

Australian Autism Biobank follow-up cohort pilot study



Background

The Australian Autism Biobank is a long-awaited resource that will aid in increasing our knowledge of the autism spectrum and co-occurring conditions.



Who took part?

Participants from the Australian Autism Biobank who consented to be contacted about follow-up or further studies.



Aim

1. Determine the return rate for follow-up study by assessing:
 - a. The rate of previous participants who consent to recontact
 - b. Percentage of study population who consent to be recontacted and who are able to be located
 - c. Percentage of study population who can be contacted who consent to participate in follow-up.
2. Obtain follow-up data on consenting participants for blood and/or saliva, questionnaires and face-to-face assessments, and pilot data for eye-tracking.
3. Comparison of sample quality obtained from Australian Autism Biobank (transport prior to processing) and samples processed on site.



How we did the research



We called families who consented to be contacted about future research and asked whether they would like to take part in a follow-up research project.



We told families it would involve a cognitive and autism assessment similar to the Australian Autism Biobank assessments and they would be given a report.



Families were asked to fill in questionnaires about their child. The assessments and questionnaires would help us to understand how children on the spectrum progress over a period of time.



Families were all asked if their child could provide a blood or saliva sample.

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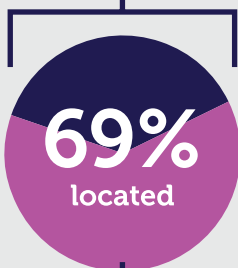
What did we find?



93% of families who participated in the Australian Autism Biobank in NSW agreed to be contacted about future studies.



Research follow-up is best done when a child is already visiting the doctor or hospital for a medical purpose.



Of these families, we were able to locate and contact 69% that fit the study criteria*.



Questionnaires should be completed online prior to attendance to reduce appointment time and administration.



58% of families who were contacted agreed to participate in the follow-up cohort pilot study.



Eye tracking tasks should be administered on portable devices to improve uptake and quality of data collection.



Families should be provided with the option to attend the nearest pathology lab for a biological sample collection.



Obtaining quality control data on the biological sample was expensive because of the relatively low number of samples.

*Families with a child aged 2-17 years and over 12 months between their participation in the Australian Autism Biobank and the follow-up



Who did the research?



AutismCRC
Biobank



UNSW
SYDNEY

Professor Valsamma Eapen, Dr Anne Masi and Feroza Khan

Acknowledgments

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Find out more

Download the evaluation report and executive summary on the Autism CRC website:

autismcrc.com.au/reports/BiobankFollowUp

Contact the Biobank team on:

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