Personalised care for early psychosis: The EXTEND study

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@EXTENDEIP https://www.psych.ox.ac.uk/research/extend

What is the EXTEND study?

The EXTEND Early Intervention in Psychosis (EIP) study is a 3-year NIHR funded research programme across multiple sites. Oxford University, Manchester Metropolitan University, Keele University, and Pennine NHS Foundation trust are leading different components of this research.

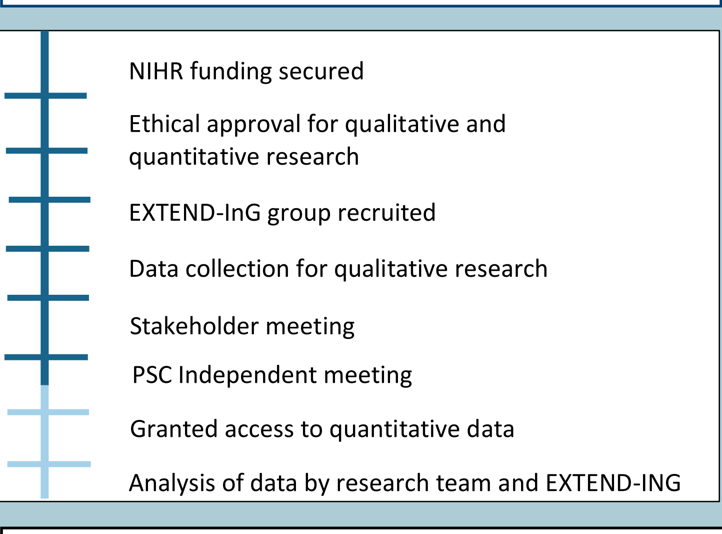
The aim of the study is to understand how to personalise the duration of EIP services for patients and carers. EIP services are commissioned to provide care for 3 years. Patients and carers get discharged at this point, regardless of their progress towards recovery. Sometimes EIP services might use their discretion and keep patients and carers on their caseload in situations of concern. But there is no formal process or guidance on this. Understanding the circumstances when more or less EIP care is necessary is a key aim of the study's research.

The research question will be answered through a combination of qualitative and quantitative methods. The quantitative component will analyse data collected from the NCAP audit and MHSDS dataset of information recorded by services regarding patient care. The qualitative component will identify themes from interviews with healthcare providers, patients, carers and commissioners to understand their experiences of EIP care and on their perspectives regarding personalising the length of care provided by EIP services.

The role of EXTEND-InG

The EXTEND-Involvement Group (EXTEND-InG) is a group of patients and carers with lived experience of early intervention in psychosis services. Their contribution to the research programme is to identify key areas to focus on that are most important to patients and carers. This helps the EXTEND research team to conduct meaningful research that will make a difference to those who use EIP services. The group is made up of 7 members and a service user advisor and carer advisor, who relay the group's perspectives to the research team.

Progress to date



NIHR funding secured

Ethical approval for qualitative and quantitative research

EXTEND-InG group recruited

Data collection for qualitative research

Stakeholder meeting

PSC Independent meeting

Granted access to quantitative data

Analysis of data by research team and EXTEND-ING

Additional opportunities

- Opportunities for EXTEND-InG to be involved in qualitative data analysis
- Opportunities for EXTEND-InG to write commentaries on the quantitative findings.
- NCAP patient and carer representative role vacancies.
- Write a blog for us, contribute to the next newsletter, or contribute to our series of a day in the life of, or send us some artwork to feature in a future issue.

The opt-out procedure

If you are a patient, carer or healthcare professional in EIP care and would like to know more about the data that is going to be used you can find out more information on data use at this link, which also details how to opt out of your data being used in the dataset. Please share this link with patients and carers who use EIP services.

https://www.psych.ox.ac.uk/research/extend/data/opt-out-information

Updates

Quantitative update

Approval for data sharing obtained from NHS Digital, Data Sharing Agreement signed November 2022

Opt-out information published and shared along with study website in November 2022. Opt-out window remains open until NCAP cohort finalised.

NCAP cohort in production with RCPsych – will be shared with NHS Digital to start data production process

Alternative data access arrangements planned via NHS England and Clinical Record Interactive Search (CRIS), resulting from discussions with wider project team including EXTEND-InG.

Qualitative update

Recruitment has already begun from some sites. Healthcare professionals and commissioners have been recruited so far.

Recruitment from other sites will begin shortly.

Ethics amendment submitted to NIHR to allow recruitment through social media. More patients and carers will be recruited for a longitudinal study.

Data analysis has begun to identify preliminary themes.

Updates

EXTEND-InG Updates

We have had two meetings so far, where we discussed the aims of the research and opt-out procedure and key variables important to the group which have been communicated to the research team.

The group contributed perspectives on why they are involved and their priorities for research, which are featured on the EXTEND website.

EXTEND-InG input on Qualitative package

EXTEND-InG have been asked to provide feedback on qualitative study ethics materials and contribute to data analysis. The group have also helped coproduce a flyer for recruitment.

EXTEND-InG input on Quantitative package

EXTEND-InG have been asked to provide commentaries to help interpret the quantitative data when this comes through.

EXTEND-InG at the stakeholder meeting

Some members attended the stakeholder/round table meeting alongside service user advisor and carer advisor to ensure lived experience perspectives inform dissemination protocol.

