

The Australian POTS Foundation is committed to supporting and encouraging the meaningful engagement of people with POTS as active partners in research, health service delivery, and health policy development. We recognise the critical value of lived experience in shaping approaches that are patient-centred, evidence-based, and impactful. By fostering collaboration between people with lived experience, researchers, and healthcare professionals, the Foundation aims to ensure that the voices and needs of those affected by postural orthostatic tachycardia syndrome (POTS) are central to advancing research, improving healthcare services, and influencing policy decisions that enhance quality of life.

If you're interested in partnering with the Australian POTS Foundation (APF) to engage people with lived experience in research, health service delivery, or health policy initiatives, we invite you to review our **Lived Experience Engagement Framework**, available on our website. These principles reflect our commitment to ensuring that all collaborations with the POTS community are meaningful, ethical, and impactful.

To help us achieve this, we ask that applications for support take the following into account:

- Sufficient time for the APF to review your protocol and request thoughtfully.
- A clear explanation of your research, health delivery goals, methodology, and anticipated outcomes.
- Alignment with the ethical people with lived experience engagement practices outlined in our Guiding Principles.
- Involvement of an APF Scientific Committee member as a Chief Investigator (CI) is encouraged for research grants where feasible. If this is not feasible due to restrictions, alternative meaningful roles for APF representatives should be included.
- Funding allocations for the APF to facilitate the recruitment, screening, and support of individuals with lived experience should be incorporated into grant budgets and proposals wherever permitted.
- Acknowledgment of Involvement: We kindly request written recognition of the APF's involvement and consumer engagement efforts in any publications, presentations, or reports related to the project.
- Sharing Outcomes: To ensure the POTS community benefits from the research, we ask that a summary of key findings and outcomes be shared with the APF in a format suitable for dissemination. This helps us keep our community informed and engaged.
- Ongoing Communication: We value collaboration and appreciate regular updates on project progress and outcomes. This helps us stay aligned and ensures the work remains meaningful to those affected by POTS.
- If you are requesting a letter of support for a grant application, the APF requires full disclosure of the research protocol (draft versions are welcome). This ensures that the project aligns with and reflects the values of the POTS community.

The APF is proud to support projects that demonstrate a strong commitment to Lived Experience engagement, include budgeted remuneration for consumers, and address the priorities and needs of the POTS community.

1. Type of Activity

(Please select the type of activity you are seeking APF's involvement in.)

Recruitment of consumers for:

Lived experience co-design/advisory committee recruitment (*For service delivery and research projects. Complete section 2,3 & 5*)

Participant research engagement (e.g., recruitment of participants for focus groups, surveys or intervention studies. Complete section 2,3 & 5)

Or

Partner support letter from the Australian POTS Foundation (For a grant applications. Complete section 2, 4 & 5)

2. Applicant Information

2.1. Name of Applicant/Primary Contact:

First Name, Last Name

2.2. Email Address:

Your email address

2.3. Phone Number:

Your contact number

2.4. Institution/Organisation Name:

Name of the institution or organisation you represent

2.5. Position/Role:

Your role within the organisation

2.6. Location:

City, State, and Country

2.7. Project Title:

2.8. Brief Description of Project:

Provide a short description of the project (50 words or less).

3. Details of Lived Experience Engagement

3.1. Type of activities:

What activities will participants be involved in?

3.2. How much time is expected for activity engagement?

3.3. Provide an expected timeline for the engagement activities.

Eg: four meetings a year over 5-year project

3.4. Do you plan to engage the APF to facilitate engagement activities

(APF can provide facilitation of co-design and focus group activities. See our Lived Experience Engagement Framework for more information)

3.5. Provide projected details of participant and Foundation remuneration.

See our Lived Experience Engagement Framework for more information

4. For Partner Support Letters Only – (Research Grants)

4.1. Principal Investigator(s) and Collaborators:

List the names and affiliations of any proposed Chief Investigators (CI).

4.2. Involvement of an APF Scientific Committee Appointed Member:

Note that the APF requires a member of its Scientific Committee to be meaningfully engaged on any grant application.

Please confirm this has been considered.

Yes, an APF Scientific Committee appointed member will be included.

No (If no please comment why not)

4.3. Remuneration:

Confirm that appropriate sitting fees will be provided for lived experience participants and/or the APF Scientific Committee appointed member.

Yes, sitting fees are budgeted.

Yes, APF facilitation and recruitment fees are budgeted.

4.4. Time for Consideration:

APF requires adequate time to evaluate the protocol and determine suitability for partnership. Please confirm you have accounted for this.

What is the date by which you require the letter of support

5. For all applications: Please confirm the following:

We will provide a summary of outcomes suitable for community dissemination through the APF?

Yes

No (If no please comment why not)

We will acknowledge the involvement of the APF and its community in project outputs (e.g., publications, presentations)?

Yes

No (If no please comment why not)

Acknowledgement and Agreement

Please review our **Lived Experience Engagement Framework** before submitting your application. By signing below, you confirm that you have read and understood these principles and agree to adhere to them throughout the proposed engagement.

Signature: _____

Date: _____

Submission Instructions

Please email your completed application form and any relevant documents to **research@potsfoundation.org.au**.

For further information, refer to our **Guiding Principles on Lived Experience Engagement** which can be found on our website or contact us directly.