

# CECiLiA Study Newsletter

Issue 2: April 2026



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

This second newsletter covers:

- Our news
- How to take part
- What else Trusts/organisations can do
- Our Lived Experience Advisory Panels

## Who we are

The project CECiLiA team includes people working at universities, NHS Trusts, and organisations for people with learning disabilities, autistic people, plus families & carers. Find out more about us:

<https://cecilia.org.uk/who-we-are>

## More information

Find out more and see videos here:

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

Follow us on LinkedIn:

[www.linkedin.com/company/  
projectcecilia](http://www.linkedin.com/company/projectcecilia)

## What we plan to do

We want to know 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.



[Click here to catch up  
on our first newsletter](#)

This research has four different parts, called stages:

### **Stage 1 - What is happening in England?**

Asking people to complete surveys to let us know their experiences of C(E)TRs.

### **Stage 2 - What do people say about their experiences?**

Finding out what happens at C(E)TR meetings by watching and listening to some meetings.

### **Stage 3 - What has helped or hindered people?**

Using information that the NHS already collects to make 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?**

Putting together what we have found out in Stages 1, 2 and 3 once these are complete to consider what the best ways of doing C(E)TRs are.

# Our news

## Stage 1

432 people have completed a survey as of the end of March 2026. Of these:

- 60 were people with learning disabilities and autistic people
- 30 were family members or carers
- 342 were professionals



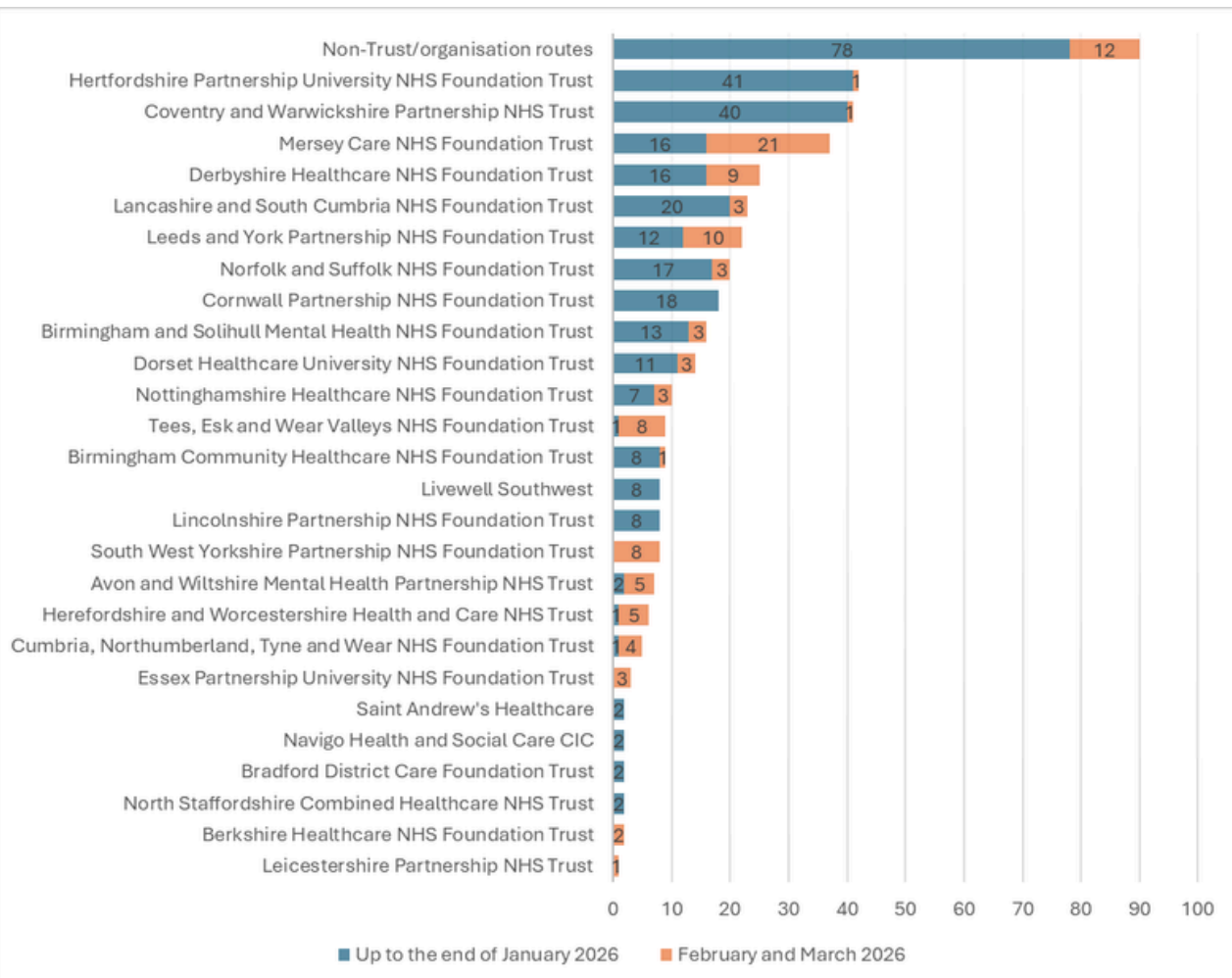
Thank you very much to everyone who has taken the time to do this.

