Australian
POTS
Foundation

Lived Experience Engagement Framework

Guiding Principles for Ethical, Inclusive, and Sustainable Partnerships

Contents

1. Introduction

The integration of lived experience engagement is becoming an essential requirement across health research, policy development, healthcare models, and government initiatives. However, while the expectation for lived experience involvement is increasing, guidance on what meaningful engagement looks like and how it should be implemented is still evolving.

This framework provides a structured approach to lived experience engagement across key sectors, outlining different engagement methods, ethical considerations, recruitment best practices, and compensation models.

2. Where Lived Experience Engagement is Sought

Lived experience engagement is crucial in multiple sectors, including:

✅ **Research** – Ensuring studies reflect the priorities, experiences, and needs of those affected by a condition.

✅ **Health Policy** – Embedding patient perspectives in legislative and funding decisions.

✅ **Health Models of Care & Service Delivery** – Designing systems that are responsive to patient needs.

✅ **Government Bodies** – Informing inquiries, funding allocations, and policy reform.

Engagement in these areas can take various forms, from co-design and advisory committees to focus groups and surveys.

3. 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.

4. Include a Range of Perspectives

The voices of individuals with lived experience are essential in capturing the broader experiences of people with POTS. Actively engaging diverse perspectives—including those from underrepresented groups—ensures that research, policy, and support services are inclusive and reflective of the entire POTS community. This includes:

- People of diverse genders
- Individuals from Culturally and Linguistically Diverse (CALD) backgrounds
- Those living in both rural and urban areas
- Individuals across different ages and life stages

5. What Does NOT Constitute Consumer Engagement?

For engagement to be meaningful, it must be structured, reciprocal, and fully integrated into decision-making processes. The following examples illustrate practices that do NOT constitute meaningful engagement:

- Reading consumer stories or policy submissions without direct interaction.
- Speaking with patients in clinical settings and assuming their perspectives are fully captured.
- Applying for consumer body support without embedding lived experience in design or decision-making.
- Recruiting based on convenience (e.g., academics or clinicians with the condition in question, rather than ensuring diverse representation through peak bodies).

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.

7. Terminology

Community consultation processes have established that, in general, people with POTS prefer not to be referred to as ‘consumers,’ as this implies a choice in engaging with healthcare rather than a necessity. It also alludes to the cost burden they are to society through no fault of their own. Instead, there is a strong preference for person-first language, such as **‘people with POTS’** or **‘people with lived experience.’**

8. Ethical Considerations

Ethical challenges often arise due to historical research and governance frameworks that may not reflect modern engagement practices.

◆ **Distinguishing Research Participants from Research Partners**

- There is a distinction between research partners and research participants. People with lived experience can be both, but the focus of this document is research partner role. Research partners can include stakeholders from a range of disciplines (e.g., academic experts, clinical experts, policy experts, subject matter experts, technical experts, lived experience experts). These stakeholders can form part of the wider research team, governance groups, or committees that support the operation or governance of the wider research project. In general, the contribution of lived experience in the context of their role as a research partner in the wider research team does not require ethical approval.

◆ **Distinguishing research activities from activities that occur to inform research**

- Co-design can be used to inform a research project or be conducted within a research framework, and the distinction determines whether ethics approval is required. When co-design engages stakeholders to shape research priorities, refine study materials, or improve accessibility, it is considered stakeholder engagement, and ethics approval is not required. However, when co-design occurs within a research project—where people with lived experience participate as research subjects, contribute data, or inform findings—ethics approval is required.

◆ **Ensuring Safeguards Without Overprotection**

- Lived experience experts should be recruited from representative bodies to ensure adequate support and a level of safeguarding.
- Individuals with lived experience who participate in co-design that occurs prior to formal research projects should be recognised and engaged as subject matter experts.
- It is essential to avoid paternalistic approaches that undermine lived experience expertise, autonomy, and equal standing in the design process.

9. Types of Lived Experience Engagement

Lived experience engagement exists on a spectrum from active to passive participation. This framework outlines key engagement models and their best-practice implementation.

9.1 Co-Creation Partnerships

Definition: A highly collaborative process where individuals with lived experience are equal partners in designing research, policy, or service delivery. They are actively involved in problem identification, design, implementation, and evaluation.

◆ **Engagement Type:** Active

◆ **Engagement Level:** Commences with the project design and continues throughout the research project as part of the research team.

◆ **Ethics Approval:** Not required—lived experience participants should be viewed as research partners, akin to subject matter experts. Note: The research project may include a co-design component that recruits participants. This is a separate activity that would require ethics approval. The lived experience expert may work with the research team on this component of their study and they would not be considered a participant.

◆ **Recruitment:** Through peak/representative bodies to ensure community alignment, representative body support, and diverse participation.

◆ **Compensation:** Participants should be remunerated for their time, as with most subject matter experts.

