

THE OBESITY COLLECTIVE &  
WEIGHT ISSUES NETWORK

# LIVED-EXPERIENCE REPRESENTATIVES IN OBESITY

A Strategic Plan for Enhancing Consumer  
Engagement in Obesity Related Research &  
Health Policy Development.

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Prepared by  
The Obesity Collective



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**Obesity  
Collective**  
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# Executive Summary

## LEAP Operational Model Overview

This document outlines a comprehensive plan for the establishment and ongoing operation of a dedicated online forum for lived-experience representatives of people with obesity. The primary goal of this forum is to significantly enhance consumer engagement in obesity-related research and health policy development. By providing a safe, accessible, and structured online space, the forum will empower individuals with lived experience to share their perspectives, contribute to discussions, and directly influence the direction of research priorities and policy decisions, ensuring that initiatives are truly person-centred and effective. This plan also integrates key considerations regarding participant wellbeing, ethical engagement, a structured business approach, and sustainable operational models, drawing insights from various lived experience frameworks and reports, including the WIN Digital Think Tank (DTT) discussions, the ANU Lived Experience Framework, NSW Engaging with Lived Experience Framework, Access Health and Community Lived and Living Experience Framework, and the Western NSW Local Health District Consumer and Carer Representative Orientation.

# Summary

## Proposed Operation of The Online Lived Experience Advisory Panels (LEAPs)

*PREVIOUSLY REFERRED TO AS DIGITAL THINK TANKS (DTT)*

### **Volunteer recruitment and upskilling**

- Volunteer LEAP panel members recruited from within community of people living with obesity
- Volunteers screened and their skills and interests determined
- Volunteers training in the technology used to support LEAPs online sessions and offered opportunity to upskill through identified health consumer and research training modules
- Volunteers encouraged to interact and engage with each other online and through special forums and events
- Volunteers added to a national database

### **Digital Think Tank infrastructure and systems established**

- LEAPs steering group/ advisory groups established
- LEAPs Manager, project officer and support staff recruited
- Support staff include access to psychologist, academic research adviser, data analyst
- Facilitators who control the functioning of each LEAPs session are recruited from within volunteers and provided with additional training/support
- Systems for receiving, assessing and responding to engagement request established
- Systems for receiving fees and payment of recompense to volunteers are established

# Summary

## Proposed Operation of The Online Lived-Experience Advisory Panels (LEAPs)

*PREVIOUSLY REFERRED TO AS DIGITAL THINK TANKS(DTT)*

### **Operation of LEAPs**

- Request for engagement submitted by research or policy group
- Merit and requirements of request considered by LEAPs manager
- Manager clarifies the issues requiring discussion input by LEAPs
- LEAPs project officer assembles a panel (6-8) of volunteers based on interest or skills
- Facilitators conduct the first online session where research group provides background and identifies input required from LEAPs.
- Facilitators conduct a second LEAPs with only lived experience panellists involved. The panel may request further clarification from the researchers or any of the LEAPs advisors.
- This process is continued until LEAPs panel feels comfortable with their responses. A report of these responses is prepared by the project officer.
- A meeting is arranged with the researchers to feed back their considered views and hear researchers' responses and any additional concerns

### **Review and evaluation of LEAPs operations and performance**

- Quarterly reports with annual review
- Performance assessed against KPIs

# Rationale

## Developing Online Lived-Experience Forums

Obesity is a complex and multifaceted health challenge with significant individual and societal impacts. Historically, the development of health research and policy in this area has often been driven by clinical and academic perspectives, with limited direct input from individuals who live with obesity (Brett et al., 2014). This traditional approach risks creating interventions and policies that may not fully align with the real-world needs, experiences, and priorities of the affected community, potentially leading to reduced effectiveness and engagement (NSW Government, 2020).

However, there is a growing and undeniable recognition of the significant value that lived experience brings to research and health system design and improvement. Engaging people with lived experience is no longer seen as a mere 'tick-box' exercise but as a strategic imperative for creating truly person-centred initiatives (NSW Government, 2020). Individuals with lived experience possess unique, experiential knowledge that complements professional expertise, offering invaluable insights into the daily realities, challenges, and preferences associated with living with obesity (ANU, 2017). This direct involvement ensures that programs and policies are not only more responsive and relevant but also safer, of higher quality, more accessible, and ultimately more cost-effective (NSW Government, 2020). Furthermore, actively involving people with lived experience is a crucial step towards breaking down the pervasive stigma and discrimination often associated with obesity, fostering a more inclusive and empathetic approach to care (Access Health and Community, 2023; NSW Government, 2020).

The effective engagement of individuals with lived experience is increasingly recognised as fundamental to developing relevant and impactful health research and policy (Brett et al., 2014; NSW Government, 2020). Online forums, in particular, serve as crucial platforms for facilitating this engagement due to their accessibility, scalability, and ability to foster diverse participation (Access Health and Community, 2023). They overcome geographical barriers, allowing a broader representation of voices, including those from traditionally hard-to-reach communities or individuals with mobility challenges (ANU, 2017). Furthermore, digital platforms can empower individuals by providing a safe, asynchronous space where participants can contribute at their own pace, reducing potential pressures associated with face-to-face interactions (SE London NHS 2025). Such environments are vital for cultivating trust and ensuring that lived experience perspectives are genuinely integrated into co-design and decision-making processes, rather than merely being consulted in a tokenistic manner (NSW Government, 2020; Western NSW Local Health District, 2025).

