

Lived Experience Participation Review



No Harm, No Discrimination

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A Word from our CEO

This is a significant and exciting period in the alcohol, tobacco and other drug sector in Tasmania as it heralds a new era of participation from the people and the communities accessing our services.

In 2021 there is already widespread support across the Tasmanian ATOD sector for more meaningful lived experience participation, but most have limited time, capacity and resources to devote to this aspect of their operation. In November 2020, the Tasmanian government has made lived experience participation a clear priority in their 'Reform Agenda for the Alcohol and other Drug Sector in Tasmania'.

This is the right time for all organisations in the sector to review how they listen to and involve the people who are accessing their services.

The ATDC is strongly committed to identifying and supporting lived experience representatives to provide advocacy, expertise and knowledge into the co-design of strategies, policies, procedures and programs across all levels of the ATOD service provision.

Whatever this inquiry reveals about the current lived experience participation levels within individual organisations, there is clearly scope for our communities to better consider, harness and act on the insights and expertise that people with lived experience can provide through meaningful participation activities.

Alison Lai
Chief Executive Officer, ATDC

Introduction

The Lived Experience Participation Self-Assessment Review is an opportunity to take a gentle, practical step to improving lived experience participation at your organisation. The review is a quick way to give insight into what your organisation has done well in the past and is currently doing well.

Some benefits of this review are that it promotes alignment among the people within your organisation through reflective discussion, it strives to bring staff closer to the people they are serving, and it creates awareness of the current best practice for lived experience participation in our sector.

It's unlikely that any organisation and staff have ever felt completely comfortable with the changes that leading practice lived experience participation advocates for because making changes may invite a level of uncertainty into the service. I understand that the positive changes we are making here at the ATDC are the result of many years of lobbying to create designated staff positions to integrate meaningful and positive lived experience participation into our organisation.

Citizenship, equality, respect, dignity, and human rights are the heart of all lived experience participation. It seems important to me to keep these bigger themes in mind along with the issues being tackled within the alcohol and other drug sector such as stigma, marginalisation of groups and power imbalances. It can be as simple as consistently checking in with the people, process, or situations by asking *'Is this equitable? Is this dignified? Is this empowering?'*

Thank you for making the time to complete this review. The ATDC welcomes any feedback and encourages your evaluations to improve this review for the future.

Greg Taylor
Community Engagement Project Officer, ATDC
June 2021

Notes on Terminology

Dropping the jargon: transitioning away from the term 'consumer'

In 2021, the ATDC is proposing to make a conscious transition away from using the term 'consumer' to describe a person (or family member/friend) who has experienced a dependence on alcohol or other drugs. This is partly informed by a series of informal interviews in the sector conducted by the Consumer Engagement Project Officer, subsequent discussions with ATDC staff, and 'consumers' themselves.

The main reasons for this proposal are:

- 1) The ATDC wants to promote the use of simple language.
- 2) Being labelled a 'consumer' might be detrimental to the efforts to engage an individual or group. On some level a person might feel:
 - dehumanised
 - solely defined or limited by this term
 - reduced to being solely one-dimensional
- 3) While the term 'consumer' might be entrenched in the vocabulary of the wider health system as someone who accesses or 'consumes' a service, in the alcohol and other drug context the term can have an unintended duality and conjure imagery of 'consuming', 'imbibing' or 'ingesting' liquids and other substances into the body, and these connotations can contribute to the feelings listed in 2) above.
- 4) When a person discovers that they are referred to as a 'consumer', it might contribute to feelings of othering, a change in the dynamic, alter their responses and ultimately damage the engagement to a degree that is hard to measure.

For these reasons it was determined by the ATDC that the label 'consumer' in the AOD context has become problematic enough to consider alternatives. As the peak body for the AOD sector in Tasmania, the ATDC strives to be a leader in best practice and this includes not perpetuating the use of language that has dated and is potentially harmful. The ATDC recognises that the terms 'consumer' and 'consumer engagement/participation' have currency throughout the health sector and may still be needed for internal reporting.

