

Large-Scale Data Sharing

To do more powerful research, it is helpful for researchers to share information they get from studying human samples. They do this by putting it into one or more scientific databases, where it is stored along with information from other studies. Researchers can then study the combined information to learn even more about the conditions they are researching. If you agree to take part in this study, some of your genetic and health information might be placed into one or more scientific databases. There are many different kinds of scientific databases; some are maintained by universities, some are maintained by the federal government, and some are maintained by private companies. A researcher who wants to study the information must apply to the database. Different databases may have different ways of reviewing such requests. Researchers with an approved study may be able to see and use your information, along with that from many other people. Your name and other information that could directly identify you (such as address or Medicare number) will never be placed into a scientific database. However, because your genetic information is unique to you, there is a small chance that someone could trace it back to you. The risk of this happening is very small, but may grow in the future. Researchers will always have a duty to protect your privacy and to keep your information confidential.

Withdrawing consent

You are free to stop taking part in this study at any time. If you choose to withdraw consent, we will destroy all of the information we have collected, including the biological samples.

What happens to the results of the study?

Individual results

We would not normally communicate individual results or anticipated findings (related to Autism) from this study to anyone. You should remain under the care of their usual practitioner/s. Researchers must study samples and information from many people over many years before they can know if the results have meaning. We will not give the results to your doctor. We will not put them on your medical record.

We will also not report any Incidental Findings (not related to autism) from the genetic studies that are carried out on your samples. Incidental Findings are those which are unrelated to the research but which may come up when genome sequencing is undertaken. With advances in genome sequencing, it is unknown how and to what extent each individual's samples will be analysed. If you want to obtain clinical predictive genetic testing then you should discuss that with your usual doctor.

There is a small chance that researchers could discover something that might be important to your health or medical care right now. If this happens, we will contact you to see if you want to learn more.

We will not provide you any anticipated (related to ASD) or incidental (not related to autism) findings from the genetic studies that are carried out on your samples. With advances in genome sequencing we are unable to track genetic findings unrelated to our core research goals of genetic and behavioural differences in autism. If you want to obtain clinical predictive genetic testing then you should discuss that with your usual doctor.

Statutory or contractual duties may require you to disclose results of genetic tests or analysis to third parties (for example, insurance companies, employers, financial and educational institutions), particularly where results provide information about health prospects. If the results of the participant's genetic tests are not available to you or you choose not to receive the results, then any future requests for insurance will not be affected by participating in this research. If you do obtain the results of the genetic tests, you may then be obliged to disclose this on any future application for insurance or employment, should it be requested.

Group results

We will use the information we collect to publish scientific reports with important discoveries. We will also communicate our findings to the public through presentations. Published reports on the results will not mention any identifying information, such as names or addresses.

Who do I contact if you have any concerns about the running of the study?

Approval to conduct this research has been provided by the University of Western Australia, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to participate, may raise any questions or issues with the researchers at any time.

In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics Office at the University of Western Australia on (08) 6488 3703 or by emailing to humanethics@uwa.edu.au.

All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.

Who do I contact for more information?

If you would like any more information about this study, please do not hesitate to contact the Study Coordinator, Ms Alexis Harun. She will be very happy to answer your questions:

Alexis Harun | Study Coordinator
 T | (08) 9489 7927 E | autism.research@telethonkids.org.au

Thank you for your time.

PARTICIPANT INFORMATION SHEET

Beyond childhood:

Understanding autism in adolescence and adulthood



Why are we doing this study?

The last four decades has seen a substantial amount of research that has advanced our understanding of autism. However, there is still a large gap in knowledge about what happens when children with autism reach adolescence and adulthood.

A valuable resource in Western Australia is the WA Autism Register, which was started in 1999. Data were collected at the time of diagnosis, including diagnostic information, parental consent for their child's details to be used, and also an opportunity for parents to agree to be contacted in the future about new research projects.

We are now seeking to make another important advance by recontacting individuals on the Autism Register who gave their contact details at the time of their child's diagnosis. Our aim is to see how children have changed since they were diagnosed, and understand their achievements and challenges over time.

We hope that this research will help inform how we can help individuals on the autism spectrum reach their full potential.

Who is carrying out this study?

The study is being conducted by a team of researchers based in Perth and Brisbane. The Perth researchers are from the Telethon Kids Institute and Curtin University. The Brisbane researchers are from the University of Queensland.

The study leader is Professor Andrew Whitehouse, who is based at the Telethon Kids Institute, Perth.

Why have I been invited to take part?

You have been informed about this study because you have been diagnosed with autism and your parents/caregivers elected for their contact details to be lodged with the Western Australian Autism Register at the time of diagnosis.

We are contacting all caregivers lodged to the Autism Register who provided consent to be contacted for future research.

What will happen if I agree to take part?

You will have been informed about this study by a member of the Autism Register. Once you or your parent(s)/caregiver have indicated an interest to know more about this study (either by return mail, email or telephone), your parents/caregiver will be telephoned by a study team member, who will describe to you the study requirements.

This study has three parts. Participation in any part is **OPTIONAL**. It is possible to participate in one, two or three parts of the study.

Part 1:

The first part of the study is the completion of questionnaires which we will ask your parents/caregivers to complete. They are able to complete the questionnaires either on the internet or on paper, whichever is most convenient for them. We anticipate that this will take no longer than 1.5 hours.

