

**CHILDREN'S HEALTH QUEENSLAND  
PARENT/GUARDIAN INFORMATION STATEMENT**



**Project Title**                      **Long Term Outcomes after Pediatric Sepsis**  
**HREC Number**                      **HREC/21/QCHQ/80647**  
**Investigator**                      **Ms Jessicah Minogue**  
**Version Number:**                      **V1**                      **Version Date: 13/10/2021**

Thank you for taking the time to read this **Parent/Guardian Information Statement**. We would like to ask you and your child 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 your child 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 and your child can 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 would like to take part in the research project, a member of our research team will be in contact with you via telephone to speak with you further about the study and gain consent for your participation in the study.

We will give you a copy of this information to keep.

## **1. What is the research project about?**

Sepsis in children has been identified as one of the most preventable deaths in children. Current research has successfully been able to reduce this through new research that treats and identifies sepsis earlier. Though improvements continue to be seen, minimal information is currently known about the long-term survivorship of these children. The purpose of this research project is to therefore investigate this gap and explore what long-term outcomes are related to these children and their families.

Participation will involve completing a survey looking at a variety of both child and parent/caregiver topics. Each of the 10 sections have been carefully selected to capture information that is important in helping us to determine what long-term outcomes could be impacting families post sepsis. You are invited to participate in this research project because your child was identified on a Sepsis carepath in a Queensland Paediatric Emergency department and treated for sepsis approximately 2 years ago. Questions will be asked about the following:

### About your child

1. Demographics
2. Growth and Development
3. Quality of Life
4. Distress (children >2 years)
5. Adaptive Behaviour
6. Executive Function (children >2 years)

### About you

1. Parenting Stress
2. Psychosocial
3. Distress
4. Feedback

From this project, we hope to better understand the impact of sepsis survival to improve our understanding and healthcare provision into the future. If you wish to receive a report of your results, a copy can be sent to your GP on completion of the survey.

## **2. Who is funding the research project?**

This research project is being undertaken as part of a Master of Philosophy by Ms Jessicah Minogue. The Queensland State-Wide Sepsis Collaborative Group have kindly agreed to support and fund the costs related to survey use for this study.

## **3. What if I wish to withdraw from the research project?**

Your participation in this research project is entirely voluntary. If you agree to participate you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate is voluntary and will in no way impact upon your current or future relationship with your child's treating medical team or associated external organisation/s. If you do agree to participate you can withdraw from the research project during your participation without comment or penalty. Any information already obtained that can be linked to you will be destroyed.

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

It is expected that this research project will not directly benefit you. The outcomes of the research, however, may benefit our ability to provide improved care to your child/children into the future.

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

Risk associated with this study may include emotional discomfort related to some of the questions in the survey. The research team includes the support of sepsis specific social workers a neuropsychologist and who are available to ensure appropriate support and referrals are attended to if incidental findings arise because of this study.

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

All comments and responses are coded, i.e. it will be possible to re-identify you. A re-identifying code stored separately to personal information (e.g. name, address), will only be accessible to the research team, and the code plus identifying information will be destroyed after completion of the study.

Any personal information that could potentially identify you will be removed or changed before results and publications are made public. The information that will be removed includes, names and date of birth. Any data collected as part of this research project will be stored securely as per QUT's Management of research data policy. Data will be stored for a minimum of 5 years and can 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.

**7. 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:** Ms Jessicah Minogue or A/Prof Debbie Long

**Contact telephone:** 0491 675 625

**Email:** [jessicahrachel.minogue@hdr.qut.edu.au](mailto:jessicahrachel.minogue@hdr.qut.edu.au)  
[da.long@qut.edu.au](mailto:da.long@qut.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-ordinator on: 3069 7002 or email [CHQETHICS@health.qld.gov.au](mailto:CHQETHICS@health.qld.gov.au)

**Local Governance Contact Information:**

**Name:** Research Governance Officer

**Contact telephone:** 3069 7008

**Email:** [chg\\_rgo@health.qld.gov.au](mailto:chg_rgo@health.qld.gov.au)