In external correspondence, the ATDC has made the decision to preference using:

- **'lived experience advocate'** or **'advocate'** over the term 'consumer' (singular)
- **'lived experience community'** over the term 'consumers' (plural)
- **'lived experience advocate service'** over the term 'consumer representative service'
- **'lived experience participation'** over the terms 'consumer engagement' or 'consumer participation'

This document and review uses this terminology.

Quick Guide to completing the Review

1. Nominate one of your staff members for the facilitator role.
2. Your facilitator will be given the task of guiding your staff through the Review.
3. Encourage both staff and people accessing your service or with relevant lived experience to participate
4. Send report to the ATDC for evaluation feedback or use the 'Assessing your Organisation's Responses' guide (pp 18-20)

Facilitator Role

As the facilitator, you will lead the Review for your colleagues and the lived experience advocates. By doing this task well, you will save everyone's time. If there is no one available for the facilitator role, it's possible that an ATDC staff member can fulfill this role. Please contact the ATDC to request this service.

Facilitator Tasks

Two weeks before the review

- 1) Consider which lived experience advocates will join your staff to participate for this review. Ideally these will be individuals who have recently and/or regularly accessed your services, or have relevant lived experience. Invite them for the time they can make it and discuss any barriers to fulfilling their commitment.
- 2) Schedule the date, time and venue and make invitations to staff and lived experience participants.
- 3) Email or provide the 'Key Information for Participants' to each participant (pp 21)

On the day before the review

- 1) Check in with lived experience advocates that their attendance is still possible
- 2) Print some spare Review documents (pages 6-17) in case some participants want to follow on or make their own notes
- 3) Nominate a note taker who will capture perspectives in the review

During the review

- 1) Welcome participants and frame the Review by quickly summarising what it is (see 'Introduction' pp 2), and the terminology used (pp 4).
- 2) Read aloud each question and ensure the key points or quotes are captured by the note taker. The note taker will tick boxes and enter written content. If there is a perspective that is deemed important but is contested, place an asterisk after it – like this*
- 3) Ensure both staff participants and lived experience participants have the chance to contribute
- 4) Take a break when needed to keep participants engaged

After the review

- 1) Distribute and collect evaluation forms for the ATDC
- 2) Consider how your organisation would like to handle the learnings. If you would like to keep this process internal, please refer to 'Assessing your Organisation's Responses' guide (page 18-20). If your organisation would like an external review, a response analysis report can be prepared by ATDC staff
- 3) Share with all participants (staff and lived experience advocates) how the feedback influenced and impacted the organisation

LIVED EXPERIENCE PARTICIPATION SELF-ASSESSMENT REVIEW

KEY INFORMATION

- The Review has 45 questions and will take approximately 2 hours
- It is designed to be taken with staff participants and participants who have accessed the service or have a relevant lived experience of alcohol or other drugs
- Each section has discussion questions alongside some tick-a-box questions. For the discussion questions, a note taker will try to capture notes that reflect the discussions
- Contributions will be de-identified
- As there is a breadth of treatment and support settings, not all questions will neatly apply to every service. If a question is not applicable to your service, mark it N/A
- For more information (or clarification during the Review), your facilitator can also present information from the Introduction (pp 2) and Terminology Notes (pp 4)

SECTION 1: Understanding the experience of someone accessing our service

Creating Awareness of our Services

Q1 How can the public learn about what our organisation services are?

Q2 How does our organisation present information about our service in our reception?

Q3 How does our organisation inform people accessing our service about other similar services?

Physical environment

Q4 The information we provide in our reception, waiting room and/or consultation room is:

- easy to see
- presented in an uncrowded way
- current and accurate
- written in everyday language
- at an appropriate height for everyone

Q5 Is all relevant sector information provided to service users, not only the services and treatment options that our services provides or promotes?

- Yes
- No
- Unsure

First Contact

Q6 What happens when it becomes clear that our service is going to meet the specific needs of someone?

Q7 What happens when it becomes clear that our service is not going to meet the specific needs of someone?

Collecting Personal Information

Q8 How does our organisation share information with, and collect information from, someone accessing our service for the first time?

Q9 When collecting personal information, how does our organisation ensure someone feels safe and confident with how we handle their data?

Rights and Responsibilities

Q10 How does our organisation inform people of our mutual rights and responsibilities?

