



Queensland Paediatric Sepsis Program

## Paediatric Post Sepsis Model of Care



Children’s Health Queensland pays respect to the Traditional Custodians of the lands on which we walk, work, talk and live.

We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders past, present and future.



**Queensland Paediatric Sepsis Program  
Paediatric Post Sepsis Model of Care**

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## What is the purpose of this document?

The purpose of this document is to assist services to understand the needs of families following a diagnosis of sepsis for their child or following their child's death due to sepsis. An extensive community consultation process was undertaken to collect information about the lived experience of families and the experience of health professionals working with them.

## How should you use this document?

Services are encouraged to use this document to:

- Understand the lived experience and impacts of a sepsis diagnosis for children and families following discharge from hospital
- Understand the lived experience and impacts of a child's death due to sepsis
- Understand the key actions needed to sustainably provide post sepsis care for families with surviving children and for bereaved families across Queensland.

## What are the next steps?

These findings will be used to inform the development of a Paediatric Post Sepsis Model of Care (surviving and bereaved).

By providing a structured approach to post sepsis care, families will feel empowered to access appropriate services and supports and services will be able to provide early intervention to children and families post discharge.

# Executive Summary

## Background

Survival from paediatric sepsis has increased; however, it is estimated that 28-34 percent of paediatric survivors experience long term morbidity and or disability, resulting in lifelong impacts for children, their families, and communities. These impacts are significant in both scale and range; with effects on cognitive, physical, psychosocial, educational, and family functioning.

Overall, there is a large gap in the understanding of paediatric sepsis survivorship with limited appreciation of the nature of the syndrome, and its contributing causes. In addition, for those who are bereaved due to sepsis, there is a significant gap in provision of any structured bereavement support.

The failure to understand the long-term impacts of sepsis (for surviving and bereaved) leaves clinicians and families unable to identify and access effective post sepsis interventions. Children diagnosed with sepsis and their families experience decreased health-related quality of life and place greater demand on hospital systems. One of the key recommendations of the National Safety and Quality Health Service's (NSQHS) Sepsis Clinical Care Standard relates to care after hospital, identifying that patients who survive sepsis should receive "individualised follow-up care to optimise functional outcomes, minimise recurrence, reduce rehospitalisation and manage the ongoing health effects of sepsis". Whilst there are current successful models of care in other clinical areas, there are no current guidelines or models of care to meet the needs of children and families experiencing these lifelong impacts of sepsis.

## Project aims

The primary aims of this project were to gain an understanding of the needs of children diagnosed with sepsis and their families following their child's discharge from hospital (for surviving children) or following their child's death (for bereaved families).

## Method

An extensive community consultation process was undertaken over a four-month period and included focus groups and individual interviews with parents of children diagnosed with sepsis (surviving and bereaved) and healthcare professionals from across Queensland. The community consultation process was undertaken by the Lead Investigator who is an Advanced Social Worker with the Queensland Paediatric Sepsis Program (QPSP) and a Co-Facilitator. Recruitment aimed for adequate representation of all geographic areas across Queensland including rural, remote, regional, and metropolitan areas, and representation from Aboriginal and Torres Strait Islander people. Thematic analysis identified key themes relating to the needs of children diagnosed with sepsis and their families (surviving and bereaved) and will be used to inform the development of a Paediatric Post Sepsis Model of Care.

## Summary of themes/issues

### Themes and subthemes - SURVIVING

#### 1. Survivorship Plan

- 1.1 Survivorship plan
- 1.2 Sepsis resources
- 1.3 Current resources
- 1.4 Gaps in resources
- 1.5 Challenges for rural and remote
- 1.6 Benefits of group support

#### 2. Understanding lived experience

- 2.1 Initial impacts
- 2.2 Long-term impacts
- 2.3 Parent's experience

#### 3. Clinician's guideline for care

- 3.1 Key contacts
- 3.2 Discharge planning
- 3.3 Considerations for implementation
- 3.4 In hospital support
- 3.5 Out of hospital care
- 3.6 Practicalities
- 3.7 Role of primary care

#### 4. Communication process

- 4.1 Communicating with families
- 4.2 Communication between clinicians
- 4.3 Empowering family

#### 5. Education

- 5.1 Clinician education
- 5.2 Public awareness

### Themes and subthemes - BEREAVED

#### 1. Bereaved Care Plan

- 1.1 Peer Support
- 1.2 Continuing bonds
- 1.3 Challenges for rural and remote

#### 2. Understanding lived experience

- 2.1 Experience of bereavement support

#### 3. Clinician's guideline for care

- 3.1 Key contacts
- 3.2 Process for post sepsis bereavement care
- 3.3 Practicalities
- 3.4 Role of primary care
- 3.5 Resources

#### 4. Communication process

- 4.1 Communication process
- 4.2 Communicating with families

## Summary of actions

In summary, the key themes can be distilled into the development of a Survivorship Plan for the parents of children with ongoing impacts (surviving), a Bereaved Care Plan for the parents of children who die due to sepsis (bereaved) and a Clinical Guideline for Healthcare Professionals to offer guidance and resources to utilise in their ongoing management of these children, post hospital admission.

All actions should align with the National Safety and Quality Health Service (NSQHS) Sepsis Clinical Care Standard in a way that reflects an understanding of the lived experience of those affected by sepsis. There should be an open and beneficial communication process between relevant parties and an education process that informs families and clinicians about post sepsis care. The Paediatric Post Sepsis Model of Care should identify and use existing networks, infrastructures, resources, and services, where possible.

## Future recommendations

The findings from this project will be used to inform the development of a Paediatric Post Sepsis Model of Care (surviving and bereaved). Funding will be sought for a pilot implementation, before scaling to all Queensland Health services.

By providing a structured approach to post sepsis care,

- a) families should feel empowered to access appropriate services and supports, and
- b) services should be able to provide early intervention to children and families post discharge.

# Introduction

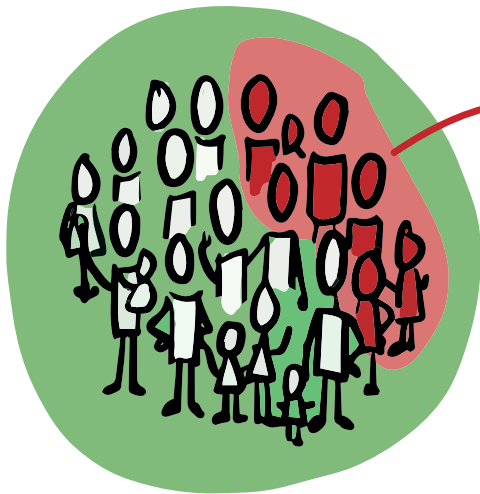
This section provides a detailed overview of the project, including background, aims, and the method.