◆ **Facilitation:** APF may either recruit and screen co-design partners or fully facilitate the co-design process, depending on project needs and available funding.

9.2 Lived Experience Advisory Committees

Definition: A structured committee of lived experience representatives who provide ongoing perspectives on projects, policies, or service improvements.

🔷 **Engagement Type:** Active
🔷 **Engagement Level:** Regular (e.g., quarterly or bi-monthly throughout the project).
🔷 **Optimal Size:** 6–12 members
🔷 **Ethics Approval:** Not required unless the committee itself is being researched.
🔷 **Recruitment:** Through peak/representative bodies to ensure community alignment, representative body support, and diverse participation.
🔷 **Compensation:** Sitting fee.
🔷 **Considerations:** Meetings should accommodate energy limitations for POTS participants (e.g., flexible formats, remote options).
🔷 **Facilitation:** APF may either recruit and screen advisory committee members or fully facilitate the committee's operation, depending on project needs and available funding.

9.3 Focus Groups, Interviews & Surveys

Definition: Facilitated discussions or structured interviews and surveys where participants provide insights on specific topics.

🔷 **Engagement Type:** Can be active or passive.
🔷 **Engagement Level:** Dependent on project requirements—may be a one-off or iterative throughout the project.
🔷 **Ethics Approval:** Required if data is used for research.
🔷 **Recruitment:** Through peak/representative bodies to ensure community alignment, representative body support, and diverse participation.
🔷 **Compensation:** Should be offered for focus groups; optional for surveys.
🔷 **Facilitation:** APF may either recruit and screen participants or fully facilitate focus groups, interviews, and surveys, depending on project needs and available funding.

9.4 Partner Letters & Endorsements

Definition: Seeking lived experience organisation support or input via letters, statements, or endorsements.

🔷 **Engagement Type:** Active
🔷 **Engagement Level:** APF requires ongoing engagement in projects it supports through the allocation of an appointed representative to a steering/oversight committee or as a CI/AI (Chief Investigator/Associate Investigator).
🔷 **Ethics Approval:** Not required.
🔷 **Recruitment:** Direct with the APF.
🔷 **Compensation:** Letters of support do not require payment. However, sitting fees apply for allocated representatives participating in steering/oversight committees or as CI/AI.
🔷 **Facilitation:** APF has an application process to ensure that the letter of support reflects community alignment with the research or policy being implemented.

10. Live Experience Involvement & Impact Throughout POTS Research*

10.1 Study Design

Inform the research agenda & improve the relevance of research to those with POTS.

- Highlight current gaps in POTS research that are important to those with lived experience.
- Refine research objectives to ensure they address real-world concerns of those with POTS.

- Inform decisions about scope, target population, and intended research outcomes.
- Ensure research reflects the lived realities of managing POTS day-to-day.

10.2 Research Proposal

Ensure that the research prioritises the perspective of those with lived experience, valuing respect, representation, and inclusion.

- Provide input on definitions of POTS, inclusion criteria, and relevant subgroups.
- Advise on ethical considerations, including sensitivities around misdiagnosis and medical trauma.
- Recommend when additional consumer input should be sought for further refinement.
- Offer constructive feedback on research proposals and study methodologies.

10.2 Undertaking & Managing

Improve the appropriateness, accessibility, and credibility of research; facilitate recruitment and provide access to networks.

- Identify effective ways to recruit participants, including diverse representation from regional areas and those with complex comorbidities.
- Provide links to POTS-specific support networks and advocacy groups.
- Promote studies through community networks, ensuring broad and inclusive participation.
- Highlight participation challenges such as travel fatigue, financial constraints, and access barriers.
- Review study materials, including surveys and outcome measures, for clarity and relevance.
- Suggest stakeholders with lived experience and clinical expertise to contribute to advisory panels and Delphi studies.
- Provide access to national leaders in autonomic research and policy advocacy.

10.3 Analysis & Interpretation

Ensure that findings reflect real-world implications for those with POTS.

- Inform classification of symptom severity and treatment outcomes.
- Review outcome measures to ensure they align with lived experiences.
- Provide insights into knowledge gaps by staying engaged with literature and community forums.
- Ground interpretation of results in their practical implications for improving daily life and healthcare experiences.

10.4 Dissemination

Share research findings with key stakeholders and the broader POTS community.

- Co-author publications to ensure accessibility and accuracy in reporting findings.
- Distribute findings through POTS networks, advocacy groups, and professional organisations.
- Advise on accessible formats for sharing results, ensuring they reach those who need them most.
- Engage in policy advocacy to drive research translation into better care and systemic improvements in diagnosis and treatment pathways.

10.5 Monitoring & Evaluation

Sustain involvement and ongoing reflection to ensure meaningful engagement.

- Participate in regular research meetings to address challenges as they arise.
- Reflect on roles and learning opportunities to enhance lived experience involvement models.
- Contribute personal statements and case studies to contextualise findings within real-life experiences.

