European Autism GEnomics Registry (EAGER)

What is EAGER?

EAGER is a research registry established as part of AIMS-2-TRIALS to support recruitment for future clinical trials and research studies, based on genetics, behavioural and health information, and individual preferences. The study ran from 2023–2025 and was developed through consultation with community representatives, including autistic people, family/carers of autistic people, parents/carers of people with rare genetic conditions, and representatives from European rare disease organisations.

EAGER aims to accelerate the development of more effective and personalised support by helping to identify and recruit people who may be eligible for future studies.

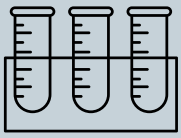
Participants

EAGER includes 1153 participants recruited across 12 sites in 8 European countries. Of those, 749 autistic individuals and 404 individuals with neurodevelopmental-associated rare genetic conditions are included. The age range is from 2 years and above.

Data Collected



Questionnaires: Participants completed a set of questionnaires to collect information about history of neurodevelopmental, mental health and physical health conditions. Questionnaires also include demographics, autistic traits, mental health traits, quality of life, along with participant priorities for future research.

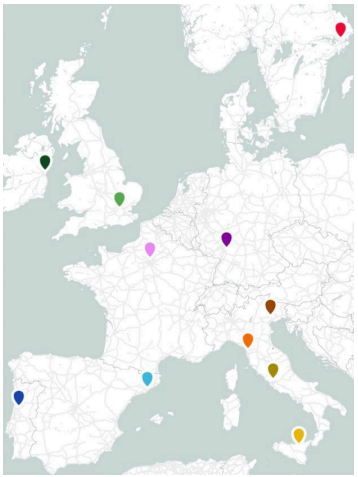


Biological samples: Participants also provided a saliva or blood sample. These samples are used to provide genetic information related to neurodevelopment.

Who is involved?

The centers involved in conducting the study include:

- UK: King's College London and Guy's and St Thomas' NHS Foundation Trust
- Germany: Heidelberg University Hospital
- Ireland: Trinity College Dublin
- Sweden: Karolinska Institute
- France: Assistance Publique – Hôpitaux de Paris
- Portugal: University of Coimbra
- Italy: Associazione Oasi Maria SS. Onlus, Fondazione Stella Maris, and Associazione La Nostra Famiglia Istituto Scientifico Eugenio Medea
- Spain: Hospital Clínic de Barcelona, and Fundació Sant Joan de Déu



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