## Sepsis

Sepsis is the body's overwhelming and life-threatening response to an infection, resulting in damage to the organs and tissues<sup>[1]</sup>

AN estimated  
**21.9 MILLION**

children survive sepsis globally each year<sup>[2]</sup>



These impacts are significant in both scale and range; with effects on

**28-34%  
Paediatric  
Survivors**

experience long term morbidity and/or disability, resulting in lifelong impacts for children, their families, and communities<sup>[3-6]</sup>

**Physical, cognitive, psychosocial,  
educational & family functioning**<sup>[3-13]</sup>

This range of 'new or worsening cognitive, physical, and mental health impairments that persist beyond hospitalisation'<sup>[13]</sup> has been defined in adults as **post-sepsis syndrome**

## Background

There is a large gap in the understanding of paediatric sepsis survivorship with limited appreciation of the nature of the syndrome, and its contributing causes. The narrow evidence base of post sepsis syndrome in children has focused on new or worsening cognitive and physical impairments with little focus on additional psychological, educational, and family impacts<sup>[3-13]</sup>. The Life After Paediatric Sepsis Evaluation (LAPSE) study was a landmark study on identifying paediatric sepsis outcomes and morbidities in sepsis survivorship<sup>[14]</sup>. 35 percent of children in this study were reported to have not regained their baseline health related quality of life 12 months post discharge<sup>[14]</sup>. New research, such as the Long-term Outcomes after paediatric Sepsis (LOTUS) study is underway to better understand paediatric sepsis survivors and their long-term morbidities<sup>[15]</sup>. The LOTUS study seeks to provide "a comprehensive understanding of the long-term outcomes associated with paediatric sepsis survivorship in children treated in a non-PICU environment"<sup>[15]</sup>.

The failure to understand the long-term impacts of sepsis leaves clinicians and families unable to understand and access effective post sepsis interventions. Insufficient training and resources for outpatient intervention means follow-up for children and their families is focused on short term recovery with little consideration of, or ability to screen for long-term complications after hospital discharge<sup>[13-16]</sup>.

Families are reported to be unaware and uninformed of the risk for ongoing impacts of sepsis, while primary care physicians and specialists are also often unaware of the frequent occurrence of these impacts<sup>[16]</sup>. One of the key recommendations of the National Safety and Quality Health Service's (NSQHS) Sepsis Clinical Care Standard<sup>[17]</sup> relates to care after hospital, identifying that patients who survive sepsis should receive "individualised follow-up care to optimise functional outcomes, minimise recurrence, reduce rehospitalisation and manage the ongoing health effects of sepsis". This is identified as requiring "structured, holistic and coordinated post-discharge care and education that involves the patient, their family, carer, general practitioner and other clinicians." Further, it is recommended that support and information is "provided to the family or carer of a patient who has died from sepsis"<sup>[17]</sup>.

Examples of successful models of family support have occurred in other clinical areas, including cancer, acquired brain injury, stroke and bereavement. The Queensland Paediatric Sepsis Program (QPSP) have developed and implemented a range of resources and processes to provide support to the child and family throughout the early stages of their sepsis journey, from acute phase of diagnosis to discharge<sup>[18]</sup>. Some examples of innovative practice in post sepsis care are emerging. One US study<sup>[19]</sup> has shared the findings of a model that aimed to provide structured, coordinated post-discharge sepsis care. The Children's Hospital of Philadelphia implemented an "efficient low-cost paediatric sepsis survivorship program, using existing systems of care, when available", with a core focus on educating families about post sepsis symptoms, screening for potential new morbidity concerns and referral to existing health care systems. Much can be learned from this study where follow-up was coordinated by a Nurse Coordinator, with critical care experience who provided education and referral options to families during admission and arranged one telephone follow up call, 2-3 months post discharge.

## **Aims of project**

The primary aims of this project were to gain an understanding of the needs of children diagnosed with sepsis and their families following their child's discharge from hospital (for surviving children) or following their child's death (for bereaved families). This data would then be used to inform the development of a Paediatric Post Sepsis Model of Care, to be used by all Queensland Health services.

## **Method**

### **Summary**

An extensive community consultation process was undertaken over a four month period and included focus groups and individual interviews with parents of children diagnosed with sepsis (surviving and bereaved) and healthcare professionals from all areas of Queensland.

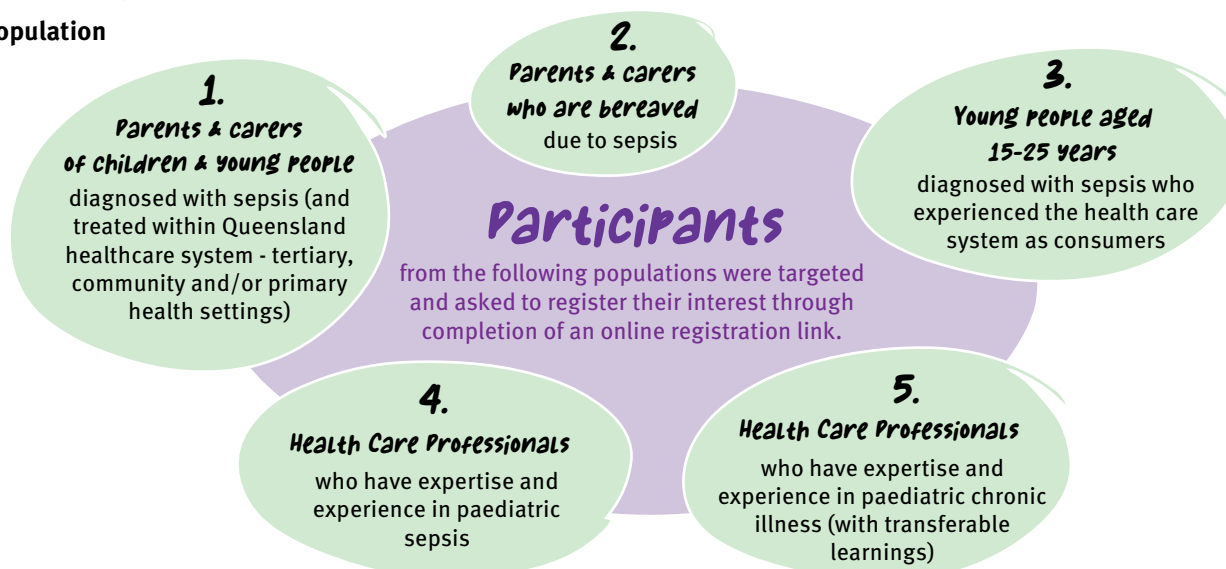
The community consultation process was undertaken by the Lead Investigator who is an Advanced Social Worker with the Queensland Paediatric Sepsis Program (QPSP) and a co-facilitator. Recruitment aimed for adequate representation of all geographic areas across Qld, including rural, remote, regional, and metropolitan areas, and representation from Aboriginal and Torres Strait Islander people.

Thematic analysis identified key themes relating to the needs of children diagnosed with sepsis and their families (surviving and bereaved) and will be used to inform the development of a Paediatric Post Sepsis Model of Care.

The Human Research Ethics Committee at the Queensland Children's Hospital approved this study (EX/2022/QCHQ/89145).

## Community Consultation Process

### Population



### Recruitment

Purposive sampling, using a snowball approach (non-random selection in which participants can recruit or recommend other participants) was used to recruit participants to the focus groups.

#### Recruitment channels:

- Health professionals:
  - email to all health professionals registered on QPSP database
  - email to previous contacts not registered on QPSP database
  - promotion through multiple channels including Sepsis Australia pages, Children's Health Queensland Comms channels, Primary Health Network newsletters, General Practice Liaison Officer network newsletters, etc; and
  - email to GPs working with consumers actively involved with QPSP.
- Consumers:
  - email to all consumers registered with QPSP Family Support Network
  - promotion through Health Consumers Qld; and
  - promotion through Facebook pages of consumers actively involved with QPSP.

Participants who registered interest were directly contacted via email by the Lead Investigator and offered a time for participation in an online focus group or individual online interview. They also received a Participant Information Statement and Consent Form for completion prior to participation.

### Focus groups and interviews

74 total people (12 consumers and 62 Health Professionals) registered interest and were offered a time for participation in a focus group.