# Rationale

## Developing Online Lived-Experience Forums

The establishment of a dedicated online forum for lived-experience representatives of people with obesity is a critical mechanism to harness this invaluable perspective. Online platforms offer distinct advantages that address many of the barriers inherent in traditional engagement methods:

**Enhanced Accessibility and Reach:** Digital forums transcend geographical limitations, enabling participation from a diverse range of individuals, including those in rural or remote areas, or those facing mobility challenges (Access Health and Community, 2023; ANU, 2017; Western NSW Local Health District, 2025). This broadens representation and ensures that a wider spectrum of experiences is captured.

**Flexibility and Psychological Safety:** Online environments allow for communication and discussion to be asynchronous (doesn't require real-time back-and-forth), meaning participants can contribute at their own pace and at times that suit them (SE London NHS, 2025). This flexibility can reduce the pressure often associated with face-to-face meetings, creating a more psychologically safe space for individuals to share sensitive personal stories and experiences (Western NSW Local Health District, 2025). The ability to reflect before responding can lead to more considered and impactful contributions.

**Scalability and Efficiency:** Online forums can efficiently manage contributions from a larger number of participants than is feasible in traditional settings, allowing for broader consultations and feedback loops.

**Community Building and Peer Support:** These platforms naturally foster a sense of community among participants, enabling peer-to-peer support, shared learning, and collective advocacy, which are vital for empowerment and sustained engagement (Access Health and Community, 2023).

This document outlines a comprehensive plan for the establishment and ongoing operation of such an online forum. By leveraging the unique benefits of a digital platform, this initiative aims to create a robust, influential, and sustainable mechanism for meaningful consumer engagement, ensuring that the voices of people with lived experience are central to shaping obesity-related research and health policy.

\*Within the weight Issues Network these forums have previously been referred to as Digital Think Tanks.

# Rationale

## Overarching Goal and Specific Objectives



**Increase Representation:** Recruit and retain a diverse group of lived-experience representatives from various backgrounds, demographics, and stages of their journey with obesity, actively addressing potential barriers to participation for individuals from low socioeconomic status (SES), culturally and linguistically diverse (CALD) backgrounds, and those with differing learning/communication styles.



**Facilitate Dialogue:** Create an active, respectful, and psychologically safe online environment for representatives to share insights, discuss challenges, and collaborate on solutions related to obesity, explicitly incorporating trauma-informed care principles.



**Inform Research:** Provide a direct conduit for researchers to seek input, co-design studies, and disseminate findings in an accessible manner to the lived-experience community, ensuring ethical engagement, appropriate use of personal stories (purposeful disclosure), and clear reporting back on how input was utilized.



**Influence Policy:** Enable policy makers to consult with and receive feedback from lived-experience representatives on proposed policies, guidelines, and public health campaigns, fostering genuine co-design at the policy/strategy level.



**Build Capacity:** Offer comprehensive training and resources to representatives to enhance their understanding of research processes, policy advocacy, critical thinking, effective communication, and coping strategies for engaging with sensitive topics.

# Important Issues

## Forum Development Considerations

A number of issues need to be defined before these LEAPs can be established and made operational. Two key issues include the appropriate characteristics of the members of these forums and the online platform or structure that will enable the conduct of these forums.

### **Discussion Forum membership**

The primary recruitment target for this forum is individuals who have lived experience with obesity and are willing to represent the consumer perspective. This should include a mix of:

- Individuals currently living with obesity.
- Individuals who have undergone weight management interventions (surgery, pharmacology, behavioural programs).
- Caregivers or family members of individuals with obesity (where appropriate and with clear boundaries).
- Individuals from diverse socio-economic, cultural, and geographical backgrounds, ensuring a broad representation of experiences. This includes actively seeking participation from individuals with differing learning and communication styles, genders, low socioeconomic status (SES), First Nations communities and culturally and linguistically diverse (CALD) backgrounds.

It is important to understand that a broad recruitment strategy will result in individuals with varying levels of digital literacy, requiring an accessible platform design and potential support for access to technology and internet.

**Recommendation:** A diverse range of volunteers be recruited from across Australia that nominate their personal capacity, skills and interests in the consumer representation process and the extent of their proposed involvement. The membership of each individual LEAP panel can be constituted from this pool of volunteers to enable a mix of skills and facilitate representativeness. To provide for this mix it is proposed that each LEAP panel should be composed of between 6 and 10 consumer representatives in addition to any facilitation and support staff.

# Important Issues

## Forum Development Considerations

### Platform Selection

The selection of the online platform is crucial for accessibility, functionality, and community building.

### Key Considerations:

- Ease of Use: Intuitive interface for posting, commenting, and navigating, suitable for users with varying technical skills.
- Security & Privacy: Must offer robust data encryption, secure login, and compliance with relevant data protection regulations.
- Scalability: Ability to grow with the number of users and content.
- Cost-Effectiveness: Balance features with budget constraints.
- Some desirable Features:
  - a. Discussion threads/forums (categorized by topic: research, policy, personal stories, support).
  - b. Private messaging capabilities.
  - c. Polls and surveys for quick feedback.
  - d. Document sharing (e.g., research summaries, policy briefs).
  - e. Event calendar (for online meetings, workshops).
  - f. Moderation tools.
  - g. User profiles (optional, with privacy controls).
  - h. Accessibility features (e.g., screen reader compatibility, adjustable font sizes, language translation capabilities).