We have been finding people by:



- 26 NHS Trusts and non-NHS health and social care organisations advertising this research. We are still talking to a few more Trusts and organisations about being involved
- Advertising the study in various other ways not involving Trusts and organisations e.g., mailing lists and groups

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 continues to pick up pace...



## Stage 1 reflection - we need to hear from more people with learning disabilities and autistic people as well as family members

Professional recruitment is going well. However, we have had fewer responses from people with learning disabilities and autistic people as well as from family members. It is important that their views are included within this research.

We have been thinking about how we can tell more people about this research and make taking part easier. This has involved some really useful discussion with sites, we have found it really useful to work together in this way - thank you! Ideas so far include:



### Thinking about how we are communicating with people



- Making sure we are clear about long it will take to do the survey, how many questions there are, and what benefits completing it will have
- Thinking how to make completing easier e.g., a physical reminder of multiple choice question options
- Make sure we are reaching people at all the different points where they should be offered a C(E)TR, including people who may not know they have been offered or attended one

### Making sure Trusts/organisations know how we can make taking part easier for people

- Our staff can visit to promote the survey (e.g., at patient meetings)
- Our staff can support people to complete surveys
- If anyone does not want to do the survey (e.g., because it is too long) they can be offered a Talking Mats interview instead

Some Trusts have completed paper-based surveys face to face with people with learning disabilities and autistic people. This seems to work really well. We will continue to encourage other Trust staff to do this.

We have scheduled regular meetings with Trust and organisation staff each month. At these we will discuss study progress, consider common recruitment barriers, and share good practice including successful recruitment ideas.



### Thinking how to tell more people about this research



- Exploring how to share information within special schools
- Looking for events where we could tell people about this research
- Considering how to share information more widely via the media e.g., press release, journalists
- Asking for information to be shared again by organisations and groups that have already kindly done so, and looking for any who we have not already contacted

## Stage 2

We are looking for Trusts and organisations to be involved in identifying people to take part in this stage. This involves us watching what happens at C(E)TR meetings and talking to some people attending about their experiences.

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 currently have three Trusts involved. These are looking for suitable people to involve. We expect to begin following people through their C(E)TRs in the coming months.

We are also talking with several other Trusts/organisations about possibly 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](mailto:cecilia@contacts.bham.ac.uk).



## 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.



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.

As well as collecting this aggregated data, we are still 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 putting these together tells us about the whole story of people having C(E)TRs.

