



## Australian Autism Biobank: Fee schedule

Autism CRC is a not-for-profit Company with DGR status. Established in 2013, under the Commonwealth Government's Cooperative Research Centres Program, Autism CRC is the independent national source of evidence for best practice.

### Background

Autism CRC's Australian Autism Biobank recruited 1,154 autistic children (2 – 17 years old), 261 non-autistic siblings, and 150 non-autistic non-related children. Parents of the autistic children were also recruited; 774 mothers and 523 fathers. A further 15 children recruited showed signs of autism but did not qualify for a diagnosis of autism.

The full protocol paper for the Australian Autism Biobank protocol has been published<sup>1</sup> and is available at: <https://rdcu.be/5lbE>

### Participants

The Australian Autism Biobank had an inclusive recruitment strategy, as outlined in Table 1. 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 an autistic child participant was a confirmed diagnosis of autism. Any known comorbidities were noted in The Family History Questionnaire or during the parental interview.

The non-autistic groups were 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 was not an exclusion criterion, but this information will be available for researchers if required.

Not all data and samples are available for each individual participant, please contact the Australian Autism Biobank directly to discuss the number of samples/items available for your particular requirements (for example the number of autistic children for whom a stool sample, Food Frequency Questionnaire and Autism Diagnostic Observation Schedule – 2 (ADOS) assessment are all available).



Table 1: Participant inclusion and exclusion criteria

| Participant type                                    | Inclusion criteria  | Exclusion criteria   |
|---|---|--|
| <b>Autistic children</b>                            | <ul style="list-style-type: none"> <li>2 – 17 years old</li> <li>Diagnosed with autism according to the DSM criteria</li> </ul>   | <ul style="list-style-type: none"> <li>Parents with insufficient English or cognitive capacity to provide informed consent</li> </ul>  |
| <b>Non-autistic siblings</b>                        | <ul style="list-style-type: none"> <li>2 – 17 years old</li> <li>Sibling of an autistic child with who is enrolled as an autism proband/participant in the Australian Autism Biobank</li> </ul> | <ul style="list-style-type: none"> <li>Parents with insufficient English or cognitive capacity to provide informed consent</li> <li>Diagnosis of autism</li> </ul>   |
| <b>Non-autistic non-related children (controls)</b> | <ul style="list-style-type: none"> <li>2 – 17 years old</li> </ul>  | <ul style="list-style-type: none"> <li>Parents with insufficient English or cognitive capacity to provide informed consent</li> <li>Diagnosed with, referred for or suspected of being autistic</li> </ul>   |
| <b>Queried for an autism diagnosis (ASDQ)</b>       | <ul style="list-style-type: none"> <li>2 – 17 years old</li> <li>Referred for testing or suspected of autism at some stage but did not meet criteria for diagnosis</li> </ul>                   | <ul style="list-style-type: none"> <li>Parents with insufficient English or cognitive capacity to provide informed consent</li> <li>Diagnosis of autism (if this happens subsequently to testing as ASDQ database will be updated to reflect the record as autism not ASDQ)</li> </ul> |

## Fees for access

There are three types of fees payable for applications to access Australian Autism 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. These fees are outlined in Appendix A.

### Application fee

The application fee covers the 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 or autism community representatives. An independent Biobank or longitudinal study 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 depletion of samples and responsible conservation of supply of biospecimens within the Biobank.

### **Extraction and data support costs**

All successful applications will be charged a fee for data extraction, access and other supports. Additional support beyond the initial time allocated will be charged at a set hourly rate.

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.

### **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 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 *Biobank and Databank 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 taking into consideration the Australian Autism Biobank as a research resource and the interests of the autistic, autism and research communities.

Any prices are exclusive of any relevant taxes.

### **Further information**

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](mailto:biobank@autismcrc.com.au).

Register your Expression of Interest through the Australian Autism Biobank website at [autismcrc.com.au/biobank](http://autismcrc.com.au/biobank).



## References

1. Alvares GA, Dawson PA, Dissanayake C, Eapen V, Gratten J, Grove R, Henders A, Heussler H, Lawson L, Masi A, Raymond E, Rose F, Wallace L, Wray NR, Whitehouse AJO; Australian Autism Biobank team. Study protocol for the Australian Autism Biobank: an international resource to advance autism discovery research. *BMC Pediatr.* 2018 Aug 27;18(1):284. doi: 10.1186/s12887-018-1255-z. PMID: 30149807; PMCID: PMC6112136.