# Important Issues

## Forum Development Considerations

### **Platform Types (Examples):**

- Basic Microsoft-based platform: using 365 Teams and other MS programs or zoom
- Dedicated Forum Software: (e.g., Flarum, Discourse, Vanilla Forums, phpBB) - Offers high customisation and control.
- Community Platform: (e.g., Mighty Networks, Circle) - Provides a broader range of community features beyond just forums, potentially including courses or live events.
- Custom-built Solution: (Higher cost, but maximum flexibility) - Only if highly specific requirements cannot be met by off-the-shelf solutions.

**Recommendation:** Start with a system based on Microsoft 365 with SharePoint, Teams or in combination with Zoom online meeting software, as it is familiar, widely available and accessible – although it does not have dedicated forum functions. Over time as the forum matures, shifting to an off-the-shelf forum software or community platform would enable more functionality and add more complex features.

# Establishment Phase

## Governance and Legal Framework

Establishing a robust governance and legal framework is crucial for the success and sustainability of any community group. It provides a clear structure for decision-making, ensures accountability, and helps to build trust with members and the wider community. To enable the effective operation of the LEAPs a series of policies and guidelines will need to be developed covering issues such as:

**Mission and Values Statement:** Develop a specific mission statement and values statement for the forum to guide its principles, objectives, and decision-making, emphasizing practical initiatives that directly benefit the community.

**Business Plan:** Create a clear business plan that defines the forum's services, value proposition, target membership, audience, markets, and potential collaborations with other existing think tanks and stigma groups. Clarity on the operational model is essential before finalizing the business plan.

**Steering Committee:** Establish a diverse steering committee comprising lived-experience representatives, researchers, policy experts, and patient advocacy group representatives. This committee will guide the forum's strategic direction and oversee operations, ensuring accountability and good design.

**Terms of Reference (ToR):** Develop clear ToR for the steering committee and any sub-committees (e.g., Assessment Committee/Board), outlining roles, responsibilities, and decision-making processes, including voting rights where applicable.

**Code of Conduct:** Draft a comprehensive Code of Conduct for all forum participants, emphasizing respectful communication, privacy, ethical engagement, and the importance of maintaining psychological safety. This will be mandatory for all members and explicitly address conflict of interest.

# Establishment Phase

## Governance and Legal Framework

**Privacy Policy & Terms of Use:** Develop robust privacy policies and terms of use that comply with relevant data protection laws, clearly outlining data collection, storage, usage, and sharing practices, including procedures for anonymizing data when insights are shared externally. These can be modelled on policies developed by other consumer health organisations.

**Consent Process:** Implement a clear informed consent process for all participants, explaining the forum's purpose, data handling, their rights, and the potential impact of sharing personal stories, ensuring participants are not asked for personal stories when not necessary.

**Intellectual Property (IP):** Define clear guidelines regarding the ownership and use of content shared within the forum, especially when contributing to research or policy documents. This includes negotiating potential for shared intellectual property with engaging organisations through formal contracts.

**Risk Management:** Establish a comprehensive risk management framework to address legal, contractual, and tax risks including assessing liability insurance of applicants.



# Recruitment and Onboarding

## Strategies for Engaging Community Members

This will occur in line with the established principle of diversity within the proposed pool of consumer volunteers.

### **Recruitment Strategy:**

- Partner with existing patient advocacy groups, obesity organisations (e.g., Weight Issues Network - WIN), and healthcare providers (e.g., metabolic clinics) to reach potential representatives.
- Utilise targeted and sensitive social media campaigns, noting past successes.
- Emphasise the opportunity to make a real impact on research and policy.
- Network with other advocacy groups experiencing stigma, including eating disorders, diabetes, and cancer groups, to broaden outreach.

**Diversity & Inclusion:** Actively seek to recruit individuals from diverse backgrounds (age, gender, ethnicity, socioeconomic status, First Nations Communities geographical location, learning/communication styles), ensuring comprehensive representation. Consider a diversity survey of the membership.

- Address potential barriers for low SES participants, such as access to technology, and explore solutions like providing devices or internet access. Language translation and video interviews may be needed.

**Application/Expression of Interest:** Develop a simple application process to gauge interest, commitment, and basic understanding of the LEAPs purpose. This may include an online engagement assessment form to assess intentions and ensure due diligence on the applicant (see Appendix A for example).

**Vetting:** Implement a vetting process to ensure relevant lived experience, avoid conflicts of interest, and declare commercial interests. This process should also assess the applicant's understanding of the forum's ethical guidelines and commitment to constructive engagement.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

### **Onboarding Program:**

- **Induction Booklet/Handbook:** Create a comprehensive digital welcome pack/handbook with forum guidelines, FAQs, privacy policy, a brief introduction to the steering committee, onboarding expectations, confidentiality clauses, how to provide constructive input, the goals of the forum, and crucial psychological safety and mental health support resources (e.g., Lifeline, Employee Assistance Program).
- **Tutorials:** Offer simple, user-friendly tutorials (text, video) on how to use the forum platform.
- **Initial Orientation Session:** Host an introductory online session (webinar) to welcome new members, explain the forum's mission, discuss psychological safety, and answer questions.
- **Education:** Provide education to panel members on background regarding grant and research processes, critical thinking skills, and understanding commercial-in-confidence information. A preliminary list of appropriate, existing training opportunities has been developed and attached as Appendix c.