One thing we will do is make some best practice guidance for doing C(E)TR. We will make sure this is shared in different ways and to different people who need it.



## How to take part

### Complete a survey

Are you someone who has had a C(E)TR in the last 12 months? If so, have you completed our survey yet? We want to hear from 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. The best way to tell people about our research is to give them a link to the study website, which includes videos:

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

If you know anyone who could complete a survey or anyone who know others who could complete a survey tell them to go to:

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

You can also tell them to follow us on LinkedIn:

[www.linkedin.com/company/projectcecilia](http://www.linkedin.com/company/projectcecilia)



### Get involved

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:

[cecilia@contacts.bham.ac.uk](mailto:cecilia@contacts.bham.ac.uk)



## What else Trusts/organisations can do

### Attend monthly meetings

We recently held the first monthly meeting to discuss study progress, consider common recruitment barriers, and share good practice including successful recruitment ideas. It was really good to discuss how different Trusts/organisations have been finding things.



Next meetings are planned for:

Tue 21<sup>st</sup> April 1000-1100  
Fri 15<sup>th</sup> May 0900-1000  
Tue 23<sup>rd</sup> June 1000-1100  
Fri 17<sup>th</sup> July 0900-1000  
Tue 11<sup>th</sup> August 1000-1100

If you have not received an invite please get in touch via:

[cecilia@contacts.bham.ac.uk](mailto:cecilia@contacts.bham.ac.uk)

### Organise a Continuing Professional Development (CPD) session from us

Some sites have asked if we can provide CPD sessions for staff. We are very happy to offer such sessions on a wide range of topics, full details at <https://cecilia.org.uk/training-opportunities/> These include:

#### Research topics:

- Recruiting autistic people and people with learning disabilities (including those who lack capacity) into research
- Developing Talking Mats for research

#### Assessment:

- Assessment of Risk and manageability of Individuals with Developmental and Intellectual Limitations who Offend (ARMIDILO-S) training
- Models/assessment of speech, language and communication

#### Positive Behavioural Support:

- Quality of life and quality of the environment in specialist inpatient settings for people with learning disabilities and autistic people.
- Understanding the research evidence behind Positive Behavioural Support in specialist forensic settings

#### Learning disability and autism:

- Understanding learning disability and autism in forensic specialist settings (in person or online) aetiology, characteristics and approaches to interventions for offending behaviour and behaviours that challenge.
- Mental Capacity and Capacity to Consent.

As well as sharing our expertise, such sessions are a good way of us mentioning this research to Trust staff in a different way. If you would like to discuss arranging a session please contact:

[cecilia@contacts.bham.ac.uk](mailto: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.

### What Our Lived Experience Advisory Panel member Lauren has to say

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 Lauren from the Lived Experience Advisory Panel for autistic people:

"I've actually found myself in a situation recently where I'm realising more and more how important the findings of this research might be to my future and the changes made to CETR's could be life changing / saving for me especially as things continue to deteriorate and my support needs are not able to be appropriately met. I would love to think that one day after this research and the recommendations & changes are hopefully implemented that Autistic and Learning Disabled individuals can feel that CETR's work as they should, are useful, effective, efficient and will make sure the most appropriate actions / supports are carried out to safeguard their wellbeing, best interests, safety and future, in the least restrictive ways, which sadly is not currently happening and when we're living in a world with such a mismatch of training levels and understanding this can put Autistic people at huge risk especially if they fall into crisis or experience placement breakdown."



Thank you for taking the time to read about this research

## Reminder - How to take part

### Those who have had a C(E)TR in the last 12 months

Complete a survey

[https://cecilia.org.uk/take-a-survey\\_](https://cecilia.org.uk/take-a-survey_)

### Everyone

Tell people about our research

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

### Trusts/organisations

Take part  
Attend monthly meetings  
Arrange a CPD session

[cecilia@contacts.bham.ac.uk](mailto:cecilia@contacts.bham.ac.uk)