



Guiding Principles
For
Lived Experience Engagement
In
Research and Health Policy
Development

Engaging People with POTS in Research and Policy Development

The Australian POTS Foundation (APF), as the only peak body representing people with POTS in Australia, encourages researchers and health policy groups to adopt best practices for engaging our community in meaningful and effective ways. We strongly recommend following these principles to ensure authentic lived experience participation:

1. Recruitment Through the Peak Body

To ensure diverse representation, researchers and policy groups should recruit POTS participants through the APF. This approach aligns with the **Consumer Health Forum's (CHF)** principle that individuals with lived experience should be nominated by an appropriate representative network, ensuring they are placed with the confidence of their community and supported by a consultative base. Direct recruitment of individuals without engaging a representative network is discouraged.

2. Include a Range of Perspectives

Avoid sourcing participants solely from academic or research environments. The voices of non-academic individuals are critical in representing the broader lived experiences of individuals with POTS, particularly those from under-represented groups, including:

- **Gender diversity**
 - **Culturally and Linguistically Diverse (CALD)** backgrounds
 - **Rural and urban areas**
 - **A range of ages and life stages**
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3. Principles of Co-Design

APF encourages researchers to adopt principles of **co-design**, which involve engaging consumers people with lived experience in implementation, and evaluation of research projects. By involving individuals as co-creators rather than just participants, research outcomes are more likely to reflect the real needs and priorities of the community.

4. Community as Participants vs Partners

It is important to distinguish between recruiting individuals with lived experience as **participants** and as **partners** in research:

- **Participants:** In this role, people with POTS contribute data or insights for a study and are typically not involved in broader research processes. Ethics approval is generally required before researchers can engage with participants.
- **Partners:** People with lived experience of POTS act as collaborators in the research process, contributing to study design, methodology, and dissemination of findings. This

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approach does not typically require ethics approval for initial engagement but involves sustained collaboration throughout the project.

Recruiting people with POTS as partners fosters genuine collaboration and ensures research outcomes are meaningful and actionable for the community.

5. Support and Remunerate Participants and Partners

Recognise the value of lived experience by providing fair remuneration for time and contributions, ensuring equitable access and reinforcing the importance of their expertise. Cover associated costs such as travel when required. Contribute to expenses incurred by governing and representative bodies, including recruitment, support, and facilitation of lived experience engagement. Their contribution ensures the safeguarding, support, and facilitation needed to sustain meaningful engagement and embed lived experience at the core of decision-making and advocacy efforts.

6. Accommodations for People with Lived Experience of POTS

Engaging individuals with POTS requires thoughtful accommodations, given the fluctuating and often debilitating nature of the condition:

- **Flexible Meeting Formats:** Conduct online meetings with access to recordings for those unable to attend live due to illness.
 - **Symptom-Aware Scheduling:** Schedule meetings after lunch to accommodate the common worsening of symptoms in the morning.
 - **Environment Sensitivity:** Avoid high-stimulus settings, as these can exacerbate symptoms such as brain fog and fatigue.
 - **Iterative Engagement:** Allow for flexibility and follow-up participation to ensure input isn't lost during symptom flare-ups.
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7. Terminology

In general, people with POTS have indicated a preference not to be called 'consumers,' as this implies that they are making a 'choice' to engage with healthcare rather than doing so out of necessity. It also alludes to the cost burden of care. Generally, there is a preference for person-first terms such as 'people with POTS' or 'people with lived experience.'

8. Lived Experience Representation on Committees

Lived experience representation is vital for policy development and decision-making processes. Drawing from CHF guidelines, we recommend:

- Including people with POTS on national committees with health remits.
- Supporting lived experience representatives with resources, training, and mentorship to navigate professional committee environments.

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- Ensuring lived experience representatives have access to information and checklists to prepare for their roles effectively.

As CHF notes, *“The role of a consumer representative is to provide a consumer perspective, contributing experiences, ensuring consumer concerns are recognised, and protecting the interests of service users.”* For more on CHF principles, visit [Consumer Health Forum](#).

The APF’s Commitment

We are committed to ensuring researchers and policymakers can access the expertise of people with POTS while fostering a culture of inclusivity and respect. By adopting these recommendations, you will not only amplify the voices of people with POTS but also contribute to research and health policy that truly reflect their needs and priorities.