Tailored Care

Q11 How does our organisation create awareness that our service is flexible and can be tailored to suit their specific needs (wherever safe and possible)?

Service-User Feedback

Q12 What are the ways that people accessing our services can provide us feedback?

Q13 How is this feedback handled by our organisation?

Q14 How is feedback collected? *(tick more than one if relevant)*

- Online forms via our website
- Email
- Phone
- Social Media
- Surveys
- General conversation
- Formal meetings
- Other (can specify)

Q15 In our experience, people accessing our service are more likely to provide feedback after...

- Positive experiences
- Negative experiences
- Both positive and negative experiences
- Unsure

Q16 A person who submits internal feedback to our organisation can: *(tick more than one if relevant)*

- Expect that their feedback is not reviewed/addressed
- Expect that their feedback will be reviewed/addressed but is unlikely to make an impact
- Expect a verbal or written response to their feedback
- Have confidence that their feedback is reviewed by staff in a systematic way and can make an impact

Unsolicited Feedback

Q17 What are some possible motivations for someone leaving feedback on a public forum?

Q18 Has a person who has used our service ever left a review online?

- Yes
- No
- Unsure

Q19 Does our organisation have a procedure for handling unsolicited feedback?

- Yes
- No
- Unsure

Q20 Does a staff member have responsibility for monitoring unsolicited feedback in their position description?

- Yes
- No
- Unsure
- Not applicable

Q21 Our organisation responds to:

- All reviews
- All reviews that provide some considered comments (not only a star rating)
- Mainly positive reviews
- Mainly negative reviews
- None
- Unsure
- Not applicable

Trust

Q22 What are some things our organisation is doing/has done well to build trust with the people accessing our services?

Q23 What are some situations that have damaged trust between our organisation and the people accessing our services? Have these issues been addressed? If yes, how?

SECTION 2: Attitudes, Capacity and Perceived Impacts

This section asks about lived experience participation at our organisation. This might include how our organisation informs, consults, involves, collaborates and empowers the people who are accessing our services (or people with lived experience) to influence both our service and the alcohol and other drug sector.

Q24 What areas of our organisation benefit (or would benefit) the most from lived experience participation?

Q25 What are (or have been) the main barriers to lived experience participation at our organisation?

Attitudes toward Lived experience Participation

Q26 What is the general staff attitude toward lived experience participation within our organisation?

- We recognise it is important and it is part of our systems and processes
- We recognise it is important but it not part of our systems and processes
- There is no general awareness
- Other (welcome to specify)

Capacity

Q27 Does our organisation have an interest in improving lived experience participation?

- Yes, and we have the capacity
- Yes, but we don't currently have the capacity
- Unsure
- No

Q28 Are lived experience participation activities seen as an 'extra' for staff members to coordinate? (ie. not in position descriptions)

- Yes
- No
- Unsure
- We don't have currently have any lived experience participation

Q29 Does our organisation provide fair remuneration (pay) for the time and expertise of our lived experience participants?

- Yes
- No

Perception of Impacts

Q30 In our collective experience, the processes of lived experience participation in our organisation:

- make no impact on our service delivery
- make minimal impact on our service delivery
- make a small but significant impact to improving our service delivery
- make meaningful and tangible impact to improving our service delivery

Q31 Has any lived experience participation activity or process led to training or professional development opportunities for an individual?

- Yes
- No
- Unsure

Q32 Has any lived experience participation activity or process led to further paid employment for an individual at our workplace or elsewhere? *(select more than one if relevant)*

- Yes, salaried employment
- Yes, casual employment
- Yes, occasional employment
- No
- Unsure

Q33 Has any lived experience participation activity or process led to an opportunity for a person with relevant lived experience to present training to staff or the sector?

- Yes
- No
- Unsure

SECTION 3: Measuring Lived Experience Participation at the Service Level

This section asks about the ways that our service informs, engages with, and works with the people accessing our service to influence and strengthen our service delivery. It asks about how the structure of our organisation accommodates and supports processes of lived experience participation.

Q34 How do we INFORM the people accessing our services?