The questionnaires will ask your parent(s)/caregiver about your developmental and medical history, including your schooling, employment, social relationships and mental health. Our aim is to obtain a good understanding of the achievements and challenges you have encountered since diagnosis.

We will also ask if you would be able to complete a questionnaire based on yourself. If you consent to do so, we will provide you with a questionnaire (either on the internet or in paper form). These questionnaires will take no longer than 1 hour to complete.

Part 2:

The second part of the study is a face-to-face session at the Telethon Kids Institute.

During this session, we will conduct a short interview with your parents/ caregiver regarding your developmental and medical history. We will also involve you in a number of behavioural assessments that measure problem solving, language and social skills. This will take approximately 2.5 hours.

We would also like to collect

- 1 A 3D facial photograph: There is increasing evidence that the shape and dimensions of a person's face may provide important information about the causes of developmental difficulties. The 3-dimensional photograph will enable us to examine facial dimensions with sub-millimetre precision.
- 2 Information from health and medical professionals who have previously assessed you. We will request permission from you to discuss your development with these clinicians.
- 3 Medical records: We would like to review your medical records that are stored in hospitals in your state. This will help us understand the link between early child development and physical health.

Part 3:

A third part of this study is the collection of blood from yourself, and your biological parents. From the blood samples we will be able to examine genetic material (DNA) as well as other biological information. This information will help us to understand more about what biological factors that may contribute to the development of autism, and how autism can change across the life-course.

Each blood sample will be around 20ml (four teaspoons). Blood will be taken from the arm, and a small 'prick' sensation would be felt as the needle enters the skin. The blood will then fill a test tube for around 10 seconds. The procedure will take around 10 minutes and will be carried out by qualified and experienced staff.

These samples will be stored in a secure freezer at the Telethon Kids Institute.

Your family can participate in as much or as little of this study as you like.

What will happen with the blood samples?

Blood comprises many substances and we will be extracting three elements from each sample: DeoxyriboNucleic Acid (DNA), peripheral blood mononuclear cell (PBMC) and plasma. Each element will be stored in secure freezers at the Telethon Kids Institute for later analysis. DNA is the chemical substances that carries the genetic information required for the reproduction, growth, development and function of the human body, including the brain. The DNA will be analysed in search of genes of possible importance to autism and related disorders. We will also investigate the PBMCs to examine immune function, and plasma for exposures to common chemicals in the environment.

What are the possible disadvantages in taking part?

The questionnaires ask some personal information about your family. You are able to answer as many of the questions as you like. Importantly, all information is kept confidential and secure.

Some discomfort may be experienced when a blood sample is taken. A local anaesthetic cream can be applied beforehand to minimise pain. Afterwards a small bruise at the site of blood collection may develop. The procedures will be carried out by qualified staff at the Telethon Kids Institute.

The DNA analysis may identify instances where the father is biologically unrelated to you. These results will be kept strictly confidential and not disclosed to anyone outside of the research team, unless there is written agreement from both the mother and father of the individual with autism.

There is no cost for taking part in this study. If you take part in Part 2 of this study, we will reimburse your family for your travel costs (up to \$20), also you for your time (\$50).

What are the possible benefits in taking part?

The information we get from this study will be very important in helping us understand autism across the life-course. In particular, the study will help us identify what factors in childhood may predict adult outcomes, and how can we better target our interventions and supports. Your family could be involved in an important scientific advance.

Storage of information

Research into child development is complex and these studies can take many years. We plan to keep all information collected for this study.

As soon as you enter the study, you and your family will be given a code number. All of the information that we collect will be labelled with this code number, and NOT your name. This will ensure your information is kept private.

The information from the questionnaires (Part 1) and behavioural tests (Part 2) would be kept in a locked filing cabinet at the Telethon Kids Institute. This information will also be stored in an electronic database. This database will be secured with passwords, and only seen by the researchers in this study. Sections of the behavioural assessment (Part 2) will be video recorded for scoring purposes and will be destroyed once the behavioural assessment is scored.

The blood samples (Part 3) we collect will also be labelled with a code number. DNA, PBMCs and plasma will be extracted from the samples at the Telethon Kids Institute, and then stored in a locked freezer at the site.

If you decide to donate biological samples you and your family are able to request at a later date that these samples are removed from the biobank and destroyed.

Use of your information

The information we collect is very valuable to the autism research community. The information we get from the surveys, behavioural tests and biological samples will be used by our research team to understand the development of individuals with autism from childhood to adulthood. Your samples will NOT be used for research involving reproductive technology, human embryos, or cloning.

We would also like the information we collect from you to be available to other researchers around Australia and the world for collaborative research purposes. Sharing information between research groups is critical to making research advances, and we would like this study to be part of this important process. We will only ever do this when we are sure that ethical and privacy approvals are in place.

There may be occasions when the data we collect (including genetic data) are published along with our research articles. Your data will always be labelled with a code, and no identifying information (names, addresses) will be revealed. The facial photos will not be shared beyond our study team.

Access to the blood samples (including DNA, PBMCs and plasma) will be managed the study team. The team will only ever allow other researchers to use the samples without identifying information if they have ethical and privacy approvals, and where there is a clear potential benefit of the proposed research to the community.