Registered consumers and health professionals (HP) were randomly allocated to separate focus groups of either consumers or HP. Within the consumer groups, separate groups were then allocated for parents and carers of children affected by sepsis and bereaved parents. We did not receive any registrations from young people diagnosed with sepsis. All registered consumer participants were allocated to focus groups. Some registered HP participants were not able to attend set time for focus groups and were therefore offered individual interviews.

A maximum of 4 participants were allocated to each consumer focus group and maximum 6 participants to each HP focus group. Focus groups were conducted online, via Microsoft Teams, by the Lead Investigator and Co-Facilitator, in a semi structured interview style, with open-ended questions and prompts. This method encourages interaction among participants in a manner that provides flexibility for the participants to disclose authentic beliefs, feelings and experiences while ensuring rapport, psychological safety, and confidentiality<sup>[20]</sup>. For the HP groups, the Co-Facilitator was a member of the QPSP team. For the consumer focus groups, the Co-Facilitator was an independent facilitator with experience in group facilitation with consumers. Focus group sessions lasted 2-2.5 hours.

For the HPs who participated in an individual interview, these were conducted online by the Lead Investigator, in a semi structured interview style, with the same open-ended questions and prompts.



## Participants

Of 74 registered individuals, 43 individuals participated in the community consultation process (Figure 1). This included 11 consumers and 32 Health Professionals.

Almost all the geographical areas across Queensland were represented by at least one HP (15 of the 16 Hospital and Health Services areas). Whilst 5 Aboriginal and Torres Strait Islander Health Workers registered for participation, only one attended.

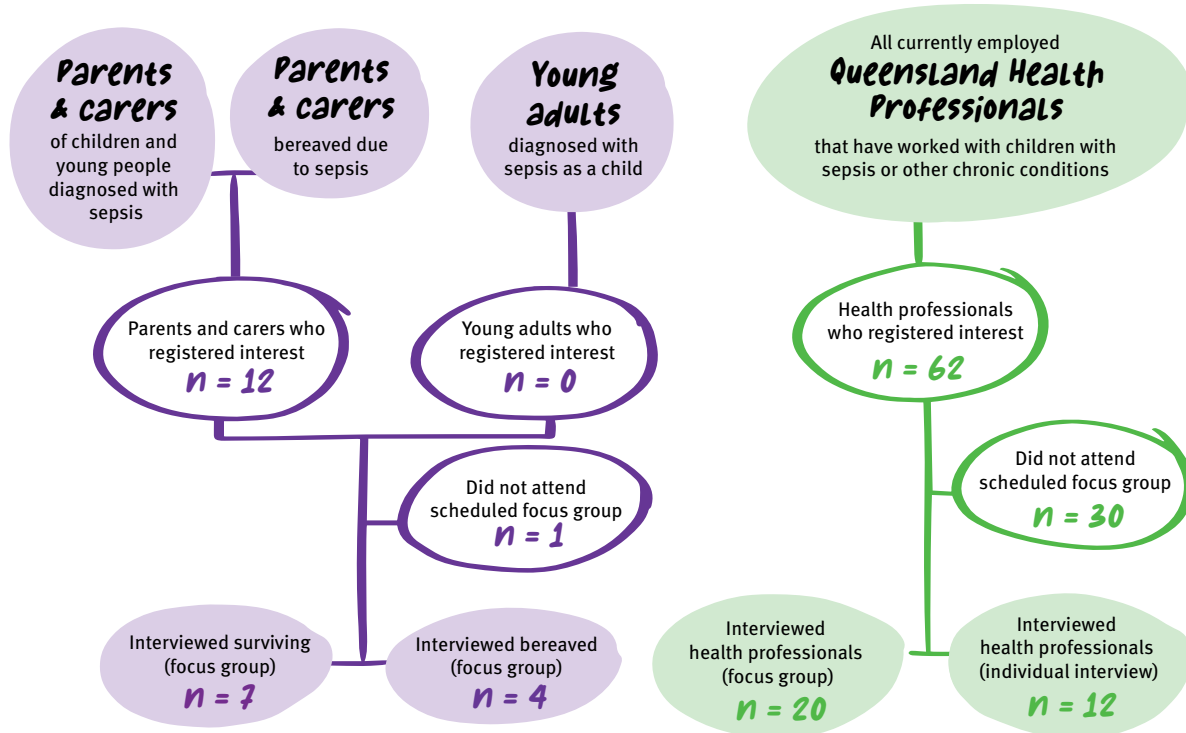


Figure 1: Participants in focus groups and interviews

## Thematic analysis

All focus groups and interviews were recorded and transcribed using the Microsoft Teams transcription service, and checked by the Lead Investigator, with assistance of a second Project Officer.

An open, inductive thematic analysis was conducted using Braun and Clarke’s 6 phase framework<sup>[21]</sup> (Figure 2) to understand the needs of children diagnosed with sepsis and their families following their child’s discharge from hospital (surviving) or following their child’s death (bereaved). The “surviving” data from the HP and consumers was analysed separately from the “bereaved” data.

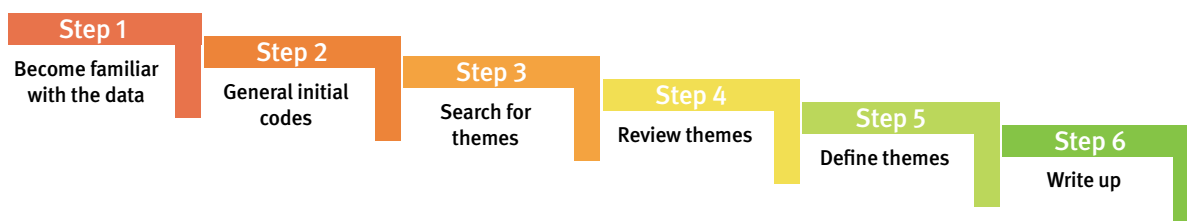


Figure 2: Braun and Clarke’s 6 phase framework<sup>[21]</sup>

The coding frame was developed inductively from the large volume of data generating codes, subthemes, and themes for the “surviving” data and “bereaved” data.

