



Victorian Trial of the Toddler Development Instrument (TDI) Information Statement for Parents and Caregivers

Dear Parent/Primary Caregiver,

Thank you for taking the time to read this Participant Information Statement. This document is four pages long and tells you about the research project, which is to trial the Toddler Development Instrument (TDI). The information is to help you decide whether or not you would like to take part. Please read this Information Statement carefully and ask your health professional if you have any questions.

What is this research project about?

We are inviting you to take part in our research project to test the TDI in Victoria. The TDI is a questionnaire for parents/primary caregivers of 16-20 month old children. It was created by the Human Early Learning Partnership (HELP) at the University of British Columbia (UBC) in Canada, together with parents and caregivers, early child development professionals, policy makers, and researchers. It aims to collect information about the early needs and experiences of toddlers and their families.

We would like to find out whether you are able to access services that you need as a parent, and whether it is possible to get this information from parents at Maternal Child Health and Immunisation visits. By asking all parents/caregivers of 18 month olds to participate, we can find out whether or not we can routinely respond to some key gaps in the information about communities and families that we currently have available to us. By better understanding these experiences, we can work towards strengthening family and community resources to better support children, families, and communities.

This project has been funded by the Ian Potter Foundation and the Victorian Department of Education and Training.

What is involved in participating?

We are inviting you to participate in this study by filling out the TDI questionnaire. The questionnaire will take about 10-20 minutes to complete. The TDI includes questions about your toddler's daily activities including development, activities, health, eating habits, and more. It will also ask about caregiver and family situations including access to community resources, parent/caregiver support, wellbeing, and more. All parents/caregiver of toddlers in your community will be asked to participate. If you choose to participate, you do not need to answer any questions that you are not comfortable answering. We have been careful to make sure that the questions do not upset you. However, if you are worried about any of the questions, the health professional administering this survey (e.g. nurse, GP etc.) will be available to discuss your concerns and refer you onto support services should you require them.

As this is a new study, we may also wish to ask you for some feedback on the TDI questionnaire experience after completion. This could take about 5-10 minutes to complete at a later stage. This feedback will help us improve the TDI to make it clear and easy to use.

We would also like your permission to link to other data to collect information that will help us better understand the needs and experiences of your child over time. Health research is very important as it looks at how health care is managed and how services are delivered and used. Data linkage is a way of connecting information held by different groups or services in a way that protects a person's privacy. Being able to link data can be very useful in health research. It can provide a more accurate picture of the overall health and well-being of group of people. More recently health information has been linked to other areas, including education. For example, with your consent, information from the TDI may in the future be linked to information from the Australian Early Development Census, which is undertaken in the child's first year of full-time school. Other possible surveys we might link with include, but are not limited to, the School Entrant Health Questionnaire (also in the first year of school) and NAPLAN.

What are the alternatives to taking part? Can I withdraw?

Your participation in this study is voluntary. This means it is your choice and you do not have to take part if you do not want to. If you decide you do not want to take part, it will not affect the treatment and care you receive at the Royal Children's Hospital, your Maternal Child Health service, or any other health service. If you give your consent and change your mind, you can withdraw your child from the project. You do not need to tell us the reason why you or your child want to stop being in the project. If you leave the study, we will use any information already collected unless you tell us not to.

What are the risks and benefits involved with participating?

The only inconvenience to you is the time to complete the survey and send it to us. The questions in the survey have not been designed to cause you distress. However, if you are worried by any of the questions you do not have to answer them. The survey may raise concerns for you or your child – if so, you can talk to the health professional administering the survey, such as your Maternal Child Health nurse. They have been trained to assist you and can refer you to helpful resources and services.

We do not expect there to be any direct benefit to you. However, by participating, you will help us better understand the experiences of toddlers and their families in Victoria. This information may help inform early years programs and policies to make them more supportive.

How will the TDI data be used and how will my privacy be protected?

In this study we will collect and use personal and health information about your child for research purposes. Any information we collect that can identify your child will be treated as confidential. It will be used only in this project, unless otherwise specified. We can disclose the information only with your permission, except as required by law.

All information will be stored in a secure computer database managed by the SRC. Paper questionnaires will be stored at the SRC in secure, locked filing cabinets, which can only be accessed by the research team. Except as required by law, only the following people may access information collected as part of this research project:

- The research team involved with this project
- The Royal Children's Hospital Human Research Ethics Committee

The stored information will be de-identified. This means that we will remove identifying information such as your child's name and give the information a special code number. Only the research team can match your child's name to their code number, if it is necessary to do so.

The Maternal Child Health service and related health professionals will distribute the survey. They will not have access to the individual answers you provide. This means that the information you give will be completely private. Any information collected using the TDI will be reported at a community level. That means that your responses will be combined with others who live in the same area as you. This is done to protect the privacy of participants. No individual responses are ever shared in any research summaries.

You have the right to access and correct the information we collect and store about your child. This is in accordance with relevant Australian and/or Victorian privacy and other relevant laws. Please contact us if you would like to access this information. We are required to keep information collected as part of this research for at least 5 years following the last publication of the project. Results may be presented at conferences or published in medical journals. We will provide a community level summary report on completion of the project and make it available on our website:

<http://www.melbournechildrens.com/atp/comprehensive-monitoring-project/>

We hope that you will take part. You do not need to complete a consent form to take part in this project. You can complete the survey electronically or on paper and return it to us in the prepaid envelope. If you have any questions, or would like further information about this project, please call Cathie Nolan on (03) 9651 3539.

The survey can be accessed at **www.srcentre.com.au/tdi** or to go straight to the survey, please scan the QR code:



Yours sincerely,

A handwritten signature in black ink, appearing to read 'Cathie Nolan', written in a cursive style.

Cathie Nolan
Project Director
Principal Investigator
Department of Education & Training

A handwritten signature in black ink, appearing to read 'Craig Olsson', written in a cursive style.

Professor Craig Olsson
Scientific Director
Principal Investigator
Deakin University & Murdoch Children's Research Institute

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.

This research project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.