

Information booklet for Parents/Caregivers

Background Information

The Online Autism Register collects information on everyone who receives a new diagnosis of an Autism Spectrum Disorder (ASD) in Western Australia.

Clinicians involved in the diagnostic process are encouraged to send diagnostic information to the Online Autism Register at the time of diagnosis.

The WA Register for Autism Spectrum Disorders has been running since 1999 with clinicians sending diagnostic information via paper forms. Since 2017 the WA Register has transitioned to an 'Online Autism Register'. The WA Autism Register was created with the purpose of knowing how many children are diagnosed in WA each year and increasing our knowledge of ASD.

Why has my family been chosen to participate?

Your family is receiving this information booklet because your child has received a diagnosis of ASD.

What sort of information is kept on the Online Autism Register?

The Online Autism Register will store de-identified information from your child's diagnostic assessments of language, adaptive behaviour and cognition. This information will be received directly by the Online Autism Register. There will also be an opportunity for you to provide extra information to the Online Autism Register such as contact details and consent to be contacted about future research. Your clinician will provide you with a URL weblink to a secure webpage to do so.

How do I contribute further information to the Online Autism Register?

At the time of diagnosis your clinician will enter your child's diagnostic information including some identifiable information such as your child's name, date of birth and gender. This information will only be entered for the purpose of creating an alpha numeric ID code. Your child's identifiable information will then be removed.

Should you wish to provide consent to have your contact information stored on the Online Autism Register, please visit www.telethonkids.org.au/autismregister. On this website you will be directed to the Autism Register Portal.

On this webform you will be asked to provide consent and enter your child's name, date of birth and gender. This commonly used process will allow for a duplicate alpha numeric ID code to be created similar to when your clinician lodged information. This will allow the Autism Register to link your contact details with your child's diagnostic information.

Following this process, the webform will direct you to enter your contact details (name, preferred contact number, email and/or postal address). You may provide as little or as much of this information as you would like. Entering this information will give you the opportunity to be contacted about future research opportunities. The Autism Register will only contact you using your preferred contact details for future projects that the Autism Register is involved in.

Uses and Aim of the Register

The Online Autism Register aims to provide data and information to assist with:

- Knowing how many people are diagnosed in Western Australia each year
- Increasing our knowledge of ASD
- Understanding the possible reasons behind the world-wide trend of increasing numbers of people being diagnosed
- Helping to guide the planning of local resources to cater for the needs of individuals with ASD as well as their families and carers.

Storage, access and use of information collected

The information stored in the Online Autism Register will be valuable to the autism research community. This Online Autism Register will be an ongoing data collection process. The data received online held securely behind firewalls within the Telethon Kids Institute. Any person wishing to access data for research purposes or otherwise, can have access to tabulated data on request, and for more detailed data must have ethical approval from a recognised WA-based ethics committee and a 'Data Access Committee'. Data applications from external researchers will be considered by a 'Data Access Committee', comprising Prof Andrew Whitehouse, Dr Emma Glasson, and Dr John Wray. If the committee determines (by consensus) that the data request is investigating a topic that is of benefit to the autism scientific community, and that project has procured ethical approval/waiver from a registered Human Research Ethics Committee, then the committee will provide the external researchers with the requested data. No identifiable information (including names, addresses, & post code) will be provided to external researchers.

Withdrawing consent

If you have decided to contribute further information to the Online Autism Register, you are free to withdraw your consent at any time. Your decision to withdraw consent will not influence the care your child receives from any of the personnel involved in your child's health care. If you wish to withdraw your consent, we will remove your information. You can withdraw your consent by contacting us in writing or via our contact details below to withdraw your information.

Obtaining consent from your child

Once your child turns 18 years of age, we will recontact your family to see if your child would like to provide consent and their own personal contact details.

If they have the cognitive capacity to provide consent at this time, they will have the choice to provide consent and extra contact details to be contacted about future autism research.

Who is involved in the Online Autism Register?

The Online Autism Register is a joint venture between the major diagnostic centres for autism within Western Australia and is managed by a representative committee of professional and consumers. The Online Autism Register is supported by the autism community.

Will I receive updates on the progress of the Online Autism Register?

At the end of each year, we will send you a newsletter (if you have provided contact details) that will inform you about the progress of the study, as well as the other research taking place in our group. Should you not provide contact information to the Online Autism Register we will publish this newsletter on our website (autism.telethonkids.org.au/autismregister).

Who do I contact if I have any concerns about the running of this project?

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 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.

Further Information

If you have any questions or would like more information, please visit our website or contact us:

Website: www.autism.telethonkids.org.au/autismregister

Email: autismregister@telethonkids.org.au

Phone: (08) 6319 1833

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