

**BACKGROUND** - Sepsis Australia, hosted by The George Institute for Global Health, is a collaborative of individuals and organisations who are working to improve outcomes for Australian patients with sepsis and to provide information and support to the families and friends of people with sepsis. Sepsis Australia does not duplicate the efforts of its state, territory, professional and consumer partners, but rather provides an avenue through which members can collaborate to better disseminate information about sepsis to healthcare workers and the general community. Sepsis Australia is hosted by The George Institute for Global Health.

**MISSION** - to reduce the Australian burden of disease (death and disability) due to sepsis by:

- increasing awareness of sepsis in the general community and by politicians, policymakers, and healthcare workers
- coordinating a national approach to World Sepsis Day on 13 September
- partnering with collaborating organisations to support all state and territory health services, professional societies and colleges, and clinicians promulgating best practice such as the NSW CEC “Sepsis Kills” program and other local initiatives to tackle sepsis across the entire healthcare spectrum
- working to ensure a high national standard of sepsis awareness, prevention, clinical care, post-sepsis care, and support through the development and dissemination of comprehensive clinical care standards
- developing education resources and building sepsis research capacity.

Our mission will be achieved by supporting patients with sepsis and their families and friends by:

- raising public awareness to ensure that the signs of sepsis become well known in the community so that patients with sepsis seek appropriate treatment without delay
- providing information about sepsis and its consequences
- providing an avenue for the development of patient/carer-led support groups
- providing a platform for community engagement.

### **SEPSIS AUSTRALIA CONSUMER PARTNER AND ADVOCACY PROGRAM (SACPAP) -**

Consumer partnerships, involvement, and advocacy are critical for Sepsis Australia to achieve its mission. Consumer partners are valued for contributing their knowledge, experience, and insights, which contribute to improving the early diagnosis and treatment of sepsis and post-care and support.

Sepsis Australia invites consumers with a lived experience of sepsis to participate in the Consumer Partnership and Advocacy Program. This group collaborates to share experience, knowledge, advice, and ideas that are captured by Sepsis Australia and applied to improved sepsis outcomes for all.

Sepsis Australia recognises that the impact of sepsis can be traumatic and does not place any expectations on the level of contribution from SACPAP members. Any level of involvement is welcomed and valuable.

**KEY FUNCTIONS** - are based on the understanding that those affected by sepsis:

- have a right to be informed about the work undertaken by Sepsis Australia to improve awareness, diagnosis, treatment, and post-care.
- are integral in delivering the Stopping Sepsis: National Action Plan, National Sepsis Program and Sepsis Clinical Care Standard
- are provided opportunities to be involved with sepsis research projects that are undertaken or validated by Sepsis Australia.
- are provided opportunities to impact the work of Sepsis Australia through their lived experience and skills.

The functions of the SACPAP are to:

- help inform Sepsis Australia's program of work
- provide guidance, advice, and input into research, projects and collaborations
- provide insight on local and regional issues and activities to improve outcomes for individuals and vulnerable populations
- assist in identifying gaps, barriers, strengths, and opportunities for improvement in the involvement of consumers and the community in the organisation's work
- ensure that relevant communications are appropriate for consumers and communities
- participate in programs aligned with their capacity, capability, and interest
- encourage others to participate in the consumer partner and advocacy network
- promote the public profile of the Institute's research.

**SACPAP ROLE** - The key role of SACPAP participants is to be the voice of consumers and community members who are or have been impacted by sepsis. Sepsis Australia conducts a regular forum to advise on the Sepsis Australia program, projects and activities, and provide a forum for open discussion on issues that impact the implementation of the sepsis program. As such, the key functions of SACPAP will be facilitated by ensuring issues and opportunities are discussed supporting feasible and meaningful objectives and timeframes. A member can decrease or increase their involvement at any time, or leave the network if preferred at anytime.

**MEMBERSHIP** - Diversity of membership is encouraged and sought to accurately represent all those impacted by Sepsis and to gain insight and knowledge on distinct impacts and issues, with the core membership consisting of:

- Sepsis survivors, their families, carers and loved one's, and those bereaved by sepsis
- Community advocates for sepsis
- Sepsis Australia Program Manager
- Sepsis Australia Digital Engagement and Events Coordinator
- SACPAP Consumer and Community Engagement Coordinator
- Presenters and external stakeholders by invitation.

