



Participant Information Statement

Full Project Title: Deakin Child Study Centre Research Registry
Deakin University Research Ethics Approval: HEAG-H 177-2016

Dear Parent,

We have recently established the Deakin Child Study Centre Research Registry (DCSC Research Registry). The DCSC Research Registry will support recruitment for child development research, and is open to children and adolescents aged between 0 and 18 years. We hope that this will save us all time by connecting the right people with the right research projects.

If you would like to be contacted for child development research we invite you to complete a short 5 minute survey. The survey will ask for your contact information, your child's name, date of birth and diagnosis (if applicable). A separate survey will need to be completed for each child you would like to be on the register. We will keep this information on a confidential list of families that are interested in being contacted in the future. We will also send you a Deakin Child Study Centre newsletter twice a year so you are up to date with the types of research we are currently involved with. We will keep this information indefinitely but you can request to be removed at any time.

If we hear about a research project that you or your child may be interested in we will send you information with the full details of the study. The information will tell you about the potential benefits and risks of that individual research project. You will then be able to respond if you are interested in learning more about that research project if you wish. It is your choice whether you agree to take part or consent for your child to take part in any future research project or not.

We do not expect there to be any direct benefit to you or your child by being on the DCSC Research Registry. Benefits or risks as a result from participating in a specific study will vary from project to project. We hope that recruitment for research looking into child development, neurodevelopmental disabilities and disorders will be done more quickly in the future if we have a list of families who might be eligible and are interested in participating in research. We also hope this saves families time. Currently many families are searching long lists of studies or are contacted about studies they are not interested in or eligible for.

The information that you give us about you and your child will be treated as confidential and only accessed by the research team involved directly with the DCSC Research Registry. We can disclose the information only with your permission, except as required by law. All information will be stored securely by the Deakin Child Study Centre, part of the School of Psychology at Deakin University.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to access and correct the information we collect and store about you and your child.

Participation in the DCSC Research Registry is voluntary. You do not have to take part if you do not want to. You can withdraw from the DCSC Research Registry at any time without giving a reason. We will not use any of your information if you choose to withdraw. If you withdraw, it will not affect your relationship with Deakin University or any other organisation or individual involved in the research.

If you are happy for your details to be added to the DCSC Research Registry and would like to consent, please complete the following questions. If you have any questions, or would like further information about this project, please contact the project officer;

Dr Carmel Sivaratnam
dcscresearchregistry@deakin.edu.au
(+613) 9246 8383, ext. 95240

Yours Sincerely,

Professor Nicole Rinehart
Professor of Psychology (Clinical)
School of Psychology, Deakin University

This research study has been approved by the Deakin Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007).

If you have any questions or concerns about any aspect of this project or your rights as a participant you may contact:

The Manager, Ethics and Biosafety, Deakin University, 221 Burwood Highway, Burwood
Victoria 3125, Telephone: (+613) 9251 7129, research-ethics@deakin.edu.au

Please quote project number: 177-2016