### **Platform Setup and Configuration:**

- **Technical Infrastructure:**
  - Select and procure the chosen forum platform and necessary integrated tools (as outlined in Section 3b).
  - Configure hosting and domain name, ensuring SSL certification for secure connections.
  - Set up access to online platforms (e.g., SharePoint) and Adobe forms for accepting applications.
- **Forum Documentation and access:**
  - Create logical categories and sub-forums (e.g., "Research Consultations," "Policy Feedback," "Sharing Experiences," "Training & Resources," "General Discussion").
  - Set up user roles and permissions (e.g., administrators, moderators, general members, guest access for researchers/policy makers).
- **Branding & Design:** Design a user-friendly and visually appealing interface consistent with the organisation's branding (if applicable), ensuring accessibility (e.g., colour contrast, font size, clear navigation).
- **Initial Content Seeding:** Populate the forum with initial welcome messages, introductory posts, and a few discussion prompts to encourage early engagement.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Content Strategy (Initial)

- **Introductory Posts:** Welcome messages from the steering committee and administrators, clearly outlining the forum's mission and values.
- **FAQ Section:** Address common questions about the forum, its purpose, how to participate, and compensation models.
- **Guidelines & Etiquette:** Clearly outline expected behaviour and communication standards, with a strong emphasis on psychological safety and respectful dialogue.
- **Initial Discussion Prompts:** Pose open-ended questions related to research priorities, policy challenges, or personal experiences to kickstart conversations.
- **Resource Library:** Begin populating a small library of relevant, easy-to-understand resources (e.g., glossary of research terms, links to reputable health organisations, mental health support, advocacy guides), including information on health literacy.



# Operational Phase

## Ongoing activities required to maintain and grow the forum

### **Moderation and Community Management:**

**Dedicated Moderation Team:** Appoint a team of trained moderators (potentially including experienced lived-experience representatives) to oversee forum activity. Moderators should be equipped to handle sensitive topics and ensure psychological safety, including providing a designated physical space for breaks if needed.

**Moderation Guidelines:** Develop clear guidelines for moderators on handling disputes, inappropriate content, ensuring adherence to the Code of Conduct, and managing discussions that may trigger distress.

**Proactive Engagement:** Moderators should actively participate in discussions, encourage new members, and foster a positive, inclusive, and supportive atmosphere.

**Conflict Resolution:** Establish a clear process for addressing conflicts or breaches of the Code of Conduct, including warnings, temporary suspensions, or permanent bans, with an emphasis on restorative approaches where possible.

**Technical Support:** Provide clear channels for users to report technical issues or seek assistance, including support for digital literacy where needed.



# Recruitment and Onboarding

## Strategies for Engaging Community Members

### **Engagement Strategies for recruited panel members**

Content and activities can be drawn for existing obesity-related or host organisations including WIN and the Obesity Collective.

**Regular Discussion Prompts:** Continuously introduce new and relevant discussion topics, polls, and surveys to keep the community active and responsive to current research and policy developments.

**Themed Weeks/Months:** Organise periods focused on specific topics (e.g., "Research on Nutrition," "Advocacy for Access to Care," "Mental Health and Obesity").

**Guest Speakers/Q&A Sessions:** Invite researchers, clinicians, or policy makers to participate in live online Q&A sessions or facilitated discussions, ensuring they are briefed on ethical engagement with lived experience.

**Recognition & Appreciation:** Acknowledge and appreciate active contributors, perhaps through a "member spotlight" or virtual badges (if platform allows), and clearly communicate the impact of their contributions.

**Feedback Mechanisms:** Regularly solicit feedback from members on how to improve the forum and its activities, including their experiences with psychological safety and support.

**Culturally Safe Engagement:** Implement methods like Yarning Circles for Aboriginal and Torres Strait Islander people to share stories and experiences in a culturally appropriate and respectful way, promoting trust and understanding.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Research and Policy Engagement Mechanisms

**Client Selection Criteria & Due Diligence:** Implement clear criteria for selecting clients (researchers, organisations, policy makers) for engagement. This includes differentiating between profit and non-profit entities. An online engagement assessment form should be used to capture assessment information, allow for due diligence on the applicant, gather evidence (e.g., Ethics Committee approval for research), and ensure the psychological safety of members by preventing requests for personal stories when not necessary or relevant (for development see Appendix D).

**Formal Contracts:** Develop a formal contract with engaging organisations that outlines expectations, intellectual property clauses, confidentiality, and the scope of engagement, including the commitment to report back to the forum (this can be a standard agreement with additions).

**Dedicated Consultation Areas:** Create specific, clearly labelled sections for researchers and policy makers to post requests for input.

**Structured Feedback Templates:** Provide templates or clear instructions for researchers/policy makers on how to frame their questions to elicit useful feedback from the community while minimising potential for re-traumatisation.

**Facilitated Discussions:** When complex research or policy documents are shared, assign a trained moderator or facilitator to guide the discussion, ensure all voices are heard, and manage sensitive content.

**Provide an opportunity for direct input:** Where issues are detailed or difficult to capture in written applications allow for the client to have direct contact with forum to explain their project.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

**Summarising Insights:** Develop a robust process for synthesising the collective insights and feedback from the forum into concise, actionable summaries for researchers and policy makers. The responsibility for report writing should ideally be a burden on the engaging organisation.

