

Data sharing information for participants

WHAT IS THE DATA BEING SHARED?

Data collected as part of the Longitudinal European Autism Project (LEAP), which included MRI brain scans, eye tracking measures, questionnaires, computer tasks and interviews.



You can read more about LEAP in our LEAP leaflet. Currently only data from the first time point of the study will be shared in this way (from 2013-2015) but there are also plans to share data collected later.

WHERE IS THE DATA GOING?

The AIMS-2-TRIALS external database is hosted on a platform called ELIXIR based at the University of Luxembourg ('ELIXIR-LU').



To ensure data is safe and protected the database uses GDPR compliant European systems and practices. GDPR is a European data protection law.

HOW DO RESEARCHERS ACCESS



Those wanting access will need to apply for LEAP data access through ELIXIR Luxembourg.



They must read and agree to the AIMS-2-TRIALS data access information, procedure and policy.



These documents have been developed with input from a group of autistic people and parents of autistic people (called A-Reps).



Data are only available to researchers beyond the AIMS-2-TRIALS Consortium from participants who consented to this.

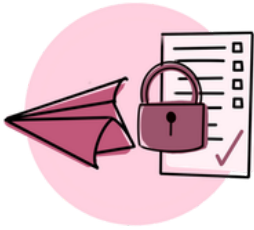


The AIMS-2-TRIALS LEAP Project Review Committee will review all project proposals. This committee includes researchers and autism community members. They will check the details of the proposal, if it meets our project ethical principles and that it is in line with what participants consented to.



Researchers applying for access to the data must consider the ethics of their project

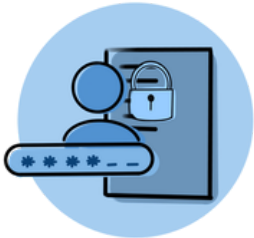
DATA PRIVACY



Your data will only be shared if agreement was given in the consent forms signed by you (or your parent where appropriate).



Your data will remain subject to the local rules and privacy policies of the research team where your data was collected.



As soon as you were included in the study, you were assigned a number, meaning your data became securely 'coded'. All study assessments use these codes, never your name.



For added data security, when your data was sent from research sites (the place where you took part in the study) to the internal database, a second secure code was given (e.g. 557465789589). Data from this database will then be shared with the external database.



Personal data like addresses, names, and emails will NOT be shared, only coded data.



If researchers who wish to access AIMS-2-TRIALS data do not follow the guidelines, their access data (including any future requests) will be stopped.

HOW CAN I WITHDRAW CONSENT?



If you no longer wish for your data to be shared, you can withdraw your data from the external database at any time. You do not have to give us a reason.



This will not affect your medical care or legal rights in any way.



However, it will not be possible to withdraw your data from projects that have already taken place.

WHERE TO GO WITH QUESTIONS AND CONCERNS?

If you have questions or wish to change your consent preferences, please contact your local research team (where you took part in the study):

London - eu-aims@kcl.ac.uk or info-compliance@kcl.ac.uk

Cambridge - cambridgeleap@medschl.cam.ac.uk or dpo@admin.cam.ac.uk

Nijmegen - aims.leap3@gmail.com or gegevensbescherming@radboudumc.nl

Mannheim - ZI_AIMS2trials_Team@zi-mannheim.de or datenschutzbeauftragter@zi-mannheim.de

If you look part in Rome or Utrecht the data is not being shared at this time.

Illustrations by Scarlett Li-Williams