# Understanding the issue

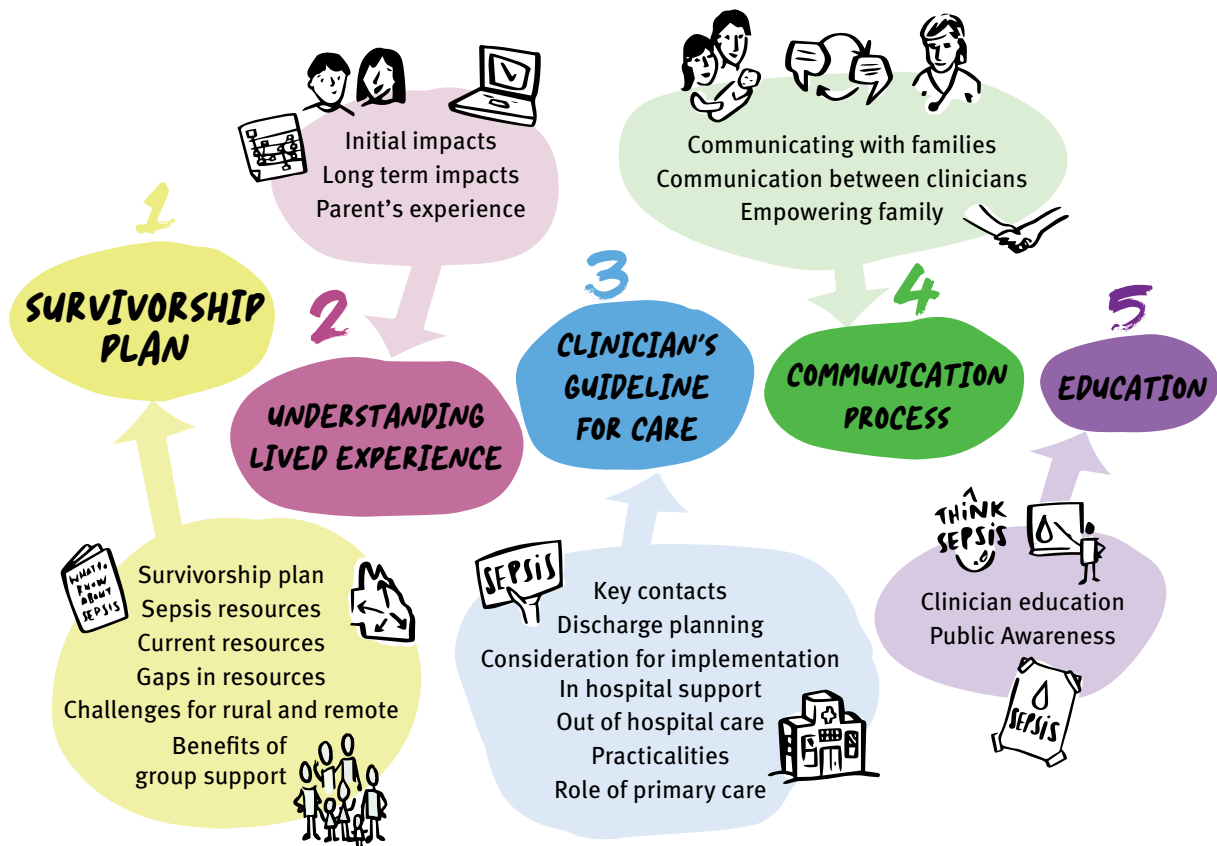
## Summary of the data

### Surviving

#### Themes and subthemes for needs of children who survive sepsis, and their families

Interviews and focus groups generated 998 key statements from consumers and health professionals relating to children surviving sepsis. These were thematically analysed to develop 39 codes, 21 subthemes and 5 themes. (See Appendix 4A for details of all identified codes, subthemes, and themes.)

These are summarised below and include key actions to inform the development of a model of post sepsis care for children and families.



## 1 Survivorship Plan

### Theme 1.1 Survivorship plan

**Summary:** Upon hospital discharge, parents and carers should receive a detailed plan including their child's diagnosis, evidence-based information about sepsis, its impacts, and links to support. This plan, provided in both booklet and electronic formats, could include education plans, healthy living guidance, diagnosis details, signs to watch for, and contacts for primary healthcare. It also outlines follow-up appointments with various healthcare teams. A follow-up phone call from a nurse or relevant team member 2-3 weeks post-discharge ensures any concerns or questions are addressed. This comprehensive approach aims to provide families with crucial information and support throughout their child's recovery.

“There would be sort of overarching themes that you could formulate into some kind of document. This is the information you need ... And things to be aware of, I guess over different points in time.”

### Theme 1.2 Sepsis resources

### Theme 1.3 Current resources

### Theme 1.4 Gaps in resources

**Summary:** For parents to be informed advocates for their child and health professionals to effectively support families affected by sepsis, access to evidence-based information is crucial. This information should be provided in an accessible format, utilising current resources when available, to counteract potentially misleading online sources. Key elements include post-discharge support details, allied health resources, psychological and family impacts, and recurrence risks. Formalised resources, like Spot on Health Pathways, may be used to inform healthcare professionals, but challenges exist, such as long waitlists for specialist care. Timely access to necessary care depends on improved coordination between services, particularly for Indigenous communities, and streamlining of referral processes.

“Need to provide key information about what to do if you need help after discharge, list of allied health support in community, how sepsis will affect members of your family, what to look out for in future, can sepsis happen again, ongoing issues to expect, what is sepsis and how does it affect the body, key contacts, self-care, how not to overreact but react soon enough, psychological effects of serious illness, counselling options.”

*“If I'd been given leaflet back on day one, I'd have probably gone, no, we're fine. But later on, I probably would have gone, maybe this is what they were talking about.”*

### Theme 1.5 Challenges for rural and remote

**Summary:** Identifying and addressing barriers to healthcare access is vital for families in rural and remote areas. After discharge, children returning to these communities often face challenges in follow-up care due to limited access to local specialists and GPs, necessitating reliance on healthcare workers and telehealth services. Coordination gaps between healthcare workers and specialists further exacerbate the issue, leading to significant delays in accessing necessary follow up.

*“They don't always have a Dr, they come to the health worker or use telehealth.”*

### Theme 1.6 Benefits of group support

**Summary:** For families affected by sepsis, group support provides validation and normalisation of their experience, enhancing their coping and sense of belonging.

*“Sharing that experience then sort of validates and normalises what you're going through.”*

## 2 Understanding lived experience

### Theme 2.1 Initial impacts

**Summary:** Post-sepsis care should address the profound impact of sepsis on both the child and their family, often underestimated by those who haven't experienced it firsthand. Returning home after surviving sepsis can be particularly challenging, as families grapple with the reality of initial impacts. Sepsis alters the entire perception of illness for families, affecting their confidence in managing future health issues and may create fears for children in accessing health care. A holistic approach to post-sepsis care should encompass psychological support and education to effectively navigate these complexities.

“We often find that unless you've experienced sepsis, you have no idea what it's like and how devastating it can be.”

### Theme 2.2 Long term impacts

**Summary:** Post-sepsis care plans should acknowledge the enduring impact on both the child and their family. Families are left to navigate the long-term effects on their own, with little external assistance. Children who've survived sepsis may present challenges in assessment, due to potential trauma. It also takes time for parents to distinguish between normal health issues and lingering anxieties.

‘I don't think there is any support for families, to process that [long term impacts], you have to find it for yourself.’

### Theme 2.3 Parent's experience

**Summary:** Post-sepsis care plans should address parents' experiences from the time of the child's diagnosis, hospital admission to post-discharge, recognising their trauma and need for support.

Transitioning home without medical teams can be daunting, and parents may feel misunderstood by GPs or other health services. Clear, timely and evidence based communication is crucial, ensuring parents feel informed and supported throughout their journey.

*“It's just been traumatic, really. It's simple as that. I can't. I can't describe it in any other way.”*

“I think in retrospect, we feel that we've communicated really well with them in hospital, and on the other side of it, the feedback I get now is, there was just so much going on.”

## 3 Clinician's Guideline for Care

### Theme 3.1 Key contacts

**Summary:** Effective post-discharge support requires a central coordinator, like a nurse navigator or social worker, to facilitate services while ensuring delivery of locally based care. This coordinator can be a vital point of contact for parents seeking guidance and reassurance, and responsible for facilitating a smooth transition from hospital to community-based care. Over time, this role could be assumed by a trusted local health professional, ensuring families receive comprehensive support tailored to their needs.

“You need a central point to coordinate the services, but then the services need to be provided from point of care, rather than that central point, so it's almost like a call-centre sort of arrangement, but with a nurse navigator.”

### Theme 3.2 Discharge planning

**Summary:** Clinicians require clear post-discharge guidelines for children recovering from sepsis, including a flagged diagnosis in discharge summaries, with a note for GPs on ongoing impacts. This structured approach ensures timely and appropriate support for sepsis survivors and their families.

