

Pricing Schedule – Australian Autism Biobank

1. Background

The Autism CRC is a not for profit Company with DGR status. We are funded by the Commonwealth Government Department of Industry and Innovation through the Cooperative Research Centres (CRC) Program and our partners.

The Australian Autism Biobank (AAB) has recruited 1152 children (2 – 17 years old) with a diagnosis on the autism spectrum, 263 non-autistic siblings, and 150 non-autistic unrelated children as controls. Parents of the children on the spectrum were also recruited with 847 mothers and 548 fathers. There was also a small group of 16 children recruited who had been queried for but ended up not qualifying for a diagnosis of autism.

The full protocol paper for the Australian Autism Biobank protocol has been published¹ and is available at: <https://rdcu.be/5lbE>

This Pricing Schedule will be reviewed in June 2019.

2. Participants

The Australian Autism Biobank has an inclusive recruitment strategy. This caters for the multifactorial nature of autism, the unknown genetic and environmental contributions and the range of research projects that may be encompassed in the future. The only criteria for inclusion as a child participant on the autism spectrum is a confirmed diagnosis of ASD. Any known comorbidities have been noted in The Family History Questionnaire or during the parental interview.

The three control groups: siblings, controls (unrelated), and ASDQ are similarly inclusive in recruitment strategy. Information is stored in The Child Development Questionnaire capturing information regarding comorbidities for these groups for researchers to access. For example, antibiotic use within the last 6 months is not an exclusion criteria, but this information will be available for researchers if required.

Participant Type	Inclusion Criteria	Exclusion Criteria
Children on the Spectrum	<ul style="list-style-type: none"> 2 – 17 years old. Diagnosed with ASD according to the DSM criteria. 	<ul style="list-style-type: none"> Parents with insufficient English or cognitive capacity to provide informed consent.
Non-autistic Siblings	<ul style="list-style-type: none"> 2 – 17 years old. Sibling of a child with an ASD diagnosis who is enrolled as an ASD proband/participant in the Australian Autism Biobank. 	<ul style="list-style-type: none"> Parents with insufficient English or cognitive capacity to provide informed consent. Diagnosis of ASD.

Non-autistic Controls	<ul style="list-style-type: none"> • 2 – 17 years old. 	<ul style="list-style-type: none"> • Parents with insufficient English or cognitive capacity to provide informed consent. • Diagnosed with, referred for or suspected of having ASD.
Queried for an autism diagnosis	<ul style="list-style-type: none"> • 2 – 17 years old. • Referred for testing or suspected of ASD at some stage but did not meet criteria for diagnosis. 	<ul style="list-style-type: none"> • Parents with insufficient English or cognitive capacity to provide informed consent. • Diagnosis of ASD (if this happens subsequently to testing as ASDQ database will be updated to reflect the record as ASD not ASDQ).

3. Fees for Access

There are three types of fees payable for applications to access Australian Biobank data and / or samples:

- Application fee: to offset the costs of reviewing the application and associated administration.
- Extraction costs: to pay for the costs of data /material retrieval and transfer.
- Cost recovery: of the original data and sample collection and ongoing administration of the Biobank.

All prices are exclusive of any relevant taxes, unless otherwise stated.

a. Application fee

The application fee is \$500 + GST which covers administrative costs of running the Access Committee and reviewing the application.

All applications are assessed by the Autism CRC Access Committee in the first instance and as required independent scientific reviewers are also consulted to provide feedback on the applications received. The Autism CRC Access Committee comprises Board, researcher, executive and autistic adult representatives. An independent Biobank expert also sits on the Committee.

Applications are assessed against a range of criteria including scientific merit of proposals, ethical clearance, consistency of aims with donor consent, and most importantly likelihood of transformational outcomes for the autistic community. In addition the Committee will consider the conservation of supply of biospecimens within the Biobank.

b. Extraction costs

The costs of extracting the samples and / or data will be charged at \$250 + GST per hour.

