this information used for?

The personal data we ask for is used **to compare it with other information the NHS holds to check how accurate it is**. This means that we might not need to collect the information in future.

What happens to the information we collect?

We use the information to look at **how well services are performing** and **what treatments and therapies are provided in different parts of the country**. We **publish reports** about this showing national and local data. The reports contain anonymised data (e.g. "9 out of 10 patients had an appointment within 2 weeks") and **do not contain any information about individuals**.

We will only use your information to compare and report on services. We will never share any information with any third parties for marketing purposes.

Who looks after your information?

The data is kept in **secure data centres which comply with regulations** (ISO 27001 security standards). We also **comply with all data protection law** and have legal contracts with anyone processing the data to make sure that they do this.

Only staff members working on the audit and data processors under contract have any access to your data. All data files are **password-protected** and **stored in restricted areas**.

How long do we keep personal information?

We are allowed to keep it for **one year** under [Section 251 approval](#). If reports are delayed for any reason and we need to keep it for a little longer we must make another application.

What other information is collected?

We also collect:

- **Contact details for services**, including staff named as audit contacts
- **Demographic data** including age, sex, ethnicity;
- **Care data** including interventions received (e.g. medication, psychological therapies), processes of care;
- **Outcome data** (information showing the results of care)

Data that does not identify the individual is retained **for as long as the audit runs** and **for five years after it is completed**.

Legal basis for processing

This is permitted under **Article 6(1)(e) of the General Data Protection Regulation (GDPR)** which allows for the processing of data where this is carried out in the public interest or to carry out government functions authorised by Acts of Parliament. This authority is delegated to our joint data controllers, HQIP and NHS England.

Collecting identifiable data is permitted under a process called **Section 251 approval**. This means that we make a special application to show that we need to collect the data to report on how well services are doing. We also must prove that we **comply with all legal requirements to keep your information secure and completely confidential**, and to inform you about your rights. (You can read more [here](#) about Section 251).

What if I do not want my information used by the audit?

You can request that we do not use your information. This is called opt-out. If you decide to do this it will have **no effect on the care you receive**.

Option 1: Opt out via your Trust

- **Contact your local NHS Trust/organisation** directly and **request to opt-out from the audit**. Your Trust/organisation will be able to tell you if they have been asked to send information about your care to the NCAP team.
- If it is **before 1st December 2020** and the Trust has been asked to participate in the audit, they will let the NCAP team know and **your information will not be submitted** to the NCAP team. The Trust will then **confirm with you that your information has not been shared**.

- If it is **after 1st December 2020**, your information has **already been sent to the NCAP team**. Your Trust will contact us, and we will **delete the information we have**, and you will be informed when this has been done.
- If you would like to **discuss any concerns about your information being used** or would like any **help in opting out**, please speak to your **care coordinator** or **[The Patient Advice and Liaison Service \(PALS\)](#)** in your local Trust.
- **Please note that once analysis is completed in March 2021 it may not be possible to remove your data from the sample.**

Option 2: Opt out via NCAP (After 1st December 2020 only)

- **Contact the NCAP team by email** (NCAP@rcpsych.ac.uk) and let them know that you don't want them to use any information on your care. **The team will ask you some questions** so that they can see if they have any information about your care.
- If NCAP does have any information about your care, the team will let you and the Trust/organisation know. The NCAP team will then **delete all information about your care** and email you and the Trust/organisation to let you know that this has been done.
- **Please note that once analysis is completed in March 2021 it may not be possible to remove your data from the sample.**

National data opt-out

NCAP complies with the National Data Opt-out policy. To find out more or to register your choice to opt out, please visit www.nhs.uk/your-nhs-data-matters.

Complaints or queries

The College takes any personal data complaints very seriously.

We encourage people to bring it to our attention if they think that our collection or use of information is unfair, misleading or inappropriate.

If you want to make a complaint about the way we have processed your personal information you can contact us using the details at the bottom of this notice.

You can also complain to the Information Commissioner's Office directly:

Wycliffe House Waterlane Wilmslow Cheshire SK9 5AF

Website: <http://www.ico.org.uk/>