EXTEND-InG Meet and greet

We are planning to have a meet and greet with the whole team. Look out for this in the near future.

Forthcoming key events

- Research Programme Steering Committee (PSC) meeting due later in January (An independent governance meeting to assess whether the research programme is progressing satisfactorily.
- The research team will present the study at Royal College of Psychiatrists Congress
- The next EXTEND-InG meeting will be in February with a chance to look at the qualitative findings and interpret them.

Contact us at @EXTENDEIP

Register for our newsletter or to participate in the study

extend@psych.ox.ac.uk

The structure of EXTEND

EXTEND involvement group

Service user & Carer Advisors

EXTEND research team

Why the EXTEND study is important to EXTEND-InG

“ Having a defined length of time for EI as opposed to your need was something I was not aware of when I first engaged with the early intervention team . . . I found it a shock that this support would stop especially as I had psychotic episodes in January this year . . . It feels in personable that the decision is time focused and not person centric and I want to see if the balance can be changed.”

- Service user

“Whilst the EIP care that I received was fantastic. I felt the length of care I received was too short and left me feeling anxious and possibly led to my relapse . . . Extending the EIP care could potentially help many service users as well as enable health care staff to provide a better level of care ...”

- Service user

“The EXTEND research project is very important to me personally as for the past two years our son has been under the care of EIT. I am particularly interested in this research project as it has the potential to shape the future direction of EIT. . . the project is highly focused on ensuring patient and carer voices are captured . . .”
- **Carer**

“. . . to give my lived experience of EIT as a carer, the fight to get into the service and the disappointment of it not being a personalised service but more based upon a time frame.” - **Carer**

“I find that a one-size fits all approach is inadequate and some patients and families may need more or less support from early intervention services depending on the severity and duration of their psychosis. I am also keen to advocate for easier access back into services following discharge from early intervention services”

- **Service user**

“I was referred to my local EIS after being discharged from hospital. At the time I did not know that irrespective of my needs the service would only be available to me for 3 years. For the initial year I struggled to open up . . . Luckily for the remaining 2 I had a genuine and compassionate Community Nurse that assisted me with feeling empowered by allowing me to take the reins on my recovery. While my recovery has had many peaks and troughs, I found that the support I urgently needed was after being discharged from the service.”

- **Service user**

“My daughter experienced her first episode of psychosis when 'early intervention' was just a whisper . . . Back then I was passionate to challenge the orthodoxy of 'late intervention' that was our lived experience as a family” – **Carer** ”

Why did you want to get involved in the EXTEND study?

“I want to give back and use my experience of psychosis and recovery through early intervention in a positive way . . . If I can be part of the team that help [sic] make this change possible it would be a wonderful achievement . . .” - **Service user**

“. . . it feels very empowering to know you are helping shaping [sic] future service provision within psychosis services to benefit others.” - **Carer**

“I want to support research that endeavours to create a more tailored approach to providing early intervention services . . . I have personally benefitted from early intervention care and know its value and its impact on my health and recovery and also to my family, but I hope through EXTEND-ING care for early intervention services we can make it even better and improve the lives of many others. . .” - **Service user**

“. . . I'm excited to be part of EXTEND's PAG to continue the challenge for a more nuanced approach.” – **Carer**

“. . . Lived experience reps have a realistic insight that professionals just don’t have. . . I am passionate about advocating for all those under EIT who have S117 after care rights” – **Carer**

“I have been working with the trust doing patient as educator work, interview panels, talking to the board etc. and I have found it empowering to be back involved and feeling useful.” - **Service user**

“Being a part of the EXTEND project gives me the opportunity to voice my concerns . . . While it is important to recognise that recovery varies depending on the individual, it should also be acknowledged that the length of time people require this kind of support is bound to differ too. In order for EIS to be person centred, they should take into consideration what length of time is conducive to the individuals involved in receiving EI support.” - **Service user**

“. . . to make sure that certain things are in place before people are discharged from early intervention because I don't want people to repeatedly become ill before things are sorted, like I unfortunately have. ” - **Service user**

Meet the team

The EXTEND Research team

Professor Paul French
Co-chief investigator

Professor Belinda Lennox
Co-chief investigator

Associate Professor Apostolos Tsiachristas Health economist

Professor Carolyn Chew-Graham Lead for qualitative studies

Professor Mike Crawford
Advisor on NCAP linkage

Professor Alex Bottle
Statistical analysis advisor

Professor Rhian Daniel
Statistical analysis advisor

Ed Penington
Researcher in health economics

Dr Alexis Cullen
Principal researcher

Dr Michelle Rickett
Research associate

Dr Tom Kingstone
Qualitative researcher

Carl Money
Statistical analysis advisor

Ameera Iqbal
Research assistant

Lucy Carr
Research assistant

Dr Ryan Williams
PhD fellow

Dr David Shiers
Carer advisor, Co-Chair of EXTEND-InG

Veenu Gupta
Service user advisor, Co-Chair of EXTEND-InG and Research associate

EXTEND-InG the patient and carer involvement group

Ninette Osei

Heidi Mcallister

Adam Francis

Clare Woodall

Jo Ward

Kane Christer

Caroline Ward

Neil Caton

EXTEND PERSONALISED CARE FOR EARLY PSYCHOSIS

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