The transfer and transport costs will vary for each study and be confirmed at the time. Where your shipping destination requires, you must provide us with all documentation to show that you have the relevant import permits for human blood products and other biospecimens.

c. Cost Recovery

Cost recovery applies to samples and data collected and administered as part of the Australian Autism Biobank. Prices are set to enable recovery of the costs of collecting the data and also facilitate maintenance of and stewardship of the resource now and into the future.

Recovery of costs can be varied by the committee in keeping with the considerations outlined in BIO001 – Biobank Access and Data Sharing Policy. For example in circumstances where technical considerations regarding specificity, reproducibility or sensitivity dictate that a larger sample set be analysed, the Access Committee may vary the amounts required for cost recovery in light of the Australian Autism Biobank as a research resource and the interests of the autistic, autism and research communities.

All prices are exclusive of any relevant taxes, unless otherwise stated.

i. Biological Samples

Costs are based on the cost of collecting the samples and the ongoing costs of administering the asset.

	Plasma (µl)	Serum (µl)	DNA (µl)	Stool (µl)	Urine (µl)	RNA (Paxgene)
Adult	2,000	1,000	400			1 tube
Child	2,000	1,000	200	8,000	16,000	1 tube
Aliquot size	100	100	50	200	200	1
Full Cost Recovery (AUD)	\$70	\$70	\$70	\$40	\$7	\$70

ii. Phenotypic Data

Phenotypic data are costed differentially for face-to-face assessments and questionnaires. A marginal cost structure is used based on the number of children on the spectrum requested in the study design. Siblings and controls are costed according to the lowest marginal cost for children on the spectrum.

Example. A Study requests Cognitive tests on 450 children on the spectrum and 100 siblings.

First 150 children on spectrum	\$20 x 150	\$3,000
Subsequent 300 Children on spectrum	\$5 x 300	\$1,500
100 Siblings	\$5 x 100	\$500
Total		\$5,000



Instrument	Availability (X)				First 150	Subsequent up to 500	Over 500
	Parent	Child on spectrum	Sibling	Control	Calculated based on number of children on spectrum in study		
Diagnostic Assessments							
Autism Diagnostic Observation Schedule – 2 (ADOS) (Module 1, 2, 3, or 4)		X			\$20	\$5	\$2
The Developmental, Diagnostic, and Dimensional Interview (3DI)		X			\$20	\$5	\$2
Cognitive Testing							
Mullen Scales of Early Learning (MSEL) (2 – 5 yrs 11 months) / Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV) (6 – 17 years)		X	X	X	\$20	\$5	\$2
Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II)	X				\$20	\$5	\$2
Questionnaires							
Vineland Adaptive Behaviour Scales Second Edition (Vineland II)		X			\$5	\$2	\$1
Family History Questionnaire (FHQ)		X			\$5	\$2	\$1
Child Development Questionnaire (CDQ)			X	X	\$5	\$2	\$1
Children’s Communication Checklist (CCC)		X			\$5	\$2	\$1
Communication Checklist – Adult (CCA)	X				\$5	\$2	\$1
Social Responsiveness Scale			X	X	\$5	\$2	\$1
Short Sensory Profile – 2		X			\$5	\$2	\$1
Physical / dietary characteristics							
Food Frequency Questionnaire		X	X	X	\$5	\$2	\$1
Tanner scales		X	X	X	\$5	\$2	\$1
Clinical Proforma	X	X	X	X	\$20	\$5	\$2



iii. Biological Data

It is anticipated that genomic biological data will start to become available on samples from the dataset from July 2019.

4. Further Queries

If you have additional questions about the scientific objectives of your proposal and their consistency with participant consent, the objectives of the Autism CRC or applying for access to access the Australian Autism Biobank in general please contact biobank@autismcrc.com.au.

Please send your application electronically to biobank@autismcrc.com.au.

5. References

1. Alvares, G. A. *et al.* Study protocol for the Australian autism biobank: an international resource to advance autism discovery research. *BMC Pediatr.* (2018). doi:10.1186/s12887-018-1255-z

DOCUMENT CONTROL

Issue: December 2018

Approved: ACRC Access Committee

Review: June 2019

Responsible: Chief Research Officer