



Parent/Guardian Information Statement

Title	Digital Support for Families Health Care Journey
Protocol Number	2
Research Team	<p>Children's Health Queensland: Shae Quabba Jessica Cheers Lacey Lubbers</p> <p>Australian Research Council Centre of Excellence for the Digital Child, Queensland University of Technology: Associate Professor Sonia White Dr Nicole Hayes</p>
Location	Queensland Children's Hospital

Thank you for taking the time to read this Information Statement and Consent Form. We would like to ask you to participate in a research project that is explained below.

It is ok to say no

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 to take part in the research. Please read this Information Statement carefully.

Before you decide if you want to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your family, friends, or health care worker.

Important things to know

- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to.
- If you decide you do not want to take part, it will not affect the treatment and care your child receives through Children's Health Queensland

If you decide you want to take part in the research project, you will be asked to tick the consent section. By ticking it you are telling us that you:

- Understand what you have read
- Consent to the taking part in the research project

You can download a copy of this Participant Information and Consent Form to keep.

1. What is the research project about?

This is a project between the Queensland Children's Hospital and researchers at the Australian Research Council Centre of Excellence for the Digital Child at Queensland University of Technology.

We want to learn how families find and use health information and services. We also want to learn how families use digital tools like websites and apps. This will help us make digital tools to support families in the future.

2. What does participation in this research involve?

This research project involves two phases (Phase 1 and Phase 2). We are hoping for a large number of families (over 100 families) to take part in Phase 1 and will invite a smaller number of families to take part in Phase 2 (20 parents and children, aged 8-12 years of age).

Phase 1: You will be asked to complete an online survey. The survey will ask you about how you find and use health information, and about digital technology use at home. The survey will take about 20 minutes to complete. The survey is completed online.

Phase 2 (Optional): If you have a child aged 8-12 years and you are interested, we may also invite you and your child to take part in a small group workshop. You will be asked to provide consent to be contacted to find out more about Phase 2. This is optional and you can complete the online survey, without providing consent for project follow-up.

Please note, we are not asking you to consent to participate in Phase 2 now. We are asking if you consent to be contacted to find out more about Phase 2.

3. Who is funding the research project?

This is a project between Children's Health Queensland and the Australian Research Council Centre of Excellence for the Digital Child at Queensland University of Technology.

4. What if I wish to withdraw from the research project?

Taking part in this project is entirely voluntary. You can withdraw from the research project at any time without comment or penalty. The decision to withdraw from the study will not affect your relationship with the Queensland Children's Hospital, your child's routine medical treatment or their relationship with the people treating them.

You can withdraw from the project by closing the online survey. If you choose to withdraw, no further information will be collected from you. Any information already completed in the survey will be kept.

If you consent to be contacted to find out more about Phase 2, you can withdraw that consent by contacting a member of the Digital Child research team.

5. What are the possible benefits for myself, my child and other people in the future?

The project may not help you and your child directly. What we learn will help us make better digital tools to support families in the future. It will also help to improve how health information is shared with families.

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

There are minimal risks associated with your participation in this project. There is the time inconvenience to complete the survey. Some questions might make you feel uncomfortable. You don't need to answer any questions you don't want to. You will also be free to stop completing the survey at any time, by closing the survey.

7. What will be done to make sure my information is confidential?

Any data collected as part of this project will be stored securely as per QUT's Management of research data policy. All data collected from individuals will be treated confidentially. Access to any information collected will be granted only to authorised persons from the research team. Your data can only be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

Personal information (e.g., name, phone number, postal and email address) that can identify you will be stored separately from all your survey responses and will only be used to contact you for Phase 2 follow-up if you consent to this and to provide the project summary if you would like to this. A codebook that links your identity to your survey responses will be stored separately and will be accessible only to authorised persons from the research team. This will never be made public or reported in any project presentations or reports arising.

De-identified survey data collected in this project may be used for future projects that are an extension of, or closely related to, this project (i.e., studying about health communication or digital technologies) in accordance with the [National Statement on Ethical Conduct in Human Research 2023](#).

8. What will happen when the research project ends?

The results of the project may be shared in talks and reports. No identifying information will be used. If you would like to receive a summary of the results of the project, you can tick the box below.

9. 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 Nicole Hayes,
Position: Project investigator, Australia Research Council Centre of Excellence for the Digital Child
Contact telephone: (07) 3138 8191
Email: n1.hayes@qut.edu.au

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). **Reviewing HREC approving this research and HREC Executive Officer details.**

10. 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 Office.

Name: HREC Coordinator
Contact telephone: (07) 3069 7002
Email: CHQETHICS@health.qld.gov.au

11. Local Governance Contact Information:

Name: Research Governance Officer
Contact telephone: (07) 3069 7008
Email: CHQ_RGO@health.qld.gov.au

Participant Consent

Declaration by Participant

By ticking the box below, you are indicating that you:

- Have read the Participant Information Sheet, or someone has read it to me in a language that I understand.
- Understand the purposes, procedures and risks of the research described in the project.
- Have had an opportunity to ask questions and I am satisfied with the answers I have received.
- Freely agree to participating in this research project as described and understand that I am free to withdraw at any time during the research project without affecting my/my child's future health care.
- Understand that I can download a copy of the Participant Information Sheet to keep.

I consent to participate in this Phase 1 online survey only.

I consent to participate in this Phase 1 online survey and to being contacted to find out more about the Phase 2 face-to-face workshops.

Optional

I would like to receive a summary of the project results.