Sepsis Support Research Program
Consumer Focus Groups Report

As part of the Sepsis Support Research Program, people with lived experience of sepsis (survivors, families, carers and bereaved) along with health professionals, participated in four focus groups at the Sepsis Australia National Consumer Symposium on the 30th of July 2026 where preliminary survey results were discussed. These findings showed that health professionals valued coordinated, person-centred care; whereas people with lived experience of sepsis placed greater emphasis on family support and communication. Following that the focus groups covered two main questions: **Question 1: What do these priorities tell us about the experiences, challenges, and needs of sepsis survivors and their families? And Question 2: What do the similarities and differences between these priorities tell us about what matters most to patients and families compared with healthcare professionals?**

This is what you told us about your experience with sepsis: Sepsis affects not only those who survive, but also families, carers, and bereaved loved ones who often continue to experience significant emotional, psychological, social, and practical consequences long after the acute illness.

These were the most significant issues identified in the focus groups:

1. Information, communication & awareness • Limited public awareness of sepsis • Poor understanding of post-sepsis syndrome • Inadequate discharge information • Communication gaps between diagnosis and care • Lack of explanation surrounding deaths from sepsis • Need for clear, timely, compassionate follow-up after a sepsis-related death	**2. Family, carer & bereaved support** • Family involvement in care and decision-making • Carer support needs • Lack of managing emotional trauma after sudden deterioration • Unanswered questions following bereavement • Complicated grief due to poor communication and support
3. Coordinated recovery & follow-up care • Limited access to rehabilitation services • Lack of follow-up after the death of a loved one • Need for care planning and coordination • Fragmented healthcare pathways • Need for ongoing health assessments • Lack of continuity of care across services • Need for bereavement and psychological support • Requirement for multidisciplinary rehabilitation	**4. Ongoing impacts of sepsis** • Physical health challenges • Cognitive difficulties • Psychological distress • Long-term recovery needs • Impact of post-sepsis syndrome • Persistent uncertainty about health
5. Community participation & daily life • Return to work challenges • Reduced social participation • Impact on daily activities and independence • Family life disruptions • Need for community support and understanding • Social isolation and reduced quality of life	**Key messages** • you called for coordinated, person-centred and family-centred post-sepsis care that recognises sepsis can affect survivors, families, carers and bereaved loved ones long after the acute illness. • Practical, timely and compassionate information, communication, follow-up and support should continue beyond hospital discharge and include those living with recovery, supporting a loved one, or coping with bereavement.

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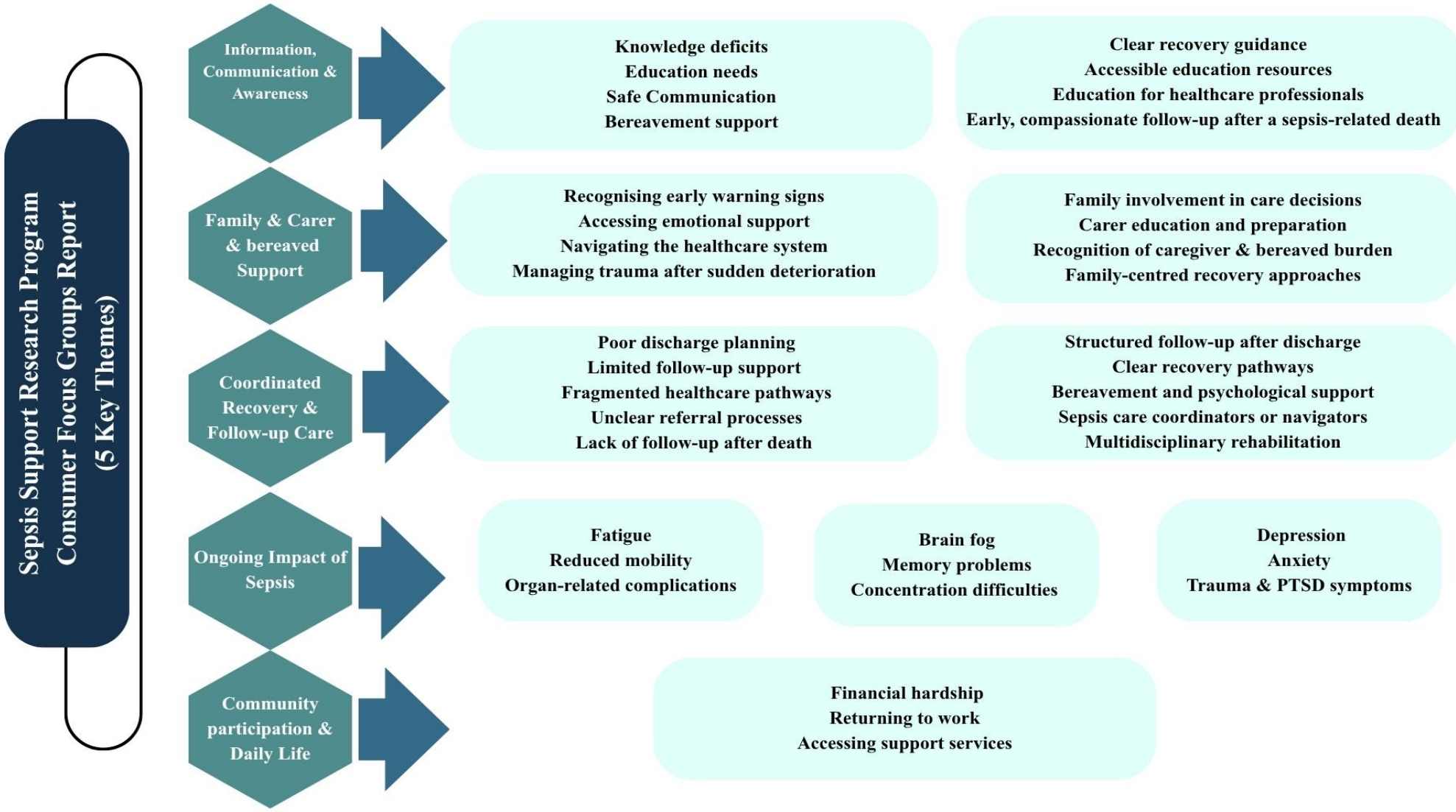

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If you have additional feedback or any question, please click on the link below:

https://forms.cloud.microsoft/r/mkxL9bWBZB