“Something that flags in your discharge summaries that sepsis is your diagnosis, it triggers like a comment that this is your discharge plan, feed it back to the GP, please note that this can have ongoing impacts for family and child.”

### Theme 3.3 Considerations for implementation

**Summary:** Clinician’s guideline for post-sepsis care should be tailored to the target population, considering both the needs of parents and clinicians’ requirements and capacity. These should be comprehensive and easily digestible, to maximise understanding and engagement between health workers and parents.

“Even post tonsillectomy they make sure that [parents] get this long print out [of information] to go home with, we don’t have that for sepsis.”

### Theme 3.4 In hospital support

**Summary:** The guideline for care needs to consider child and family’s needs for re-presentation to hospital.

*“I think having a good support system like you just mentioned for our families, I think that would be key and would make their journey a lot less stressful when they come into hospital and post discharge.”*

### Theme 3.5 Out of hospital care

**Summary:** Post-sepsis care lacks a dedicated process, impacting the provision of effective support for children and families within their local community. Availability of Aboriginal and Torres Strait Islander support varies, with urban areas generally better served. Excessive waitlists, low health literacy and difficulty accessing NDIS plans contribute to children getting lost in the system.

*“There’s no support for the initial phase of leaving, let alone the ongoing phase of navigating an NDIS plan.”*

### Theme 3.6 Practicalities

**Summary:** Consider practical suggestions to incorporate into the guideline for care.

“Saying to the family I know that you’ve probably got information overload, but later when you can’t sleep and you want just something to look at this information sheet is for you, these are some services, and you can ask questions to see if they’re suitable for you.”

### Theme 3.7 Role of primary care

**Summary:** Including primary care clinicians in the guideline for care ensures post-sepsis care processes align with primary care needs. GPs are eager for collaboration, emphasising the value of a designated person familiar with the child’s history for continuity of care and importance of communication between hospital and primary care.

“Potentially a telehealth meet up with discharging clinicians with primary care giver would be good.”

## 4 Communication process

### Theme 4.1 Communicating with families

**Summary:** Services should be patient and family centred and using a communication process with families that supports them to build trust in the healthcare system. This involves providing a central, reliable information source and ongoing education about sepsis, the impacts and available supports and resources.

“I feel like you have to ask the question, don’t you? So rather than judging what the family need or don’t need, actually asking the question, just saying how much information do you want”

### Theme 4.2 Communication between clinicians

**Summary:** Clinicians require processes for coordinated care for families impacted by sepsis. A centralised database with service suggestions could streamline support for families navigating post-sepsis care and inform clinicians who struggle to access evidence-based information.

*“Even if there was like some sort of centralised database that we could search through that had some suggestions, service providers, etc.”*

### Theme 4.3 Empowering family

**Summary:** Empowering families starts with inviting parents to actively participate in their child’s care journey and providing information as a foundation for decision-making. Culturally, it requires a shift toward recognising both parent and clinical teams as equally important.

“The very basic conversation I would have with all families at the beginning is there’s the clinical side and the medical things we can do, but this bit is what you do, which is your magic, your connection, your touch and your presence with your child.”

## 5 Education

### Theme 5.1 Clinician education

**Summary:** Clinicians require education, training, and resources to understand the impacts of sepsis and effectively support families. Clinician education should incorporate concise, impactful narratives from parents as their lived experience highlights the importance of post sepsis care.

“I think there needs to be two-way education - both to the parents about sepsis, but equally back to all of the clinicians about what this means to them. You know, the impacts on families who have experienced sepsis before, why they might present the way they present, in a heightened state or with more anxiety.”

### Theme 5.2 Public awareness

**Summary:** Families, especially parents and carers, should be provided with education, information and resources to understand the impacts of sepsis and how to access support.

“We all know the signs of stroke and heart attack. But we don’t know the signs of sepsis.”

# Understanding the issue

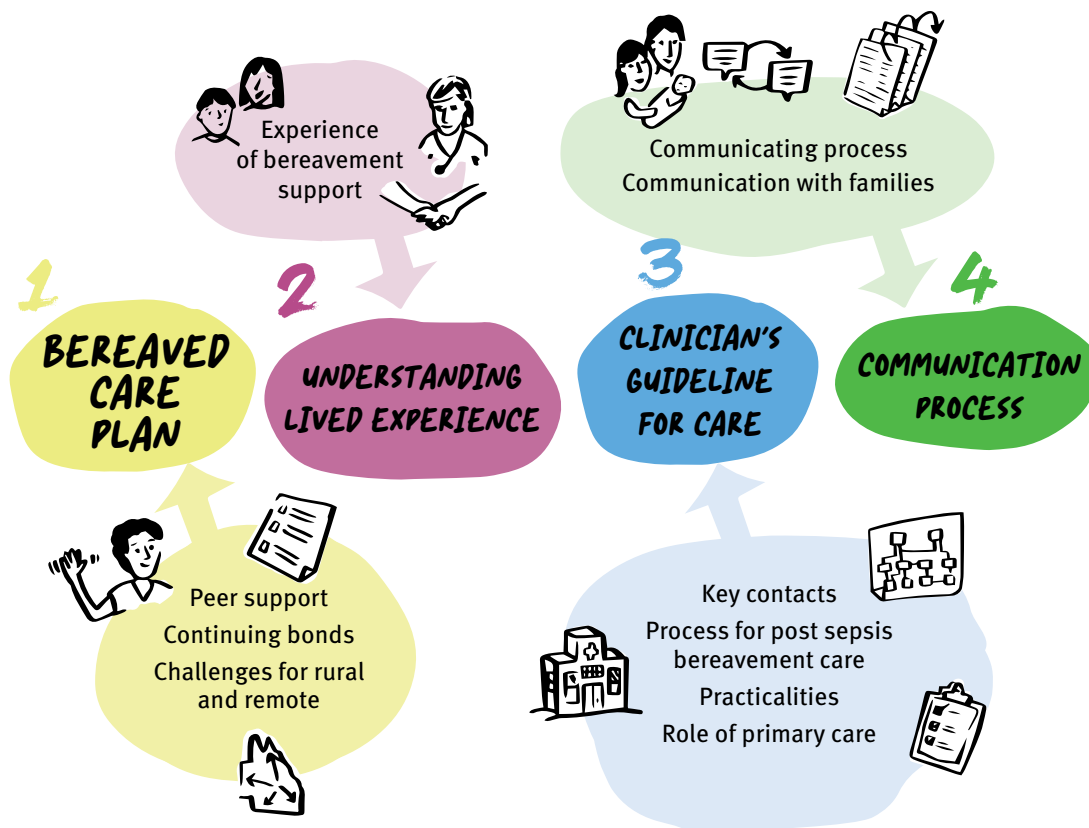
## Summary of the data

### Bereaved

#### Themes and subthemes for needs of families who are bereaved due to sepsis

Interviews and focus groups generated 224 key statements from consumers and health professionals relating to needs of bereaved families. These were thematically analysed to develop 21 codes, 11 subthemes and 4 themes. (See Appendix 4B for details of all identified codes, subthemes, and themes.)

These are summarised below and include key actions to inform the development of a model of post sepsis bereavement care for families.



## 1 Bereaved Care Plan

### Theme 1.1 Peer Support

**Summary:** For families bereaved due to sepsis, group/peer support validates and normalises their unique experience, enhanced their coping and sense of belonging.

“Doing the peer mentoring is another avenue that I’m incredibly appreciative of... I’ve tried to reach out to other support groups and it’s not quite the same. People get quite afraid when you start talking about sepsis in your child.”

