

Post Sepsis Care Consumer Survey Report

Executive Summary
February 2025

Background

Sepsis survivors often face lasting health complications, including functional limitations, cognitive impairments, and psychological issues, collectively known as post sepsis syndrome (PSS). Australian sepsis survivors report significantly higher rates of moderate to extreme deficits in all domains of health-related quality-of-life at six months after Intensive Care Unit (ICU) admission compared to population norms. These chronic disabilities persist for years after hospital discharge, affecting up to half of all sepsis survivors. These issues highlight the need for ongoing support and structured follow-up care to improve their quality of life and reduce long-term morbidity. This evaluates the experiences and impact of sepsis on survivors and the post sepsis care provided in Queensland Health facilities. It aims to identify gaps in services, supports, and resources, and to inform recommendations to address these gaps and improve care.

Method

An online survey targeting sepsis survivors was distributed between October and November 2023 through a range of channels including external media platforms and networks (Facebook sepsis support groups, Primary Healthcare Networks and Health Consumers Queensland etc.), and internal Queensland Health networks (Spotlight, eAlert, QHealth Newsletter and Sepsis eBulletin). The survey consisted of 58 questions including Likert-scale items, yes/no responses, and open-ended text responses. Data were analysed quantitatively (means, percentages) and qualitatively (coded into themes) to assess the impact of sepsis on health and daily activities, and to collate respondent feedback on their experience and the care they received.

Results

The survey gathered data from 99 eligible respondents, capturing their experiences and outcomes related to sepsis treatment and recovery. Results were analysed in alignment with the Australian Sepsis Clinical Care Standard (SCCS). The SCCS includes seven quality statements to ensure early recognition of sepsis and delivery of coordinated, best-practice care, focusing on multidisciplinary coordination, ongoing patient and carer education, clinical handovers, and comprehensive follow-up care. Data analysis focused on SCCS Quality Statements 4 through 7, which are relevant to post sepsis care.

Impact of Sepsis

The survey results show that sepsis significantly affects survivors' health and quality of life. Prior to sepsis, only 2% of participants rated their health as very poor, but this rose to 17.3% post sepsis. Conversely, those rating their health as very good dropped from 36.4% to 9.2%. Additionally, 29% of participants developed new disabilities, with 75.9% reporting that these disabilities made everyday activities much harder. Furthermore, 79.8% noted that their symptoms made it harder to work or perform daily tasks, such as going to work or school, managing household chores, and socialising. Common persistent physical symptoms included fatigue (91.9%), weak muscles (62.6%), joint pain (53.5%), memory problems (53.5%), and brain fog (59.6%). Emotional and psychological challenges were also prevalent, with 57.6% feeling anxious or less confident, 51.5% experiencing mood swings, and 47.5% losing interest in activities.

Inpatient Care

SCCS Quality Statement 4 highlights the importance of multidisciplinary coordination in hospital care for sepsis patients. Survey results found 44.9% of participants experienced problems with how their hospital care was organised. Of these, the most reported problem was coordination between the hospital and their local doctor post-discharge (affected 60.5% of these participants). Effective coordination is essential for optimising patient outcomes and satisfaction.

Quality Statement 5 emphasises ongoing education for patients and carers about sepsis and stages of recovery. While 82.8% of respondents knew they had sepsis during their hospital stay, 16.2% did not. Only 26.8% felt they always received enough information about sepsis treatment. Additionally, 52.5% were not informed about signs of worsening sepsis, and 30.5% felt that treatment was not explained in a clearly understandable way. These findings suggest the need for improved communication and standardised information delivery.

Quality Statement 6 underscores the importance of clear communication during care transitions. The survey revealed that 37% of participants felt adequately involved in care decisions, while 83% did not feel fully engaged or were unsure about their involvement. Improved communication among healthcare providers is essential for smooth transitions and effective post-discharge care.

Care After Hospital and Survivorship

Quality Statement 7 emphasises the need for comprehensive follow-up care. Survey results showed that 68.7% of respondents felt their family or home situation was not adequately considered during discharge planning. Additionally, 57.2% felt they did not receive enough information to manage their care post-discharge, and 62.2% felt not informed about signs of sepsis recurrence. Communication gaps between hospitals and local doctors were noted by 30.9% of respondents. Fifteen percent of respondents highlighted the need for comprehensive discharge information, with patients desiring detailed instructions on managing their condition post-discharge. Comprehensive discharge planning and effective post-discharge education are crucial for optimising patient outcomes and reducing re-hospitalisations.

Conclusion and Recommendations

The results of this survey clearly highlight gaps in post sepsis care, particularly in areas of care coordination, patient and carer education, communication during transitions, and comprehensive follow-up care.

Based on these findings, this report recommends the following actions.

- The findings from this survey be used to help inform the National Health and Medical Research Council (NHMRC) Sepsis Support Project in developing a model for post-sepsis care.
- The Queensland Sepsis Steering Committee (QSSC) considers the findings of this report and uses them to guide Queensland Sepsis Program (QSP) in supporting Hospital and Health Services to implement improvements in post-sepsis care, promoting alignment with the SCCS.

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