

CECiLiA Study Newsletter

Issue 1: February 2026



Welcome to the first newsletter for the CECiLiA (An evaluation of Care (EduCation) and treatment reviews for people with Learning dIsabilities and Autistic people) research project.

Thank you for taking the time to read about our work. This first newsletter will cover:

- Who we are
- What we plan to do
- What we have done so far
- How you can get involved
- Our Lived Experience Advisory Panels

You can find out more and see videos by visiting:

<https://cecilia.org.uk/>

Who we are

There are lots of different people from different organisations involved in running this research.

Some people work at universities, some at NHS Trusts, and some for organisations for people with learning disabilities, autistic people, plus families and carers.

You can find out more about us by clicking:
<https://cecilia.org.uk/who-we-are>

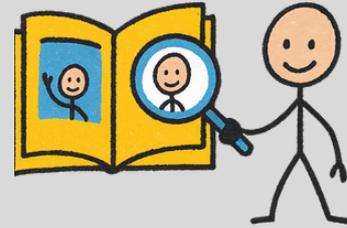


What we plan to do

We are trying to find out if Care (Education) and Treatment Reviews (C(E)TRs) are helpful for people with learning disabilities and autistic people, and if they result in positive changes.

If they do, we then want to find out if there are some ways they are carried out that work better than others.

This research has four different parts, called stages.



Stage 1 - What is happening in England?



In this stage we are asking people to complete surveys to let us know their experiences of C(E)TRs.

We want to hear from anyone involved in a C(E)TR over the last 12 months, including:

- People with learning disabilities and autistic people, including children aged 5 and older
- Families and carers
- Care (Education) and Treatment Review panel members
- Health, education, and social care professionals

As well as people completing surveys themselves, we can offer help to anyone who would like this. This could involve us talking through the survey over the phone or in person – we will do our best to do whatever people would find helpful.

We also want to hear from individuals with communication difficulties who may not be able to complete a survey, including people with moderate to severe learning disabilities. Their views about C(E)TRs are still really important for us to hear. We can offer an easy access face-to-face interview.

We will be looking for people to tell us about their experience of C(E)TRs until the end of August 2026.



Stage 2 - What do people say about their experiences?



This stage involves us finding out what happens at C(E)TR meetings by watching and listening to some meetings.

We will also be asking some of the people who attend these meetings about their experiences, including people with learning disabilities and autistic people, and families and carers.

We will be following 20 people going through the C(E)TR process, aiming to include 10 children and 10 adults.

Stage 3 - What has helped people and what has hindered them?

This stage involves using information that the NHS already collects about autistic people and people with a learning disability who are in hospital. This is publicly available, meaning anyone can access it.

This is **aggregated data**. This means the information is about lots of people at once rather than about people individually. This information does not include any personal details e.g., names, addresses.

We will be making links between what happens for people, how long it takes, and if/when they leave hospital.



Stage 4 - What is the whole story of people having C(E)TRs?



This final stage will consider what the best ways of doing C(E)TRs are.

This will involve putting together what we have found out in Stages 1, 2 and 3 once these are complete.

We will create some good practice guidance for doing Care (Education) and Treatment Reviews and make sure this is shared in different ways and to different people who need it.

What we have done so far

Stage 1

As of the end of January 2026 we have received surveys from 326 people. Of these:

- 44 were people with learning disabilities and autistic people
- 20 were family members
- 262 were professionals.

Thank you very much to everyone who has taken the time to do this.

Thank you also to the Trust staff that have been taking the time to complete paper-based surveys face to face with people with learning disabilities and autistic people, this seems to be a really effective way to hear about their experiences. If any other Trusts or organisations think this may be an approach that would work well for them please do get in touch and we can arrange posting you some paper surveys.

