CHILDREN'S HEALTH QUEENSLAND
CAREGIVER INFORMATION STATEMENT
ONLINE SURVEY

Project Title **Assessment of health outcomes and pilot testing other assessment tools for children with fetal alcohol spectrum disorder**

HREC Number **HREC/17/QRCH/272**
Investigators **Professor Karen Moritz and Dr Natasha Reid**
Version Number: **2** **Version Date: 6/2/2018**

It is ok to say no

Thank you for taking the time to read this **Caregiver Information Statement and Consent Form**. We would like to ask you to participate in a **research study** about your child's current and past health.

What is an Information Statement?

These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you decide whether or not you would like your child to take part in the research. Please read this Information Statement carefully.

Before you decide if you want to participate you may want to talk about the project with your family, friends or health care workers.

Important things to know

- It is your choice whether or not you take part in the research. You do not have to agree to if you do not want to.

What is the research project about?

To date there has been lots of research that has investigated the impacts that prenatal alcohol exposure can have on the developing brain. However, there has been limited research that has investigated the influence that prenatal alcohol exposure can have on other health outcomes. Case studies in children with FASD have identified a range of anomalies including heart and kidney defects. Recently, at the 17th International FASD conference it was suggested that rather than describing FASD as a brain-based disorder, it should be described as a "whole-body" disorder." Outcomes from an informal survey conducted in a cohort of young adults with FASD in Canada suggests they experience a range of diseases including early onset arthritis, and hypertension (i.e. high blood pressure).

The aim of the research will be to investigate early signs of chronic disease in children with FASD, allowing for timely treatment to prevent disease progression.

We are also interested in gathering some information about the health and wellbeing of caregivers to help us see what types of supports would be helpful to provide to caregivers of children with FASD.

Who is funding the research project?

There are no commercial sponsorships to be disclosed for this research.

What will I be asked to do?

You will be asked to complete an online survey that will take approximately 30-minutes. This survey will contain questions about your child's current and past health, their behaviour and your health and wellbeing.

What if I wish to withdraw from the research project?

My decision whether or not for my child to participate will not prejudice their future relations with Children's Health Queensland. If I to participate I am free to withdraw my consent and to discontinue participation at any time.

What are the possible benefits for my child and other people in the future?

The outcomes of this research will provide important information on the health and wellbeing of children with FASD. This information will be vital in guiding targets of future intervention work for children with FASD. The outcomes of this research will also help us to develop future interventions to support caregivers of children with FASD.

What are the possible risks, side-effects, discomforts and/or inconveniences?

We do not think that there will be any risks or side effects from participating in an online survey.

What will be done to make sure my child's information is confidential?

Data from the survey will be stored electronically without you or your child's name. A number will be used to identify your child. This number will be linked to your child's name and the linking file will be kept confidential and only made available to the researchers. A separate database will include your contact information. The database will be password protected with limited access available to the researcher involved in the study. Research data may be accessed by auditors, ethics committee or regulatory authorities. Research data gathered from the results of the study may be published, however identifying data is not used

Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Dr Natasha Reid
Contact telephone:	07 3069 7362
Email:	n.reid1@uq.edu.au

HREC Information:

The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC) has approved this study. If you have any concerns and/or complaints about the project, the way it is being conducted or your child's rights as a research participant, and would like to speak to someone independent of the project, please contact the HREC Co-coordinator on: 3069 7002 or email CHQETHICS@health.qld.gov.au

Local Governance Contact Information:

Name:	Dr Peng Tjun Choy
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