**Reporting Back:** Crucially, ensure that researchers and policy makers report back to the forum on how their input was used and the impact it had. This closes the feedback loop, demonstrates the value of participation, and builds trust.

**Co-design Opportunities:** Actively promote opportunities for lived-experience representatives to be involved in the co-design of research projects or policy initiatives from their inception, ensuring their perspectives are integrated from the ground up. This includes co-designing patient information, health and wellbeing programs, and pathways to care.

**Levels of Engagement:** Implement engagement strategies across individual, service/program, organisational, and policy/strategy levels, as outlined in the ANU framework, ensuring appropriate methods for each level (e.g., shared decision-making tools at individual level, advisory groups at organisational level, co-design of policy at strategy level).



# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Training and Support

**Webinars/Workshops:** Offer regular online training sessions on topics such as:

- Understanding research methodologies, grant processes, and ethical considerations.
- Effective advocacy and communication skills, including how to provide constructive input.
- Navigating health policy landscapes.
- Digital literacy skills and platform usage (if needed).
- Coping strategies for engaging with potentially sensitive topics and self-care.

**Mentorship Program:** Explore a peer-mentorship program where experienced representatives can guide newer members, fostering a supportive community. This can include "peer workers" or "peer support workers" who intentionally use their lived experience to support others.

**Resource Library Expansion:** Continuously update and expand the forum's resource library with accessible information, glossaries of terms, links to reputable health organisations, and comprehensive mental health support resources. This includes information on health literacy and respectful language.



# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Privacy and Data Security

**Ongoing Monitoring:** Regularly review and update security protocols to protect user data, including compliance with relevant data protection regulations.

**Data Anonymisation:** Implement robust procedures for anonymising or de-identifying data when insights are shared externally (e.g., in research reports) to protect individual privacy.

**Secure Communication:** Encourage the use of private messaging within the platform for sensitive discussions, rather than external, less secure channels.

**Regular Audits:** Conduct periodic security audits of the platform and data handling processes.

**Confidentiality:** Ensure all representatives comply with privacy and confidentiality through a formal Code of Conduct.



# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Monitoring and Evaluation

Evaluation strategies and tools can be based on work undertaken by other consumer health panels and using tools identified by Sydney health Partners and the NHMRC.

#### Key Performance Indicators (KPIs) could include:

- Number of active members and diversity of membership (e.g., representation from various demographic groups, including CALD and low SES).
- Engagement metrics (e.g., number of posts/comments per month, session duration, participation in different types of activities).
- Number of research/policy consultations initiated and completed.
- Quality of insights generated (qualitative assessment of relevance, depth, and actionability).
- Number of times forum insights are cited in research or policy documents.
- Member satisfaction and perceived impact (via surveys, including specific questions on psychological safety and feeling heard).
- Feedback on the effectiveness of training and support programs.
- Adherence to ethical guidelines and Code of Conduct.

**Regular Reporting:** Generate quarterly reports on forum activity, engagement, and impact for the steering committee and stakeholders.

**Annual Review:** Conduct an annual review with the steering committee to assess progress against objectives, identify areas for improvement, and adjust the strategic plan, incorporating feedback from all involved parties.

**Feedback Surveys:** Implement regular surveys to gather feedback from members on their experience, the value they perceive, suggestions for improvement, and their wellbeing. Self-report measures from people with lived experience should be the first choice for evaluating engagement impact.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Sustainability

**Funding Model:** Identify sustainable funding sources, which may include:

- Grants from research councils or philanthropic organisations.
- Partnerships with research institutions, government health authorities, and patient advocacy groups.
- Philanthropic support.
- Client fees: Consider an application processing fee for organisations seeking engagement. Differentiate recompense models for engaging organisations based on their financial capabilities (e.g., non-profits vs. for-profit corporations).
- Hybrid remuneration approach: Secure funding for paid LEAPs staff (e.g., Coordinator, Project Manager) and provide honorariums or gift cards to lived-experience participants, carefully considering the impact on members receiving welfare benefits (treating as one-off payments rather than income). Direct participation should be remunerated.

**Proposed Staffing:** It is important to secure dedicated staff or volunteers for key roles. To service these roles a mix of specific project staff, volunteer committee roles and external consultant staff will be required including:

### Project staff

- Coordinator: To answer queries, receive applications, and refer to the online form.
- Project/Program Manager: For managing the standing up of individual panels
- Panel Facilitators: To lead the panel assessment.
- Report Writer: A paid resource to collect feedback and prepare reports back to clients, ideally with the burden on the engaging organisation.
- Marketing and Social Media: For engagement and recruitment.

# Recruitment and Onboarding

## Strategies for Engaging Community Members

### Volunteer Committee Roles

- Advisory Committee/Board: For guidance and governance of the LEAPs program
- Review and evaluation committee: To oversee the review and evaluation processes

### External or Consultant Roles:

- Legal and Financial Advisors: To review contracts, confidentiality, due diligence, and IP clauses, assess liability insurance and financial and tax advice.
- IT Support: For platform access, form setup, and technical assistance.

**Partnerships:** Foster strong partnerships with research organisations, health authorities, patient groups, and industry (where appropriate and ethical) to ensure ongoing relevance, collaboration, and support. This includes leveraging existing networks like Health Consumers NSW.