### Theme 1.2 Continuing bonds

**Summary:** For bereaved families, a remembrance ceremony provides a supportive environment for the family and staff to honour their child, acknowledging the enduring connection with their child.

*“Some hospitals do a memory day or remembrance ceremony, it is the most beautiful event.”*

### Theme 1.3 Challenges for rural and remote

**Summary:** Identifying tailored solutions for limited access to bereavement care services is crucial for families in rural and remote areas.

“It’s such a journey for them [rural families who lose children]. And there isn’t really much. As a community, everyone’s on board and supports them. But it’s not a formalised process.”

## 2 Understanding lived experience

### Theme 2.1 Experience of bereavement support

**Summary:** Care for bereaved families should address the noted gaps in current bereavement support. This includes lack of bereavement support in rural areas, limited opportunities for connections with others with similar experiences, feelings of abandonment by hospital systems after their child’s death and delayed linkage with bereavement support.

*“We had SW but then as soon as we stepped away, there wasn’t anything happening in the background. So our initial thing was very much stepping away with nothing, which I found to be horrific. I found that to be really hard.”*

## 3 Clinician’s Guideline for Care

### Theme 3.1 Key contacts

**Summary:** Effective and coordinated bereavement care is dependent on engaging key contacts who can offer support within the local community. This may include palliative care teams, Indigenous elders, Connected Care nurses, CHQ Bereavement Service, social workers, counsellors, and medical staff.

“There are some benefits to it not being us, and I think it also gives families that ability in that really acute grieving phase to not be connected to our service.”

### Theme 3.2 Process for post sepsis bereavement care

**Summary:** Post-bereavement care, ideally in the community, is essential, respecting families’ reluctance to return to the hospital. With a focus on understanding and remembrance, this care should include open conversations, provision of written resources detailing support services, and ongoing follow-up.

*“We have so much that we need to do better, leaving families to, you know, leave a hospital with no understanding about what the hell happened; that’s horrendous.”*



### Theme 3.3 Practicalities

**Summary:** Consider practical suggestions to incorporate into the guideline for bereavement care.

“It can be very, very difficult to navigate [google and website] systems sometimes. That can be very daunting for a family that may even want to actually look into things. It needs to be simplified.”

### Theme 3.4 Role of primary care

**Summary:** Primary care clinicians are recognised as being a primary point of contact for many families and their role is therefore critical, both in having an informed understanding of the impacts of sepsis and available bereavement supports. However, access to GPs, particularly outside urban areas, is currently challenging, impacting care delivery.

“GP’s are a really weak link. They don’t understand it. They don’t know anything about it. Every time I go to a GP, I mention sepsis and they look at me like I’m from another planet.”

### Theme 3.5 Resources

**Summary:** Existing bereavement resources can be utilised for bereavement care and shared with families as a written resource. This includes paediatric palliative care services in Brisbane, Sepsis Peer Mentor Program, QCH Bereavement Service and bereavement services offered by Social Workers.

*“Providing a general bereavement info pack with next steps, support services etc”*

## 4 Communication Process

### Theme 4.1 Communication process

**Summary:** Services should aim to be patient and family centred and prioritising a communication process that is sensitive, informative, timely and respectful. It is vital for clinicians to provide a standardised bereavement care process that reflects empathy and understanding from all healthcare providers, rather than it being dependent on individual compassion.

“In terms of an overall process, it’s not good enough that it comes down to one person supposedly being gracious enough or kind enough to sit and have these conversations with you. That should be minimum level of care for a family to be able to have these conversations.”

### Theme 4.2 Communicating with families

**Summary:** The importance of shared conversations and the treating team providing clear information with families about their child’s death is noted, in context of parents’ lived experience of receiving a complete lack of information.

“I think if you don’t do that debrief, there’s often a lot of mistrust for coming back. We need to try to enable people to still have that faith and trust in their local health system. “

# Identifying the solution

The key actions required to sustainably provide post sepsis care to families (surviving and bereaved)

Using the key themes, we can identify the key actions required to sustainably provide post sepsis care to children with ongoing impacts of sepsis and their families (surviving) and families bereaved due to sepsis (bereaved). These actions will inform the development of a Paediatric Post Sepsis Model of Care (Figure 3).

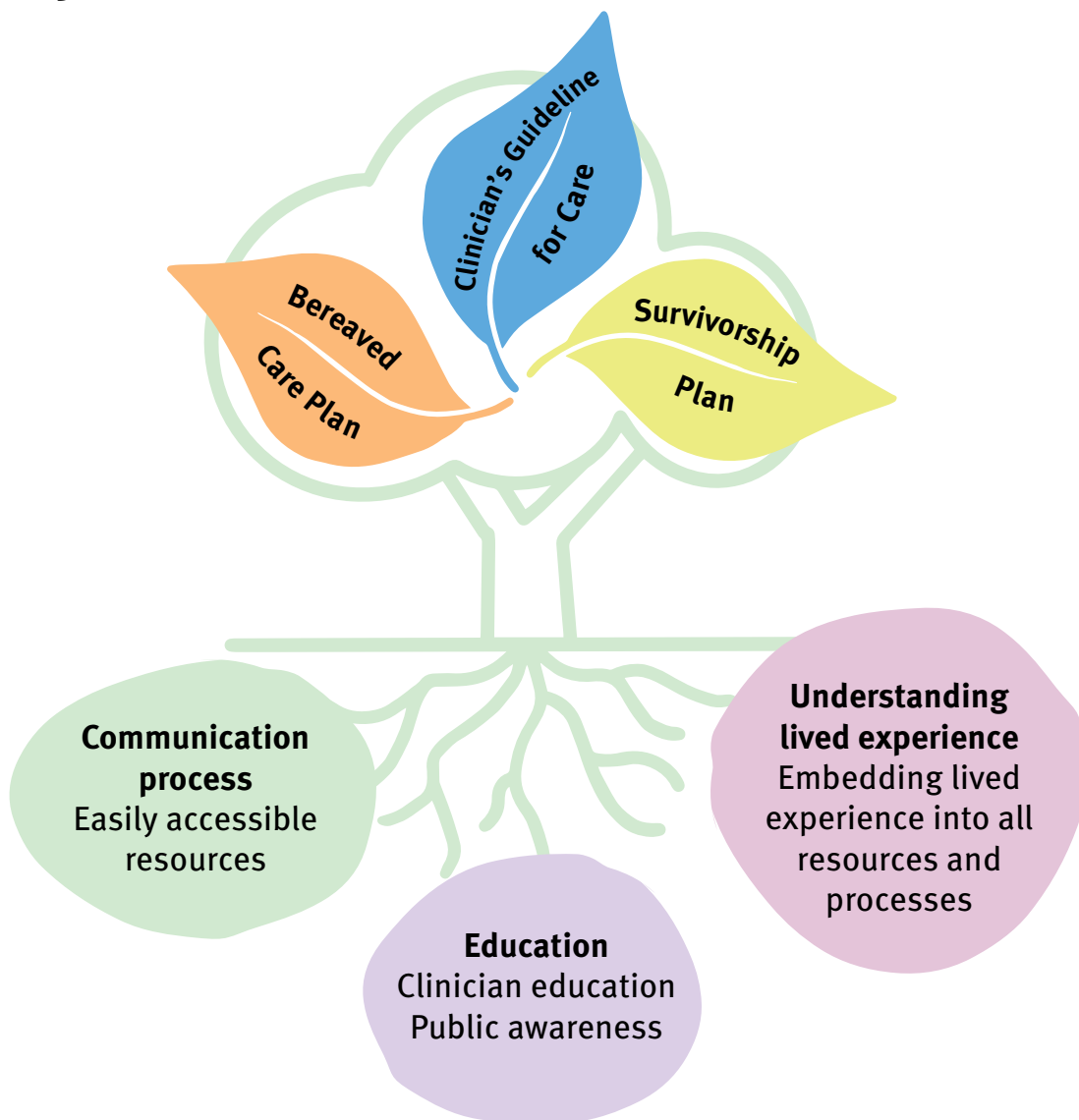


Figure 3. Themes (to identify actions) for Paediatric Post Sepsis Model of Care

In summary, the key themes can be distilled into the development of a Survivorship Plan for the parents of children with ongoing impacts (surviving), a Bereaved Care Plan for the parents of children who die due to sepsis (bereaved) and a Clinical Guideline for Healthcare Professionals to offer guidance and resources to utilise in their ongoing management of these children, post hospital admission.