SACPAP participation will be via an expression of interest (email/call). In addition to some demographics and contact information, interested individuals will be asked to briefly outline:

- their lived experience of sepsis and relevant skills, knowledge and/or experience
- what they would like to achieve by being involved
- any involvement with other consumer/community advocacy groups or networks

**CHAIR** - The Sepsis Australia Program Manager is the SACPAP Chair with responsibilities including:

- ensuring the purpose and functions of the Program are clearly articulated to all members
- chairing all Program meetings but if unavailable then default to the Consumer and Community Engagement Coordinator or a suitable substitute
- brief the participants on activities and provide advice, guidance, and direction as required
- ensuring proper conduct, running to time; and explaining agenda items to ensure all understand the content and context at hand and the decisions to be made (if any).
- encouraging broad participation in discussions and ensuring all participants feel they have equal opportunity to input and that their opinions are valued.

**SEPSIS AUSTRALIA RESPONSIBILITIES** – these include:

- supporting and facilitating meaningful partnerships between researchers and consumers
- providing advice and guidance to researchers seeking to involve consumer
- identifying and providing opportunities for consumer involvement in the program, discreet projects, education and research
- establishing the structures and processes and developing the relevant documentation required to support consumer partnerships and advocacy
- facilitating access to training and resources for both researchers and consumers.

## MEETINGS

Date/Frequency	Bi-monthly - flexible and guided by members' preference
Time commitment	1-hour meeting
Scheduling	Meetings will be scheduled at 6-week intervals at a time that suits the majority of participants. Alternative arrangements will be considered for those unable to attend either as a second follow-up meeting or a one-on-one discussion.
Attendance	<ul style="list-style-type: none"><li>• Via videoconference or teleconference.</li><li>• In recognition of each participant's own personal and professional time commitments, there is no obligation to attend each meeting if not available. A comprehensive meeting summary will be provided to support continuity of information and ongoing involvement.</li></ul>
Documentation	<ul style="list-style-type: none"><li>• A standing agenda will be provided with the addition of new research and projects as they arise.</li><li>• If required, a briefing document on specific projects or research studies will be provided prior to meeting</li></ul>
Involvement	Participants may elect to be involved through both meeting attendance and consultation via email correspondence OR solely via email correspondence depending on personal preference and availability. Activities may include: <ul style="list-style-type: none"><li>• Voluntary participation in focus groups</li><li>• Nominating as a primary consumer representative on projects and research study teams</li><li>• Providing feedback on documents, materials, and activities such as sepsis awareness initiatives</li><li>• Completion of surveys</li><li>• Other activities as they arise.</li></ul>

**SITTING FEES** - Membership in the SAC PAP is voluntary. Where members nominate to be involved in formal research and project panels such as the NSPE, payment of a sitting fee and the coverage of travel expenses will be provided. Sitting fees are based on the [Consumer Health Forum Australia Sitting Fee Policy](#). Reimbursement forms and processes are managed by Sepsis Australia.

Participation in Sepsis Australia national symposium is voluntary with no sitting fee available, however funding for travel and accommodation will be provided following consultation with and approval by the Sepsis Australia Program Manager.

**CONFIDENTIALITY** - Matters discussed at this meeting may be confidential and must be treated as such. Upon joining the Program, all members will enter into a Consumer Involvement Agreement with The George Institute which includes a Privacy and Confidentiality Agreement.

**CONFLICT OF INTEREST** - A conflict of interest can occur when there is a real or perceived conflict between a person's duties or responsibilities and their private interests or the interests of other roles they have in the community. A conflict of interest may prejudice or be seen to prejudice a person's ability to perform their duties and responsibilities objectively.

Members will be asked to complete a 'Conflict of Interest Checklist' once and declare any conflicts that arise. When meeting agendas are developed and shared, Program members need to check whether there might be actual, perceived, or potential conflicts of interest. If there are, members should contact the Sepsis Australia Program Manager to detail the conflicts and to discuss how they will be managed.