Behavioural and Emotional Outcomes in Neurodevelopmental Disorders (BEOND)

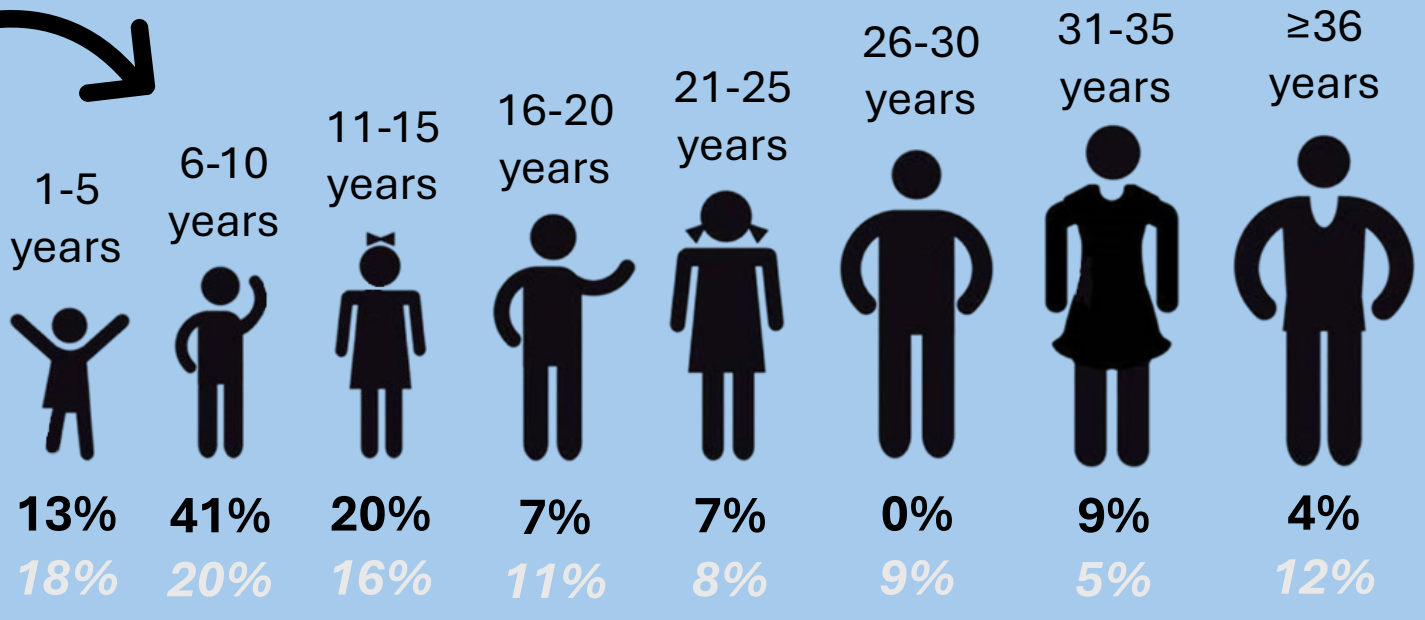
Study summary report

For the BEOND study, we recruited **627** parents and caregivers of people with rare genetic syndromes. These parents and caregivers represented **41** syndrome groups, one of which was SATB2-associated syndrome. We asked parents and caregivers to complete questionnaires about the person they care for. Below are some facts about the study.

We collected data for

46

people with SATB2-associated syndrome

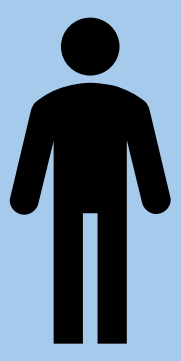


Who answered the questionnaires?