- We publish a brochure for the community that describes the services we offer
- We publish and maintain a website where the public can access information about our mission/values, services, structure, governance and ways to contact us
- We use social media platform(s) to cross-post new information
- We periodically publish and distribute an e-news(letter)

Q35 How do we CONSULT with the people accessing our services?

- We provide periodic surveys to give us feedback on service delivery
- We have a procedure for reviewing feedback from surveys/consultations to consider how the insights may influence our service delivery
- When we have a new program or project, we invite the people who access our services (and/or people with relevant lived experience) to offer constructive feedback on the design and implementation plan
- We seek the expertise of a diverse range of people with lived experience and don't rely on the same individuals for the majority of our engagements
- When we consult with people accessing our services (and/or people with relevant lived experience), we are clear about the nature of the engagement and what their feedback might realistically influence
- After consultations, we provide a written summary to participants about how their feedback influenced the topic of discussion

Q36 How do we INVOLVE the people accessing our services?

- Our clinical/treatment staff welcome people with lived experience as equals in our workplace
- Before we start a new program or project, we invite people who access our services (and/or people with relevant lived experience) to be involved in the design and implementation plan
- When we organise professional development and training for staff, we invite people who access our services (or with relevant lived experience) to participate
- When we have strategic planning days we invite people who access our services (or with relevant lived experience) to participate

The following 3 questions ask about people who access our service and/or with relevant lived experience who might have also had training and professional development to make more meaningful contributions to improving our service (sometimes called 'peer workers', 'consumer representatives' or 'community representatives'.)

Q37 How does our organisation collaborate with and empower people with lived experience to influence our service delivery?

Q38 How do we COLLABORATE with people with lived experience to improve our services?

- We induct selected people with lived experience into our organisation
- When we recruit new staff, we employ a representative with relevant lived experience to be on our interview panel
- In training and professional development activities, we require at least one session facilitated by people with relevant lived experience

Q39 How do we EMPOWER people with lived experience to improve our services?

- We facilitate (or have an association with) a lived experience community representative advisory/reference group
- The lived experience advocates that work with our organisation have an avenue to communicate with, or be represented on, our governance board or directorate
- Our organisation implements decisions on strategic, policy and program matters with the support of a community representative/advisory group
- We support people with lived experience to pursue opportunities for professional development/ training, media engagements and events/forums
- We offer support, education and mentoring for people with lived experience who are seeking to meaningfully participate at the governance level of our organisation

SECTION 4: Measuring Lived Experience Participation at the Sector Level

This section is about the big picture. The following questions ask about how our organisation invests in people who access our service and/or with relevant lived experience to have a voice and meaningfully influence at the sector level.

Q40 How does our organisation INFORM people who access our services at the sector level?

- We provide printed and online information about our policies, standards/charters we follow, and relevant legislation for the alcohol and other drug sector
- Our annual reports, budget priority statements, position papers and submissions to government are available on our website
- When legislative reform is proposed for our sector that will affect our service delivery, we actively share this information with the people accessing our service

Q41 How does our organisation CONSULT with the people accessing our service at the sector level?

- We publish a summary of sector planning and evaluation we are going to contribute to, which includes avenues for the people accessing our service to share feedback
- When legislative reform is proposed for our sector that will affect our service delivery, we engage people accessing our service (and/or with relevant lived experience) to contribute to our submission/response
- We have a periodic survey that asks people accessing our service about their experiences and possible issues encountered in the wider sector (not only limited to experiences of our service)
- When we are updating service policies or developing new service policies, we involve the people accessing our services (and/or with relevant lived experience) to ask for feedback

Q42 How does our organisation INVOLVE the people accessing our service at the sector level?

- We advocate for the inclusion of the people accessing our services in planning, review and reform processes across all sector jurisdictions and systems levels
- We have a dedicated staff position whose duties include recruiting and engaging people accessing our services (and/or people with relevant lived experience) to participate in representative opportunities and activities
- When we make a submission to state or national sector or government consultation, we include an impact statement from people accessing our services (and/or with relevant lived experience)

Q43 How does our organisation collaborate with and empower people with lived experience to influence the sector at the policy level?

Q44 How do we COLLABORATE with people with lived experience at the sector level?