**Succession Planning:** Develop a plan for leadership, moderation, and key operational roles to ensure continuity and knowledge transfer.



# Key Success Factors

## Factors to Enable the Establishment of an Effective System of LEAPs

There are a number of factors that will need to be addressed to enable the establishment of an effective system of LEAPs. However once operational, the ongoing success of the forum will require attention to good organisational practices including:

**Strong Leadership & Governance:** A committed, diverse, and well-structured steering committee and operational team that champions engagement and ensures it is done well and shapes programs.

**Active and Responsive Moderation:** Ensuring a safe, respectful, and engaging environment that explicitly prioritises psychological safety and is trauma-informed.

**Meaningful Engagement Opportunities:** Providing genuine opportunities for members to influence research and policy, with clear pathways for their input to be utilised, and ensuring their contributions are valued and acted upon.

**Clear Communication & Transparency:** Regularly reporting back on the impact of member contributions and maintaining open communication about processes and outcomes, including how feedback was used.

**Accessibility & User-Friendliness:** An intuitive platform that caters to diverse digital literacy levels and addresses technology access disparities, ensuring inclusive practices.

# Key Success Factors

## Factors to Enable the Establishment of an Effective System of LEAPs

**Diversity & Inclusion:** Ensuring a broad range of lived experiences are represented, actively seeking out and supporting marginalised voices, and recognising the impact of intersectionality.

**Trust & Safety:** Robust privacy and security measures, a clear Code of Conduct, and a strong emphasis on participant wellbeing, including access to mental health resources.

**Sustainable Funding & Operations:** A well-defined business plan, diversified funding, and adequate staffing to ensure long-term viability and appropriate remuneration for participants.

**Continuous Improvement:** Regularly evaluating engagement activities and using findings to improve future processes, fostering a culture of learning and adaptation.



# Challenges and Mitigation

## Challenges and Proposed Mitigation Actions for the Operation of the LEAPs

The operation of any new project brings many challenges with the potential to disrupt or negate possible momentum. Whilst some of these will be difficult to predict, others can be anticipated and mitigated through reflection and good planning. A list of possible challenges and proposed mitigation actions for the operation of the LEAPs is set out in the table below.

Challenge	Mitigation
Low initial engagement or drop-off in participation	Proactive and empathetic moderation, diverse discussion prompts, regular training and capacity building, clearly showcasing impact, personalised outreach, and ensuring the value of participation is evident.
Maintaining respectful and constructive dialogue and ensuring psychological safety.	Clear and enforced Code of Conduct, robust and trained moderation team, established conflict resolution protocols, promoting positive community norms, providing mental health resources, and carefully framing questions posed to participants to avoid re-traumatisation.
Ensuring genuine influence on research and policy and managing expectations regarding impact	Formalising engagement processes through contracts and structured feedback, clear reporting back mechanisms, actively promoting co-design opportunities, and fostering strong partnerships with decision-makers. Transparent communication about the scope of influence and timeframes for change.
Digital divide and accessibility issues (e.g., for low SES or CALD participants).	User-friendly platform design, offering comprehensive tutorials, providing alternative communication channels for critical information, potentially funding access to technology/internet, and offering language translation services where needed.
Funding and resource sustainability	Diversifying funding sources, demonstrating clear value and impact to attract support, leveraging volunteer contributions where appropriate, implementing client fees, and adopting a hybrid remuneration model.

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Challenge	Mitigation
Managing legal, financial, and intellectual property risks	Establishing a dedicated Assessment Committee/Board with legal and tax expertise, developing robust contracts with engaging organisations, and implementing clear IP guidelines
Vetting participants and engaging organisations to ensure genuine lived experience and ethical intentions.	Implementing a thorough application and vetting process for members, utilising an online engagement assessment form for organisations, and requiring ethical approvals for research projects.
"Professionalising" of lived experience views	Deliberate engagement with a range of people, both experienced and new to active involvement, to ensure diverse perspectives are maintained. Training should aim to increase understanding of the health system, not to homogenise views.
Consultation fatigue	Careful management of engagement frequency for individuals, clear communication of time commitments, and diversifying the pool of representatives.

# Conclusion

## Summary and Call to Action

The establishment of an online forum for lived-experience representatives of people with obesity represents a critical step towards truly patient-centred research and health policy. By following this comprehensive plan, which integrates valuable insights from various Australian lived experience frameworks and reports, the forum can become a powerful platform for amplifying the voices of those most affected by obesity. This will lead to more relevant research, more effective policies, and ultimately, improved health outcomes and quality of life for people living with obesity. This initiative will foster a collaborative ecosystem where lived experience is valued, respected, and integral to driving meaningful change.



# References

## Supporting Documentation and Sources

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# Appendix A

## Example of an Expression Of Interest Form for Joining LEAPs on Obesity

Name	
Any existing group or organisation (if relevant)	
Phone/mobile	
Email	
Preferred method of contact	
Level of involvement you wish to pursue?	<input type="checkbox"/> Just keep me informed <input type="checkbox"/> I would like to participate in training and development opportunities to improve my understanding of this process <input type="checkbox"/> I am keen to contribute as a participant in online Lived Experience Forums <input type="checkbox"/> I am interested in more actively contributing to leadership of online Lived Experience Forums
What adjustments might be needed to enable you to fully participate? E.g. internet access, computer skills, hearing impairment	
Please give us a brief overview of any relevant experience or skills you have in consumer consultations and why you are interested in this role.	