11. Budgeting for Lived Experience Engagement

Recognising and valuing lived experience engagement is crucial for ensuring sustainable and meaningful involvement. The following guidance outlines the APF's recommendations for incorporating lived experience engagement into grant proposals. Costings are flexible and will depend on the depth of the relationship, the purpose of the project, and the availability of funding. We encourage you to discuss your specific needs with us to ensure an approach that aligns with project goals and ethical engagement principles.

11.1 Hourly & Session-Based Compensation

Compensation should reflect the level of engagement and expertise required:

- Advisory Committees: $30 to $50 per person/per hour
- Co-Creation Partner/Investigator: $35 to $100 per person/per hour depending on activity, state and service
- Focus Groups: Honorariums or gift cards for participation ($25 to $50 per meeting)
- User Testing & Development Participation: Engaging people with lived experience as user testers in development requires $30–$50 per hour.
- Survey Participation: When recruiting participants to respond to surveys, a recommended payment of $25–$35 per participant is advised.

11.2 Indicative Recruitment & Screening Costs

Recruitment and screening of lived experience partners or research participants through the APF ensure diverse and representative participation. Remuneration for recruitment covers the administrative and community engagement activities undertaken by the Foundation, ensuring cost recovery as an unfunded not-for-profit organisation.

All requests for recruitment, including survey distribution, are vetted by the APF Scientific Committee to ensure alignment with our mission, ethical standards, and relevance to the POTS community. Researchers are encouraged to engage with us early to discuss the best approach. Recruitment may include social media, newsletters, direct outreach, or other engagement methods, with pricing varying based on scope and level of promotion.

- Advisory Committee/Co-Design Partner Recruitment: $50 per committee or co-design member
- Focus Group/Interview Participant Recruitment: $25 per participant
- Survey Distribution: $150–$500, depending on distribution method and engagement level.

11.3 Full-Service Facilitation Estimates

For research teams without trained personnel, the APF offers in-house expertise in engaging lived experience, including nominal group technique, co-design, and leading focus groups for qualitative research. We can provide facilitation services directly or, where necessary, contract specialised expertise to ensure high-quality engagement.

These services may be particularly valuable for teams with limited experience in facilitation, co-design, or qualitative analysis. For research teams with existing expertise, we welcome partnership approaches to collaboratively engage the POTS community. Costs below reflect a standard engagement but may vary based on project needs, duration, and complexity. The following prices are indicative only and will vary based on project duration, complexity, and specific requirements.

Engagement Type	**Estimated Cost Range**	**Scope of Work**
Focus Group – Full-Service Facilitation	$2,500 – $5,000 per project	Recruitment, moderation, and reporting
Co-Design Process – Full-Service Facilitation	$5,000 – $100,000 per project	Multi-session facilitation over months to years, including recruitment, moderation, synthesis, and reporting
Ongoing Engagement (Multi-Year Projects)	$10,000 – $50,000+	Advisory committees, iterative co-design, participant retention, and reporting over extended periods

11.4 Structuring Funding for Sustainable Engagement

Funding should be built into project budgets to ensure structured, ethical, and diverse participation. APF recommends that research and policy projects allocate funding to engage consumer bodies in the facilitation of recruitment and engagement, ensuring that lived experience involvement is valued, supported, and sustainable.

- Short-Term Projects (6 months or less): Budget for one-off or limited-session engagements (e.g., single focus groups, a few co-design workshops).
- Medium-Term Projects (6 months – 2 years): Plan for iterative engagement, including advisory committees and follow-up co-design activities.
- Long-Term Projects (2+ years): Ensure sustainable compensation for ongoing engagement, including stipends or honorariums for advisory members and structured budget allocations for facilitation.

12. Conclusion

Lived experience engagement is not a checkbox exercise—it is a fundamental requirement for ensuring health research, policy, and service delivery align with the real needs of the community. By following this framework, organisations can embed genuine, structured, and impactful lived experience engagement, leading to more effective and equitable outcomes.

13. Resources

For more information on consumer engagement, please see:

- SA Health – *Engaging with Consumers, Carers, and the Community Guide*: https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/resources/engaging+with+consumers+carers+and+the+community+guide+and+resources
- NSW Health – *All of Us: A Guide to Engaging Consumers, Carers, and Communities*: https://www.health.nsw.gov.au/patients/engagement/Pages/all-of-us.aspx
- NHMRC – *Statement on Consumer and Community Involvement in Health and Medical Research*: https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research
- SAHMRI – *Consumer and Community Engagement Framework*: https://sahmri.org.au/research/community-engagement-in-research

References:

*The examples of lived experience involvement are adapted from work undertaken at the Rosemary Bryant AO Research Centre Co-Lab, Ramsey, I. Core patient-reported outcomes for monitoring cancer survivorship at a population level, PhD Thesis, 2020, Fig 1 p.104.

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