

CHILDREN'S HEALTH QUEENSLAND
Participant Information Statement: Health Professional Focus Groups

Title	Queensland Paediatric Sepsis Program: Engaging Consumers and Health Professionals in a quality improvement project to explore post sepsis services and supports for families (surviving and bereaved).
Protocol Number	QCHQ/89145
Coordinating Principal Investigator/ Principal Investigator	Ms Alana English Associate Professor Paula Lister
Location (<i>where CPI/PI will recruit</i>)	Children's Health Queensland

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

It is ok to say no

What is an Information Statement?

These pages tell you about the quality improvement 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. 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.

Important things to know

- It is your choice whether you take part in the quality improvement project. 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 you or your care in any way.

If you decide you want to take part in the quality improvement project, you will be asked to sign the consent form. By signing it you are telling us that you:

- Understand what you have read
- Consent to taking part in the research project
- Consent to the use of your information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

1. What is the quality improvement project about?

Sepsis is life-threatening organ dysfunction due to dysregulated host response to infection(1). More than half of sepsis cases worldwide occur in children, with an estimated 25 million cases of paediatric sepsis in 2017, of whom 3.4 million died (2). Survival from sepsis has increased, but long-term

morbidity experienced by paediatric survivors is increasingly apparent, both in scale and range; with effects on physical, psychosocial, educational, and family functioning (3-9). This range of 'new or worsening cognitive, physical, and mental health impairments that persist beyond hospitalisation' (10) have been defined in adults as *post-sepsis syndrome*.

There is a large gap in the understanding of paediatric sepsis survivorship. There is limited appreciation of the nature of the syndrome, its contributing causes, and effective interventions. Sepsis can have profound effects on families but there are few reports of interventions to reduce negative impacts. Evidence of post sepsis syndrome in children, if noted, has focused on new or worsening cognitive and physical impairments with little focus on additional psychological, educational and family impacts.

This quality improvement project aims to engage with consumers and health professionals to understand the experience of families post sepsis. Methods of focus groups will be used to explore the child/young person and family's support needs following hospital admission and treatment and the perceived gaps in service. Recommendations for the development and implementation of a model of care that identifies key resources and supports for all Queensland families affected by sepsis, (surviving and bereaved) will be developed from the findings.

2. Who is funding the research project?

This project is being funded by Children's Health Queensland.

3. Why am I being asked to take part?

You have been contacted as you have experience in working with families with a child or adolescent with sepsis, or other chronic condition.

We will also be seeking participation from parents and carers who have had a child or adolescent diagnosed with and treated for sepsis in a Queensland hospital. They will participate in separate focus groups.

4. What do I need to do in this research project?

If you agree to participate you will be invited to participate in a semi-structured focus group, either within your local health service, or online, with other health professionals. The length of the focus group will be 2 hrs and the timing will depend on personal convenience and availability.

If you are unable to participate in a focus group, you can arrange an individual interview, at a time of your convenience, with the Project Lead. This interview will take approximately 1 hour.

You will be asked a set of questions that will explore your overall experience of working with families who have had a child diagnosed with sepsis, the child's medical and support needs following their hospital admission, gaps you noticed in the service they received, and your ideas for essential features of a post sepsis model of care.

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

If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time. Please contact the Project Lead, Ms Alana English if you wish to withdraw your consent.

6. What are the possible benefits for me and other people in the future?

There are no direct personal benefits offered to you through your participation in this study. You will be helping the researchers to understand your experience of working with families with a child with a chronic illness or sepsis.

You will also be guiding recommendations for the development of a post sepsis model of care, which may result in indirect benefits in your work, offering a more streamlined and targeted approach to offering care and support to families with a child with sepsis.

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

Whilst there are no anticipated risks to you resulting from participation in this project, you will be asked to reflect on your overall experience of sepsis and working with families with a child diagnosed with sepsis or bereaved due to sepsis and this could potentially cause you some discomfort. If you feel distressed, you can discuss this with the Project Lead in confidence. The Project Lead is a highly experienced Advanced Social Worker who specialises in grief, loss and trauma support. In the unlikely event that additional support or counselling is required and you provide consent, you will be connected with an external support agency that you feel comfortable with. Due regard will be given to ensure access to support with no out-of-pocket costs, although this cannot be guaranteed.

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

All data that is collected throughout the focus groups and interviews will remain confidential. This data will be de-identified prior to analysis and no names, or any identifying information will be recorded in a research database or used in any publications arising from this research. Individual information will not be shared. Focus group recordings will be viewed and transcribed by the Project Lead, with assistance of an external agency, supervised by the Project Lead.

Data may be accessed by auditors, ethics committee or regulatory authorities. Data gathered from the results of the study will be de-identified and may be written into a peer review article, presented at conferences or presented within the health care setting.

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, please contact:

Name: Ms Alana English
Email: Alana.English@health.qld.gov.au

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

HREC Information:

Project Number **EX/2022/QCHQ/89145:**

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

Local Governance Contact Information:

Name: Research Governance Officer

Contact Telephone: 07 3069 7008

Email: CHQ_RGO@health.qld.gov.au