- We have resources allocated to sustainably engage community representatives and solve logistical and financial barriers to participation
- We have the budget and a remuneration policy for our peer workers/community representatives to be paid for their time and expertise

Q45 How do we EMPOWER people with lived experience at the sector level?

- We coordinate a community representative program dedicated to building and maintaining the capacity of the people accessing our service to influence the sector
- We welcome and support people with relevant lived experience to be represented on our governance board or directorate
- We employ staff with relevant lived experience as peer workers/community representatives to help engage and coordinate the people who access our service
- We coordinate and facilitate a community representative advisory/reference group that meets periodically to co-author new and revised policies, strategic planning, position papers and submissions to stakeholder consultations
- We offer access or help make connections to professional development and mentoring opportunities to our peer workers/community representatives

Any final reflections from participants?

THANK YOU

If your organisation would like to internally review the responses, please refer to pages 18-20.

Your organisation is also welcome to share de-identified notes with the ATDC who can help collaborate on an action plan for the future.

Assessing your Organisation's Responses

Option 1:

Until April 1 2022 (and possibly beyond), the ATDC are available to work with your organisation to help review responses, identify opportunities for improvement and collaborate to design an action plan. Please contact the ATDC directly for this service.

Option 2:

If your organisation prefers to keep this review internal, here are a general and specific questions to measure responses.

General questions:

1. Was a consensus on each question easy to reach? Some questions in the review are more subjective (attitudes, capacity, inquiries into individual viewpoints) and may have elicited varied responses. If some areas were contested it might suggest that these are areas to focus on.
2. If copies of the review were handed to participants, scrutinise any discrepancies between the facilitator notes and the sheets handed to participants. It's possible that not everyone in the room felt comfortable to speak their mind in a group discussion, and might have preferred to make notes.
3. Did your organisation exhibit any obvious strengths in the review? Was it easy to tick many boxes? It's good to acknowledge these achievements with participants.
4. Did the review reveal possible weak areas in your organisation's approach to lived experience participation? The answers to the open questions (those with a box for writing) can possibly create the guides that will inform the beginnings of an action plan.

Specific questions

Q1: This question is seeking clear, short descriptions of a service, strong awareness from all staff, and multiple ways that this information is presented (verbally, website, social media, brochure, posters).

Q2: This question asks organisations to consider if people accessing services have a full awareness of comparable treatment outside their particular service. The rationale for inclusion is to educate people who are seeking support about their options to determine the best match for their treatment.

Q3: This question is aimed at preventing people 'bouncing' off the system. It encourage services to consider how they make referrals to other services, and whether more can be done to facilitate a safe, smooth connection with referred services.

Q4: Organisations who ticked all five options can be satisfied that the entry to the service is welcoming and not over-stimulating. Periodically reviewing the information (posters, brochures) presented in the physical environment and removing any dated material are important steps to creating welcoming environments.

Q6-7: These questions asks for clarity about process from staff participants and can be cross-checked with lived experience participants

Q8-10: Staff participants are likely to identify and explain a sound process as in accordance with standards/charters, but these perspectives can be cross-checked with lived experience advocates.

Q11: A good question to let lived experience advocates lead and record perspectives. Staff may also want to cite examples.

Q12: A strong result here is to have a clear avenue for people to provide feedback (this doesn't necessarily mean having several avenues).

Q13-16: These questions are about building people's faith that their feedback is a genuine chance to be systematically reviewed and make an impact. If an organisation or staff are receiving regular unsolicited feedback, it might be worth considering the responses in these questions.

Q17-21: People sometimes resort to leaving negative feedback on public forums, including social media platforms, if they have little faith in the internal feedback channels an organisation has provided. Conversely, people may also leave positive feedback which can reflect very well, since the experience of your organisation has been so good that someone has gone out of their way to put it on public record. If your organisation is receiving regular negative unsolicited feedback, there are some questions worth asking: is this feedback a one-off or is there a pattern? Did we already receive feedback internally about this issue? If no, why didn't we receive internal feedback first (review Q12-16)? What is our procedure for responding to unsolicited feedback?