# Appendix B

## Support and training opportunities for Lived Experience Participants

This appendix provides a summary of the key strategies for supporting and remunerating lived experience participants within the online forum, drawing from the main plan. Ensuring adequate support and fair compensation is crucial for ethical engagement, promoting diversity, and sustaining long-term participation.

### Support Mechanisms

**Psychological Safety:** The forum prioritizes a psychologically safe environment, incorporating trauma-informed care principles. This includes providing a designated physical space for breaks during online sessions and offering debriefing opportunities with a nominated contact or health professional.

**Mental Health Resources:** Crucial mental health support resources (e.g., Lifeline, Employee Assistance Program) will be included in the onboarding handbook and readily accessible within the forum's resource library.

**Key Contact Person:** Each participant will have a designated key contact person (an experienced representative or staff member) to provide support, assist with orientation, and address any uncertainties or concerns.

### Training and Capacity Building:

- **Induction:** A comprehensive digital induction booklet/handbook will cover forum guidelines, expectations, confidentiality, and how to provide constructive input.
- **Webinars/Workshops:** Regular online sessions will be offered on topics such as understanding research/grant processes, effective advocacy, navigating health policy, digital literacy, and coping strategies for sensitive topics.
- **Mentorship:** A peer-mentorship program will be explored to allow experienced representatives to guide newer members, fostering a supportive community.
- **Resource Library:** The forum will maintain and continuously update a library of accessible information, glossaries, and links to relevant organizations.

# Appendix B Continued

## Support and training opportunities for Lived Experience Participants

**Accessibility:** The platform will be user-friendly, catering to diverse digital literacy levels. Support for access to technology and internet may be provided for low SES participants. Language translation and face-to-face interviews may also be considered during recruitment to enhance inclusivity.

**Peer Support:** The plan encourages the involvement of "peer workers" or "peer support workers" who use their lived experience to support others, fostering a sense of shared understanding and connection.

**Conflict Resolution:** Clear processes are in place for addressing conflicts or breaches of the Code of Conduct, with an emphasis on restorative approaches.

### **Addressing Challenges Related to Support and Remuneration**

**Digital Divide:** Mitigation strategies include providing devices/internet access and offering digital literacy training.

**"Professional" Consumer Views:** While training is provided to enhance understanding, the forum will deliberately engage a diverse range of individuals (experienced and new) to maintain authentic perspectives.

**Consultation Fatigue:** Careful management of engagement frequency, clear communication of time commitments, and diversifying the pool of representatives will help mitigate fatigue.

**Funding Sustainability:** Diversifying funding sources and clearly demonstrating the forum's value and impact will be crucial to securing ongoing financial support for both operations and participant remuneration.

# Appendix C

## Remuneration and Reimbursement

**Direct Participation Payment:** Direct participation in forum activities, especially for committees, working groups, research, and co-design projects, will be remunerated. This recognizes the valuable time, knowledge, and expertise contributed by lived experience individuals.

**Hybrid Remuneration Approach:** A hybrid model will be used, encompassing:

- Salaried LEAP staff (e.g., Coordinator, Project Manager).
- Honorariums or gift cards for lived-experience participants. This approach will carefully consider the impact on members receiving welfare benefits, aiming to structure payments as one-off contributions rather than regular income where possible.

**Reimbursement of Expenses:** All reasonable out-of-pocket expenses incurred by participants (e.g., travel, alternative care expenses, printing costs if needed) will be reimbursed. This ensures that participation does not create a financial burden. This is separate to any form of remuneration for participation.

**Client Fees:** An application fee may be charged to organisations seeking engagement. Such fees will be tier and differentiated based on the engaging organisation's financial capabilities (e.g., non-profits vs. for-profit corporations).

**Transparency:** Payment and reimbursement policies will be clearly communicated to LEAP participants at the outset of any project or activity.

# Appendix D

## A Comparison of the Different Approaches to Remuneration for Health Consumer Participation in Engagement and Advisory Roles

Taken from: Paying Consumers Involved In Engagement Activities. National Prescribing Service (NPS) 2022

### Rates of remuneration and reimbursement

Consumers Health Forum of Australia do not have a specific rate that they use, however they recommend \$83.60 per hour or \$418 per day (over 5 hours) which is based on Australian Government Remuneration Tribunal recommendations. They do insist on payment for ad hoc activities.

Practice in relation to payment differs across other organisations too, however many are also based on State or National Guidelines and depend on the level of contribution made by consumers. The table below summarises practice for a range of organisations.