# Appendix A: Fee schedule

## 1. Application fee

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

## 2. Extraction and data support costs

All approved applications will be charged a fee of \$1,000 + GST, providing up to 4 hours of support around data extraction, access and other supports. Additional supports will be charged at \$250 + GST per hour. The transfer and transport costs will vary for each study and be confirmed at the time.

## 3. Cost recovery

The following tables may not include all available data and samples.

### Biological samples

|                                 | Plasma (µl) | Serum (µl)  | DNA (µl)    | RNA (Paxgene) | Stool (µl)  | Urine (µl) |
|---------------------------------|-------------|-------------|-------------|---------------|-------------|------------|
| <b>Adult (total available)</b>  | 2,000       | 1,000       | 400         | 1 tube        | N/A         | N/A        |
| <b>Child (total available)</b>  | 2,000       | 1,000       | 200         | 1 tube        | 8,000       | 16,000     |
| <b>Aliquot size</b>             | 100         | 100         | 50          | 1             | 200         | 200        |
| <b>Full cost recovery (AUD)</b> | <b>\$70</b> | <b>\$70</b> | <b>\$70</b> | <b>\$70</b>   | <b>\$40</b> | <b>\$7</b> |

## Phenotypic data

| Instrument   | Availability (X) |         |         |                                | Calculated based on number of autistic children in the study |                |          |
|--|------------------|---------|---------|--------------------------------|--|----------------|----------|
|  | Parent           | Proband | Sibling | Non-autistic non-related child | First 150  | Next up to 500 | Over 500 |
| <b>Diagnostic assessments</b>  |                  |         |         |                                |  |                |          |
| 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      |
| <b>Cognitive testing</b>   |                  |         |         |                                |  |                |          |
| Mullen Scales of Early Learning (MSEL) (2-5 yrs 11 months)                     |                  | X       | X       | X                              | \$20   | \$5            | \$2      |
| Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV) (6-17 yrs) |                  | X       | X       | X                              | \$20   | \$5            | \$2      |
| Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II)          | X                |         |         |                                | \$20   | \$5            | \$2      |
| <b>Questionnaires</b>  |                  |         |         |                                |  |                |          |
| 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      |
| Broad Autism Phenotype   | X                |         |         |                                |  |                |          |
| Social Responsiveness Scale  |                  |         | X       | X                              | \$5  | \$2            | \$1      |
| Short Sensory Profile – 2  |                  | X       |         |                                | \$5  | \$2            | \$1      |
| Early Concerns   |                  | X       |         |                                | \$5  | \$2            | \$1      |
| Oral Health Survey   |                  | X       |         |                                | \$5  | \$2            | \$1      |
| <b>Physical / dietary characteristics</b>                                      |                  |         |         |                                |  |                |          |
| Food Frequency Questionnaire   |                  | X       | X       | X                              | \$5  | \$2            | \$1      |
| Tanner scales  |                  | X       | X       | X                              | \$5  | \$2            | \$1      |
| Clinical Proforma  |                  | X       | X       | X                              | \$20   | \$5            | \$2      |

## Genomic data

| Instrument  | Availability (X) |         |         |                                | Full cost recovery |
|---|------------------|---------|---------|--------------------------------|--------------------|
|   | Parent           | Proband | Sibling | Non-autistic non-related child | Flat rate          |
| Whole Genome Sequencing   | X                | X       | X       |                                | \$10,000           |
| Genomic Wide Association Study & Single Nucleotide Polymorphism | X                | X       | X       | X                              | \$1,000            |
| Metagenomic (source: Stool)                                     |                  | X       | X       | X                              | \$1,000            |
| Methylation (source: Buffy coat)                                |                  | X       | X       | X                              | \$1,000            |
| Polygenic scores  |                  | X       | X       | X                              | \$1,000            |

## Other

| Instrument        | Availability (X) |         |         |                                | Full cost recovery |
|-------------------|------------------|---------|---------|--------------------------------|--------------------|
|                   | Parent           | Proband | Sibling | Non-autistic non-related child |                    |
| Cortisol (Hair)   |                  | X       | X       | X                              | Apply for price    |
| Melatonin (Urine) |                  | X       |         |                                | Apply for price    |