44 Mothers

1 Father

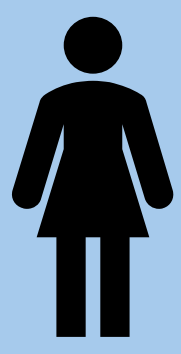
1 Carer



Male

65%

58%



Female

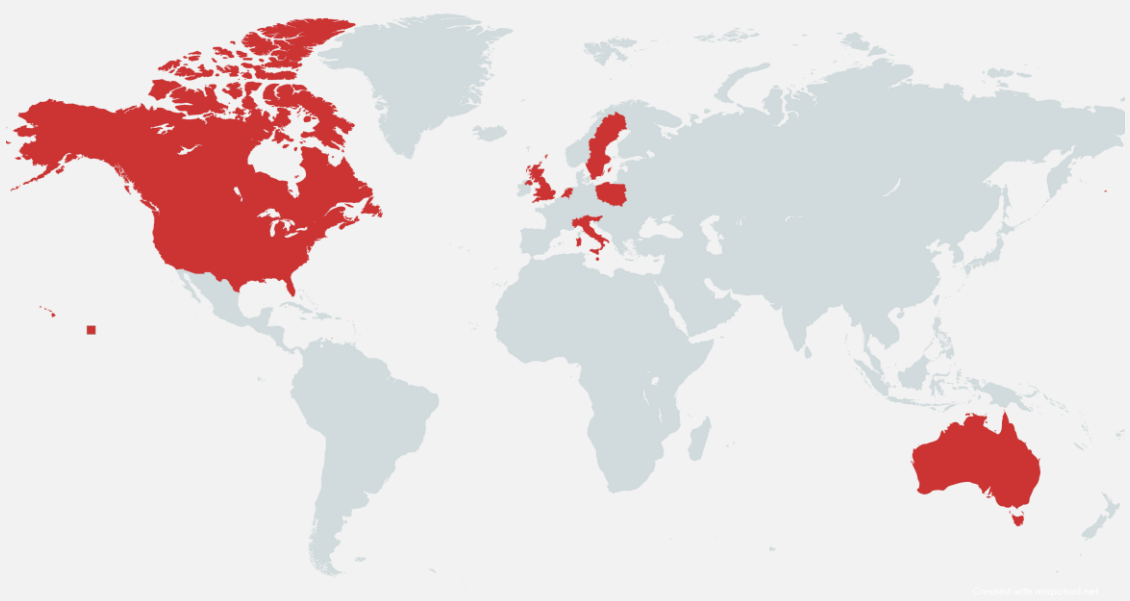
35%

42%

X People with SATB2-associated syndrome

X People across the other 40 syndromes

Where were families from?



- 13 United Kingdom
- 18 United States of America
- 4 Australia
- 2 Canada
- 2 Italy
- 1 Malta
- 3 Netherlands
- 1 Poland
- 1 Slovenia
- 1 Sweden

We collected data between

Nov 2022 – Jan 2024

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personalised feedback reports were sent to families summarising their data

Questionnaires completed online: **44**

Questionnaires completed via mail: **2**

The results of the study were shared at **15** conferences, syndrome-support events, and invited talks

The data you provided helped us to...

1 Develop a new questionnaire to assess anxiety in people with intellectual disabilities.

2 Investigate the importance of sleep for behaviour, health, and psychological outcomes in people with intellectual disabilities.

3 Further understand parent-carer wellbeing and how this relates to the support received from family doctors.

The BEOND study will open again to families in 2026!

Find out everything you need to know below.

Meet the team!

Prof Caroline Richards

Dr Hayley Crawford

Dr Joanna Moss

Dr Jane Waite

Dr Rory Devine

Dr Rory O'Sullivan

With BEOND 2026, we aim to:

Create a new measure of everyday functioning for people with rare genetic syndromes and intellectual disabilities.

Explore quality of life in people with rare genetic syndromes.

Investigate changes over time in sleep, anxiety, autism characteristics, and behaviour for people with rare genetic syndromes.

In response to families' feedback, we've made a few changes to BEOND 2026.

A 'skip' button has been added in case some questions are tricky to answer.

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The survey is now 50% shorter.

We streamlined our feedback report processes to ensure these are sent to families quicker.

What you need to know before taking part...

Who can take part?

All families with SATB2-associated syndrome are welcome to take part! We welcome families who previously took part in BEOND as well as new families.

What do I get for taking part?

All families that take part will receive a personalised feedback report which summarises their data. For families who took part in BEOND last time, we will link their past data with their current data.

Families will also be offered a £20 voucher upon completion of the survey.

What does taking part involve?

Parents/carers will complete a survey, either online or via a posted paper copy. The survey includes questions about your child/person you care for. A range of topics are covered such as health, behaviour, wellbeing, and cognition.

This information will remain confidential.

When will I be able to take part?

We intend to open the study to families in early 2026. There will be further updates towards the end of 2025.

Where can I find more information about BEOND 2026?

You can find out more about BEOND 2026 on the Cerebra Network for Neurodevelopmental Disorders website: https://www.cerebranetwork.com/beond

You can also email any queries to Dr Rory O'Sullivan at r.osullivan@bham.ac.uk