Organisation	Rate	Notes
<b>Health Consumers NSW</b>	\$42.03 per hour including preparation time + expenses	Based on Classification and Remuneration Framework for NSW Government Boards and Committees Amount increased by 2.5 percent annually
<b>Health Consumers QLD</b>	\$40 per hour including preparation time	Based on Guidelines for Consumer Representatives on Statewide Clinical Network Steering Committees, 2008
<b>Victorian Comprehensive Cancer Centre</b>	\$194 (≥ 4h) or \$97 (< 4h) for program and project involvement – liaison, advisor, team member, project governance \$50/hr for speaking engagements/panel member at events, reviewer roles in research, education, training and communication \$40/hr for participating in consultation activities such as focus groups, consultative workshops and interviews, storytelling to support communications, program development or delivery: interviews, writing, video-based.	Aligns with the Victorian Department of Premier and Cabinet's Appointment and Remuneration Guidelines
<b>Health Consumers Alliance of SA Inc</b>	travel expenses, light refreshments and a gift voucher	Hourly rate increased annually
<b>Telethon Kids</b>	\$35 per hour \$35 one off payment for attending 2 hr community conversation \$50 per hour for higher duties	Based on guidelines and policies from WA Department of Health, Mental Health Commission and Health Consumers Council WA
<b>Safer Care Victoria</b>	\$225 per day for project groups	
<b>Mental health commission</b>	\$83.60 per hour + expenses \$418 per day (over 5 hours) + expenses	Based on Australian Government Remuneration Tribunal Remuneration and Allowances for Holders of Part Time Public Office Determination, as "Offices not specified". Rates amended periodically Periods of travel are included in the overall hours preparation time is not included
<b>Mental Health Commission NSW</b>	\$220 per day	Based on NSW Public Service Commission's Classification and Remuneration Framework for NSW Boards and Committees

# Appendix E

## Example LEAP Involvement Agreement

Notes: This agreement is suitable for more formal and ongoing involvement and can be adapted as necessary.

This agreement is made between (insert name of managing organisation) and (insert name of panel member)

Thank you very much for agreeing to be part of this project as a member of the online Obesity Lived Experience Advisory Panel. The project aims to establish a strong and influential online platform that facilitates meaningful and sustained consumer engagement in obesity research and health policy from the perspective of lived experience. We will give you further information on this as part of your orientation.

### YOUR CONTACT PERSON

Your main contact person for this project will be [insert name, email and phone number – put in bold]. Please feel free to contact [insert name] with any concerns or queries– both at meetings and between meetings. [Insert name] is available between [insert working hours].

### YOUR TIME COMMITMENTS

Panel members volunteer initially for a period of two years after which we will have the opportunity to renew your commitment or choose to step away. If this changes at any point we will let you know and give you the option to alter your involvement if appropriate.

You are being asked to give the following time commitment:

- Attend online engagement and education sessions about the LEAP process (1-2 sessions of 1 hour).
- Volunteer to sit on 2-3 panels each year around issues that you comfortable to discuss (each panel may meet 2-4 times for a period of 1 hour)
- Read meeting papers and background material (30-60 minutes per meeting).
- Review panel reports for approval (20-30 minutes)
- Participate in other panel-related meetings and evaluation interviews if required (30-60 minutes)

This will not be significantly changed without your agreement.

### DETAILS RELATING TO MEETINGS

Panel discussion sessions will usually be held online via a videoconferencing app at an agreed time (usually out of office hours). We will give you plenty of notice of the timing and agenda of any meetings or panels.

### SUPPORT FOR YOUR ROLE

We want you to feel fully able to contribute to this project. You would have let us know in your application form if you have any specific support needs and we will make sure these are addressed. If there are any other needs that arise at any time, please do not hesitate to let [your contact person] know.



# Appendix E Continued

## Example LEAP Involvement Agreement

### EXPENSES AND PAYMENT (HONORARIUM)

As advised, we will recompense your time commitment with a small honorarium. As the panel sessions and meetings are generally conducted online we do not expect any travel costs but we will reimburse any agreed expenses according to reimbursement policy. Expenses should be agreed with your contact person in advance. You will need to complete an Expense Claim Form. Your contact person will provide you with this or download here. [insert where document may be accessed].

Please provide original receipts, sign the form and give it to your contact person for authorisation and processing.

As advised, there is also an honorarium payment for your work on this project. The process for claiming an honorarium is [insert].

[Include this paragraph if the consumer member has refused the honorarium]. You have told us that you do not want any honorarium payment for the time you spend working with us on this project. We appreciate that gesture. If at any point in the future you change your mind about accepting an honorarium, please speak to your contact person who will arrange for future payments (for work completed post the new agreement).

### CONFLICT OF INTEREST AND CONFIDENTIALITY

As a member of this LEAP panel you will be required to disclose any involvement you may have with other organisations, government bodies or companies which could result in a conflict of interest with the work you undertake for this project. You will also be asked to sign a privacy/confidentiality agreement. Your contact person will provide you with this [or insert where or how this document may be accessed].

### EMPLOYMENT STATUS

Consumer members are not considered to be employed by [insert organisation]. However, you will need to conduct your involvement activities as set out in this agreement. If you decide you no longer wish to be a member of the team as a consumer member you can resign at any time. If possible, we very much hope that you will give notice and let us know why you want to stop.

You and [insert name of contact person] will meet at various points during the course of the work. This will be an opportunity for you to ask additional questions and give feedback on how you are finding the role. You should not leave any pressing issues to this review, but it may be a chance to explore any additional training or support needs that you feel you may have.

We very much hope that you will enjoy the work of being a LEAP panel member on our project and very much appreciate your commitment to it.

With best wishes,

[insert project lead signature, name and job title]

+++++

This agreement was accepted by [insert consumer name, phone number and e-mail]

Signature: ----- Date:

Finally, we would like to be able to send you our newsletter and other occasional items of interest. For this purpose, we would need your permission to share your contact details with colleagues in the organisation. Please sign here to confirm that you are happy to be contacted by other staff.

Signature: ----- Date:



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