All actions should align with the NSQHS Sepsis Standard in a way that reflects an understanding of the lived experience of those affected by sepsis, an open and beneficial communication process between relevant parties and an education process that informs families and clinicians about post sepsis care. The post-sepsis model of care should identify and use existing networks, infrastructures, resources, and services, where possible.

#### Details of actions:

### Development of a Survivorship Plan

1. Parents and carers should be provided with a detailed and individualised plan, on hospital discharge, that provides them with key information about their child's diagnosis. It should provide evidence-based information about sepsis, the impacts of sepsis, and links to key supports.
2. Parents and health professionals require access to evidence-based information about sepsis and the impacts of sepsis to effectively support and advocate for children affected by sepsis. This information should be provided in a form that utilises current resources, networks and infrastructure and ensures equity of accessibility.
3. It is essential to identify solutions for families living in rural and remote areas to the known barriers in accessing health care.
4. Survivorship plans should consider group and peer support options for families affected by sepsis, as these are proven to provide validation and normalisation of their experience.
5. A nominated key contact/coordinator is essential in the provision of effective and coordinated support post discharge.

### Development of a Bereaved Care Plan

1. Care plans should consider group/peer supports for families bereaved due to sepsis, as it provides validation and normalisation of their unique sepsis experience, enhancing their coping and sense of belonging.
2. For bereaved families, a remembrance ceremony should be considered as an essential component of the care plan as it provides a supportive environment for the family and staff to honour their child.
3. It is essential to identify tailored solutions for families living in rural and remote areas, with limited access to bereavement care services.

### Development of a Clinician's Guideline for Care (surviving and bereaved)

1. Clinicians require clear post-discharge guidelines for children recovering from sepsis, including a flagged diagnosis in discharge summaries, summary of ongoing impacts, key contacts and services, and written resources.
2. Clinicians require post bereavement care guidelines, which includes written resources detailing support services, open conversations, and ongoing follow up.
3. Post discharge care requires a central coordinator / key contact to be a key communication point between services and families to ensure delivery of locally based care.
4. GPs and primary care health professionals may be the primary point of contact for many families and should be informed, educated and resourced to provide post sepsis and bereavement care in collaboration with other key health services.
5. The guideline for care should consider the needs of parents and capacity of clinicians, utilise current resources and services and include tailored solutions for vulnerable populations. These include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, those with low health literacy and those with comorbid conditions and/or disabilities.

## All actions need to:

Reflect an **understanding of the lived experience** of all those affected by sepsis (surviving and bereaved) including specific guidelines to address the needs of vulnerable groups, including Aboriginal and Torres Strait Islander people, culturally and linguistically diverse people.

1. Post sepsis care plans should consider the initial impacts and long term impacts of sepsis for the child and their family as well as the parent's/carer's experience of their child's diagnosis, hospital admission and post discharge experience.
2. Care for bereaved families should address the noted gaps in current bereavement support.

Use a **communication process** that meets the needs of those directly affected by sepsis, and those working with these families; and

1. Services should be patient and family centred and using a communication process with families that supports them to build trust in the healthcare system. This includes providing a central, reliable information source and ongoing education about sepsis, the impacts and available supports and resources.
2. Clinicians require processes that support coordinated care for families affected by sepsis, such as a centralised database with suggested services.
3. Parents and carers should be acknowledged as experts in their child and empowered to actively participate in their child's care journey.
4. Parents and carers should receive a standardised bereavement care process that reflects empathy, understanding and clear information from all healthcare providers, rather than it being dependent on individual compassion.

Be shared with public and health professionals through an **education** and public awareness campaign.

1. Clinicians should have access to education, training, and resources to understand the impacts of sepsis and effectively support families.
2. Families, especially parents and carers, should be provided with education, information and resources to understand the impacts of sepsis and how to access support.

## ALL actions Need to:

Reflect an **understanding of the lived experience** of all those affected by sepsis (surviving and bereaved)

Use a **communication process** that meets the needs of those directly affected by sepsis, and those working with these families

Be shared with public and health professionals through an **education** and public awareness campaign.

# Appendix 1: Participants

Group	#	Initial	Position / profession / setting	HHS / location / consumer
1	1	CM	CNC / Nurse / Patient safety	DDHHS
	2	CB	Emergency specialist and paediatrician / ED	GCHHS
	3	DW	Social Worker / Connected Care & Rehab	CHQHHS
	4	ES	Clinical nurse / Educator / Rural medicine	CWHHS
2	5	CC	Nurse educator	MNHHS
	6	SR	Paediatric Emergency Specialist / ED	WMHHS
	7	HA	Social Worker / Paediatric ward	WBHHS
	8	NH	CNC / Paediatric Oncology	SCHHS
3	9	KP	Registered Nurse / ED	WMHHS
	10	KT	Nurse Management Consultant / Sepsis	NT Health
	11	LR	Nurse Education Coordinator / Paediatric	NT Health
	12	SM	Paediatric Rehab Physiotherapist	CHQHHS
4	13	AW	Nurse Practitioner / Paediatric ED	CHQHHS
	14	CH	Clinical Nurse Consultant / Sepsis	MNHHS
	15	GT	Paediatric Emergency Specialist / ED	WMHHS
5	16	RP	ED Nurse / NUM Quality and Safety	WMHHS
	17	ME	Senior Medical Officer / Pharmacist	WMHHS
6	18	MH	Nurse Unit Manager	NWHHS
	19	VS	General Paediatrician	NWHHS
7	20	SJ	Paediatric Rehab Physiotherapist	CHQHHS
	21	RJ	Paramedic Educator / ICU Nurse	CHHHS
8	22	FY	General Paediatrician	SWHHS
9	23	MB	Clinical Nurse Consultant / ED	SWHHS
10	24	MB	Specialist Rehab Paediatrician	THHS
11	25	KB	Clinical Facilitator	DDHHS
12	26	OB	General Practitioner	MSHHS
13	27	MC	Executive Director Medical Services	TCHHS
14	28	LK	Senior First Nations Health Worker	THHS
15	29	DG	General Practitioner	MSHHS
16	30	CH	Specialist Paediatrician	CQHHS
17	31	RR	Emergency Physician	WMHHS
18	32	KT	ED Fellow; Clinical Lead QCH Sepsis Subgroup	CHQHHS
19	33	JH	Mother	C, s
	34	AW	Mother	C, s
	35	JE	Mother	C, s
	36	SF	Mother	C, s
20	37	DF	Mother	C, s
	38	LG	Mother	C, s
	39	CG	Father	C, s
21	40	AC	Mother	C, b
	41	RW	Mother	C, b
	42	MS	Mother	C, b
	43	JB	Mother	C, b

# Appendix 2: Health professionals' focus groups and interview questions

You have been invited to participate in these focus groups as you have expertise in working with families with a child or young person diagnosed with sepsis or other lifelong health condition. In our session today we would like to understand your current experience of working with these families and your ideas for how to provide optimal care and support.