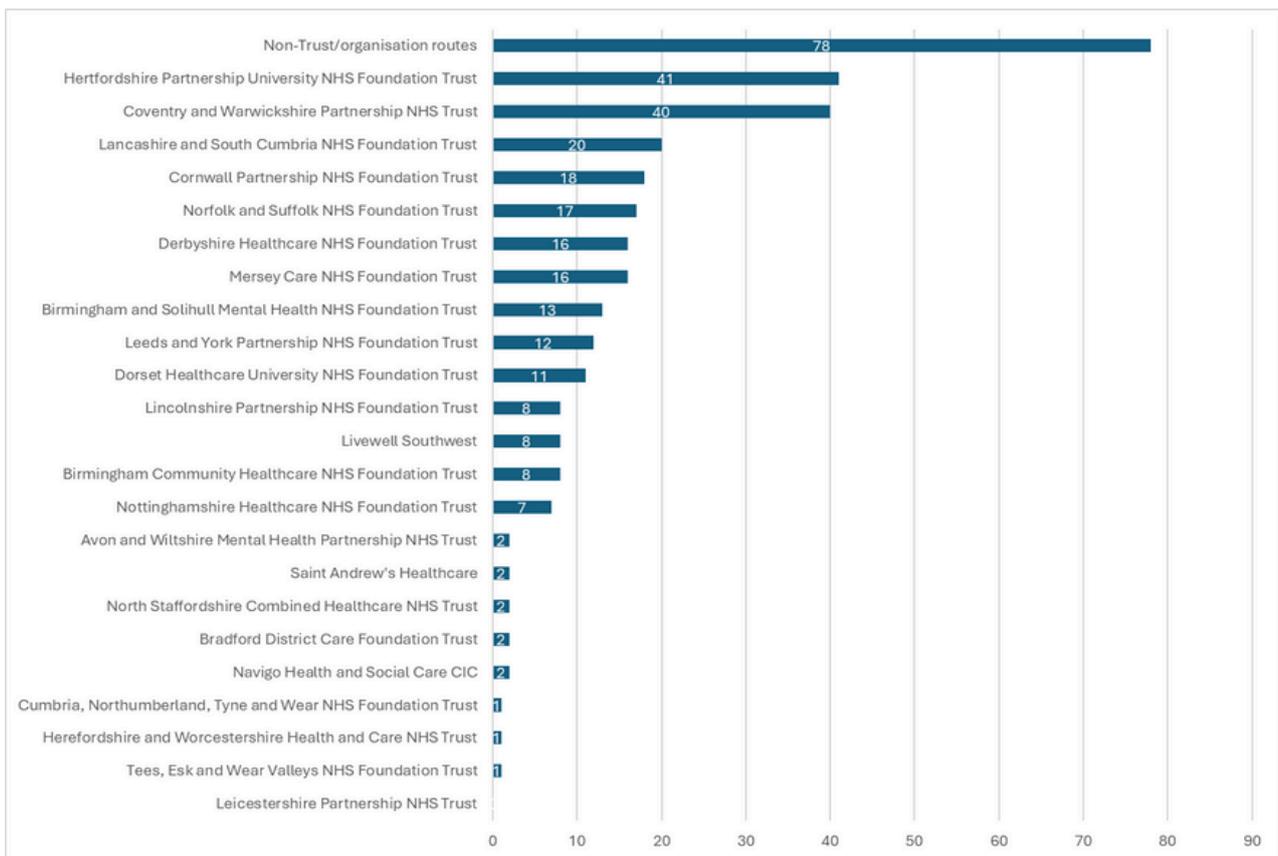
We have been finding people with the help of various NHS Trusts and non-NHS health and social care organisations. We are still talking to several more Trusts and organisations about being involved.

We have also been advertising the study in various other ways not involving Trusts and organisations e.g., mailing lists and groups (non-Trust/organisation routes).

People can also express interest directly by completing the expression of interest form on our study website:

<https://cecilia.org.uk/take-a-survey/>

The bar chart below shows where people have come from so far. Currently most people have come from non-Trust/organisation routes, but Trust/organisation recruitment has been picking up pace in recent months...



Stage 2



Towards the end of 2025 we completed required administrative processes and are now looking for Trusts and organisations to be involved in identifying people to take part in this stage. We are looking for no more than 1-3 people to follow through C(E)TR meetings per Trust/organisation, to make sure we are following people throughout different parts of England

We are currently talking with several possible Trusts/organisations about being involved. Please do get in touch if this is something you would be interested in finding out more about by emailing cecilia@contacts.bham.ac.uk. We expect to begin following people through their C(E)TRs during the first half of 2026.

Stage 3

We have been downloading new information as the NHS release it each month. This means that we will be ready to analyse this later in the project.

As well as collecting this aggregated data, we are also looking into whether it will be possible to get **individualised data**, which tells us about individual experiences. If we can get this, we would be able to look in much more detail about what type of things helped and hindered people and be much more confident in any conclusions we draw and/or any recommendations we make.

Stage 4

Once the other Stages are complete we will then consider what these tell us about the whole story of people having C(E)TRs. One thing we will do is make some best practice guidance.

How you can get involved

Complete a survey

We are very keen to hear from anyone who has had a C(E)TR in the last 12 months, including people with learning disabilities and/or autistic people, families and carers, C(E)TR panel members and health, education and social care professionals.

You can find out more and complete an expression of interest form on our study website at

<https://cecilia.org.uk/take-a-survey>

The survey should take **no more than 30 minutes** and you can receive a **£20 gift voucher** as thanks for taking part.



Tell people about our research

We want as many people as possible to know about what we are doing. This could include people who could complete a survey or people who know others who could complete a survey. The best way to tell people about our research is giving them a link to the study website, which includes videos

<https://cecilia.org.uk/>

Trust/organisation involvement

We are still looking for Trusts/organisations to be involved in Stage 1 and Stage 2 of this research.

If your Trust/organisation would like to learn more about being involved in either sharing information about surveys (Stage 1) or identifying 1-3 people for us to follow through C(E)TR meetings (Stage 2) please get in touch via the below email address and we can tell you more

cecilia@contacts.bham.ac.uk



Lived Experience Advisory Panels



Our Lived Experience Advisory Panels are one way that we are making sure that we are listening to people with lived experience.

These are three groups of people with learning disabilities, autistic people, and carers and family members who are involved throughout all stages of the research.

We have partnered with [Learning Disability England](#), the [National Autistic Society](#), and the [Challenging Behaviour Foundation](#) who each lead one of the three Lived Experience Advisory Panels.

In each newsletter we will share the view of one Lived Experience Advisory Panel member about why they are interested in this research.

This month we will hear from Sarah from the Lived Experience Advisory Panel for autistic people:

"This project has allowed me to make truly constructive meaningful use of my lived experiences of autism to inform a study of individuals' experiences of CeTRs. Within this I have learned so much from and been inspired by peers with autism."



Lived Experience Advisory Panels will be meeting online regularly throughout the project.

In addition to this, we will also bring all of the Lived Experience Advisory Panels together once a year for an in-person meeting.

The first of these was held in October 2025. At this meeting we considered how feedback from Lived Experience Advisory Panels so far had impacted the project, and focused on how we will analyse what we find.

Thank you for taking the time to read about this research