



Australian Autism Biobank follow-up cohort pilot study

EXECUTIVE SUMMARY

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UNSW
SYDNEY



AutismCRC
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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, when speaking of adults we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity. Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector, and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

Executive Summary

1.1 Study aims

1. Determine the return rate for follow-up study:
 - a. Determine rates of previous participants who consent to recontact;
 - b. Ascertain percentage of study population who consent to be recontacted who are able to be located;
 - c. Determine 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.

1.2 Findings

- Rate of previous participants who consent to recontact: 93%
- Percentage of study population who consent to recontact who were able to be located: 69%
- Percentage of study population who were contacted and agreed to participate in the follow-up cohort pilot study: 58%.

Assessments were conducted on 63 children out of a recruitment target of 65. Two families were booked but could not attend the assessment. Additional families were not contacted once the number of families corresponding to the recruitment target were booked for assessments, so the number of assessments was slightly less than the recruitment target.

1.3 Limitations

- 31% of study population were unable to be contacted after multiple attempts
- It is possible that those who were wanting a report for National Disability Insurance Scheme (NDIS) purposes may have been highly motivated to participate leading to a possible bias
- Obtaining a blood sample in this cohort without a clinical purpose was challenging
- It was not possible to obtain quality control data on the biological sample due to the low number of samples and the high costs to undertake this component of the workflow.

1.4 Implications for research and practice

Despite the large percentage of participants agreeing to be recontacted about future studies, achieving a high return rate for follow-up assessment most likely requires the face-to-face follow-up to be aligned with a clinical service (e.g. follow-up at start of school or for an assessment that would result in a report for NDIS or other purposes).

1.5 Key recommendations

1. It is recommended that a "research" follow-up should be combined with a clinical face-to-face attendance for a clinical reason or purpose.
2. All questionnaires are completed online prior to attendance to reduce appointment time and data entry related tasks.
3. Eye tracking tasks should be administered on portable devices to improve uptake and quality of data collection.
4. Families should be provided with the option to attend the nearest pathology lab for a biological sample collection.
5. Negotiations with the NSW Health Statewide Biobank (or equivalent state services) take place at study conception and design phase to ensure features such as quality control are incorporated and priced to ensure budgetary allowances are made.



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Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Independence

Guided by evidence based research, integrity and peer review



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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