1. What is your understanding of the ongoing impacts of sepsis for the child/young adult and their family (ie. What is your understanding of post sepsis syndrome)?
2. We would now like to explore your current experience of what education is provided to parents and carers about sepsis and post sepsis syndrome. We are going to explore this in relation to each point of the family's contact within the health system in which you work, including:
  - during child's hospital admission in critical care phase (PICU/ED)?
  - during child's hospital admission in ward phase?
  - at time of discharge?
  - at outpatient/follow up appointment?
  - at appointments with primary care clinician?

This question is completed as a timeline activity on screen using an interactive tool. Give participants the opportunity to "post" what education is provided at each point in timeline. Put the notes wherever they choose. FOCUS on what happens NOW; later will discuss what they would like to happen.

3. What support is provided to parents and carers following a diagnosis of sepsis for their child (surviving). Again we are going to explore this in relation to each point of the family's contact within the health system in which you work, including:
  - during child's hospital admission?
  - at time of discharge?
  - at outpatient/follow up appointment?
  - at appointment with primary care clinician?
  - long term?

This question is completed as a timeline activity on screen using an interactive tool. Give participants the opportunity to "post" what support is provided at each point in timeline. Put the notes wherever they choose. FOCUS on what happens NOW; later will discuss what they would like to happen.

4. Now let's consider bereaved families, what support is provided to parents and carers following the death of their child due to sepsis. Again we are going to explore this in relation to each point of the family's contact within the health system in which you work, including:
  - during child's hospital admission?
  - at time of death?
  - long term?

This question is completed as a timeline activity on screen using an interactive tool. Give participants the opportunity to "post" what support is provided at each point in timeline. Put the notes wherever they choose. FOCUS on what happens NOW; later will discuss what they would like to happen.

5. What do you identify as the key needs for surviving children and young people and their families following a diagnosis of sepsis, or other chronic health condition, following discharge from hospital?
6. What do you identify as the key needs for families who are bereaved, due to their child's sepsis diagnosis or other chronic health condition?

## Appendix 3A: Consumers' (surviving) focus group questions

Research indicates that children diagnosed with sepsis frequently experience a variety of impacts (medical, physical, attention to tasks, thinking and problem solving, emotional, and relating to family relationships), some of which may be lifelong. This is sometimes referred to as 'post sepsis syndrome'. In our session today, we have 2 key aims - to explore your experience of how your child and your family have been affected by sepsis, and secondly, to hear your ideas regarding the ideal model of services and supports for families like yourselves.

1. Can you tell me what it was like for you, your child and your family being able to go home after your child's admission?
2. What did you understand about the potential long term impacts of sepsis when you were able to go home after your child's admission?
3. How did you develop your current understanding of the impacts of sepsis (may have been multiple ways)?
4. What do you want health professionals to know about the impacts of sepsis (post sepsis syndrome) on:
  - your child
  - you, as their parent/carer
  - other family members?
5. Putting aside all possible challenges or barriers, what do you think are the key support needs for families with a child affected by sepsis?

## Appendix 3B: Consumers' (bereaved) focus group questions

Our research shows that when families are bereaved following a diagnosis of sepsis that they are often left feeling alone, confused and unsupported. In our session today, we have 2 key aims - to explore your experience of the health care system, and secondly, to hear your ideas regarding the ideal model of services and supports for families like yourselves.

1. Many families have shared with us their experiences from when their child died from sepsis. We know from these stories that we need to do more, do better to support families. Firstly, we'd like to understand what the support from the hospital was like for you and your family following the death of your child?
2. Can you share with us what you understood about your child's diagnosis of sepsis at the time of their hospital admission? Is that different to your understanding now?
3. How did you develop your current understanding of sepsis and the impacts of sepsis (may have been multiple ways)?
4. Putting aside all possible challenges or barriers, what do you think are the key support needs for families following the death of their child due to sepsis?

# Appendix 4A: Community consultation data SURVIVING (codes – subthemes – themes)

Code	Subtheme	Theme
Survivorship plan	Survivorship plan	Survivorship plan
Written resource	Sepsis resources	
Written resource – sepsis		
Video resource		
Verbal resource		
Community resources - non sepsis	Current resources	
Gaps in post sepsis care	Gaps in resources	
Challenges for rural and remote	Challenges for rural and remote	
Benefits of peer support	Benefits of group support	
Benefits of group support		
Care Coordinators	Key contacts	Clinician's Guideline for Care
Linkage with the right person	Discharge planning	
Discharge process		
Discharge resource		
Considerations for implementation	Considerations for implementation	
In hospital support	In hospital support	
Process for post sepsis care- clinicians	Out of hospital care	
Post sepsis service providers		
Outpatient support		
Practicalities	Practicalities	
Role of primary care	Role of primary care	
Long term impacts-familial	Long term impacts	Understanding lived experience
Long term impacts-general		
Long term impacts-psychological		
Long term impacts-cognitive		
Long term impacts-physical		
Impacts of sepsis for family	Initial impacts	
Parental adjustment	Parent's experience	
Parental role minimisation		
Parent's experience of medical staff		
Clinician's perception of family experience		
Communication needs of families	Communicating with families	
Information finding		
Information sharing		
Information sharing within teams		
Empowering family		
Knowledge gaps for clinicians	Clinician education	Education
Education for clinicians		
Public awareness		



# Appendix 4B: Community consultation data BEREAVED (codes - subthemes - themes)

Code	Subtheme	Theme
Benefits of peer support	Peer support	Bereaved Care Plan
Benefits of support group		
Remembrance	Continuing bonds	
Challenges for rural and remote	Challenges for rural and remote	
Bereavement support care team	Key contacts	Clinician's guideline for care
Key contacts		
End of life support		
Community support	Process for post sepsis bereavement care	
Process for post sepsis bereavement care		
Practicalities	Practicalities	
Role of primary care	Role of primary care	
Service resource	Resources	
Written resource		
Clinician's experience of bereavement	Experience of bereavement support	
Grief experience		
Parent's experience of bereavement		
Confusion about diagnosis	Communication process	Communication process
Information finding		
Parent's perception of communication		
Information sharing		

# Glossary

Acronym	
QPSP	Queensland Paediatric Sepsis Program
NT Health	Northern Territory Health
DDHHS	Darling Downs Hospital and Health Service
GCHHS	Gold Coast Hospital and Health Service
CHQHHS	Children’s Health Queensland Hospital and Health Service
CWHHS	Central West Hospital and Health Service
WMHHS	West Moreton Hospital and Health Service
WBHHS	Wide Bay Hospital and Health Service
SCHHS	Sunshine Coast Hospital and Health Service
MNHHS	Metro North Hospital and Health Service
NWHHS	North West Hospital and Health Service
THHS	Townsville Hospital and Health Service
TCHHS	Torres and Cape Hospital and Health Service
C, s	Consumer, surviving
C, b	Consumer, bereaved
NSQHS	National Safety and Quality Health Service
HP	Health Professional
LAPSE	Life After Paediatric Sepsis Evaluation
LOTUS	Long term Outcomes after paediatric sepsis

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Queensland Paediatric Sepsis Program

# Paediatric Post Sepsis Model of Care