Q22-23: Hearing perspectives on trust is a key part of understanding the experience of people accessing the service. For the examples where trust has been damaged, read the room to see if participants think that staff and/or organisational responses were satisfactory

Q24-25: It might be necessary to mention 'consumer engagement/participation' here to measure the true responses. These are good answers to examine for forward planning and making incremental changes to services in relation to lived experience participation

Q26: If participants could not tick one of the top two options, it might be an opportune time to consider how important lived experience participation is within the organisation and to create better awareness and alignment among staff.

Q27-28: Capacity. Staff are no doubt tired of saying and hearing it! If the general consensus is Option 1 for Q27, then your organisation is in the minority. Option 2 exhibits the desire for positive change but the efforts could lead/have led to staff burnout, unexpected departures from employment, and poor staff retention.

Q29: If this was once a 'grey-area', it isn't any longer. Lived experience participants/representatives must be paid for their time and expertise.

Q31-33: A 'yes' to any of this set of questions is fantastic as your organisation may have given someone an opportunity that has developed their skills and confidence that has been the foundation or stepping stone to greater engagement with the sector. It also illustrates a familiarity with someone's journey that exhibits that your interaction was more than a one-off.

Q34: Organisations may cover these points in accordance with their standards/charters and most will be able to tick all options. If not, consider reviewing or amending.

Q35-39: These sets of questions inquire specifically about aspects of lived experience participation currently considered to be best practice. These questions can act as insights to prompt a discussion among participants. To achieve some of these might not mean a complete overhaul and might be adding detail to procedures or processes to enhance the experience and impacts of existing lived experience participation activities.

Q40-45: Again, not many organisations globally will be able to tick every box, but these questions might trigger discussions from participants about how incremental changes can positively impact lived experience participation at your organisation. Which of these are realistic to target in the short-, medium- and long-term future?

LIVED EXPERIENCE PARTICIPATION SELF-ASSESSMENT REVIEW

KEY INFORMATION FOR PARTICIPANTS

Thank you for agreeing to be part of the Lived experience Participation Self-Assessment Review (the 'Review').

The Review is designed to measure and better understand two things:

- the experience of people accessing the organisation's service
- how the organisation involves [lived experience advocates](#) to influence its service delivery and also the alcohol and other drug sector

A [lived experience advocate](#) is a person with lived experience of alcohol or other drugs who shares their perspectives to inform and take action on issues that impact themselves and their peers.

Here is the key information for this opportunity.

- 1) The Review takes 2 hours
- 2) The Review has both discussion questions but and multiple choice questions.
- 3) There is no pre-reading.
- 4) Staff of the organisation will also be involved the Review and have been given the same information as lived experience advocates.
- 5) We are asking for perspectives to be shared in a small group setting. There will also be an option to write down perspectives if someone is not always comfortable to speak.
- 6) The Review is mainly interested in [self-advocacy](#), which means hearing about people's personal experiences, interests, need and perspectives.

If people also want and feel comfortable to represent the needs and interests of a group of people, or what is called [systemic advocacy](#), these perspectives will also be captured.

- 7) The insights gathered will give real feedback to this organisation and possible areas to focus on improving. The organisation will provide a short report to all participants about what their insights influenced and what impact they had.
- 8) Lived experience advocates will be reimbursed for their time (to be advised by the organisation).

The organisation will advise participants of the time and place of the Review.

Frequently Asked Questions

Q: What if we already know our organisation isn't doing lived experience participation very well?

A: If you know where your organisation sits in terms of lived experience participation activity, you already have a head start. This review tool will help clarify what is historically/currently happening, identify areas for improvement and offer strategies to achieve this. You may discover gaps in lived experience participation in areas outside your programs and roles, or engagement activities happening you didn't know about!

Q: Will our organisation be told we have to change everything?

A: Not at all. Another aim of the review is to measure your organisation's current capacity for lived experience participation, and that means working to your service's strengths and finding ways to build on them. All workplaces have areas they could improve on, and this could be your organisation's first step to increasing lived experience participation.

Q: Does lived experience participation improve outcomes for people with lived experience and increase job satisfaction for workers?

A: The short answer is yes! The slightly longer answer is there is a large body of research examining the impacts of lived experience participation on both people with lived experience themselves, and the workforce sector providing the services they use. This is particularly true of the health sector, and especially so with regard to both mental health services, and the alcohol and other drug sector.