



AODCCC

Alcohol and Other Drug
Consumer & Community Coalition

...beyond stigma

AODCCC Reference Group Evaluation Report 2025

Recognition of Lived Experience

We would like to acknowledge the individual and collective expertise of those with a lived or living experience of alcohol and/or other drug issues. We also acknowledge the emotional labour and vulnerability that is present in this space. We also recognise the work of those who came before us to build the foundations to enable this work to actually take place.

Introduction

The Alcohol and Other Drug Consumer & Community Coalition (AODCCC) is a membership-based organisation established in 2018 as a state peak body in Western Australia. The AODCCC's vision is community understanding shaped by the voice of people and families with lived and/or living experience of alcohol and other drugs. Our purpose is to promote the interests, education, and welfare of those affected by alcohol and other drug use.

We play a vital advocacy, representational and capacity building role for the Western Australian community. We engage our members, amplifying their voices and draw on their lived and/or living experience and expertise. Through systemic advocacy we strive to achieve our vision and mission for the betterment of those impacted by the prevalent alcohol and other drug use within Australian society. Our aim is to empower the voices of consumers, their families and supports ensuring health and wellbeing of the whole community.

Context

The AODCCC's focus is broad, active and effective consumer and community engagement. Since June 2022, the AODCCC has invested in a direct engagement member's Reference Group (RG) to support this endeavour. Recognising the importance of trust-building to enable collaboration, consumer ownership, and empowerment, particularly among hard-to-reach and hard-to-engage populations. The AODCCC has accounted for the requisite time to establish these relationships.

Individuals with lived and living experiences contribute significantly to various aspects of the AODCCC's work and to the community's acceptance of its efforts. The AODCCC aims to empower RG members by developing their engagement, advocacy, and leadership skills.

Members of the RG receive equitable compensation at a rate of \$37.50 per hour and participate in a monthly meeting held on the second Wednesday of each month, lasting for a total of two hours. Public transport and parking expenses are also reimbursed.

The AODCCC employs a combination of in-person and digital engagement strategies to ensure inclusivity of rural communities and individuals facing challenges in attending the office physically. The provided office space is equipped with all necessary facilities, including dedicated staff for RG engagement, audiovisual equipment, stationery, refreshments, and printing materials.

The RG Terms of Reference are annually reviewed and updated alongside the RG members and AODCCC team. This process ensures there is a blueprint for collaboration, productivity and accountability.

The underpinning goals of the AODCCC RG are:

- The RG support the AODCCC to engage the community to ensure grassroots input that reflects community needs and interests.
- The RG supports the AODCCC to identify what needs to change to create positive impact.
- The RG supports the AODCCC to plan how the organisation will work and what it intends to achieve.
- The RG supports the AODCCC to identify ways to track how the organisation is going and who it's reaching.
- The RG supports the AODCCC to tell the story about the organisation's success or its challenges.
- The RG supports the AODCCC to be accountable to the community and to funders.
- The RG supports the AODCCC to learn for the future.

Method

The inaugural evaluation of the AODCCC RG was conducted through a survey disseminated to all current and former RG members. Of all the members who were sent the survey, a total of 25% responded, providing both quantitative and qualitative data and feedback. The primary objective of this feedback was to aid the AODCCC in assessing the RG's performance, advocating for its consumers, supporting organisational development and growth, understanding members' experiences, and identifying areas for improvement.

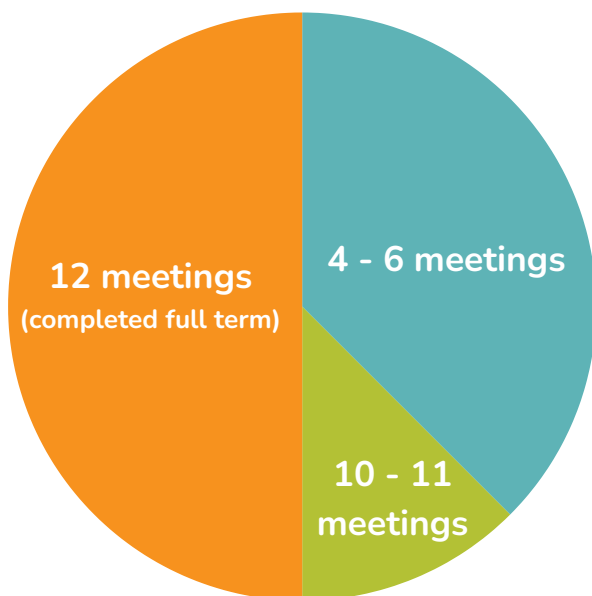
This process aims to enhance the quality of the RG and ensure that the AODCCC meets the needs of the community. The survey was completed anonymously, unless members chose to identify themselves. The process was facilitated by personalised emails to establish a direct and encouraging communication pathway, thereby increasing a sense of ownership and influence for an authentic information-gathering process. This approach fosters a heightened sense of community and satisfaction, while maintaining grassroots authenticity.

Each survey question included a comment section, enabling participants to elaborate or provide context in their own words, and to express their views or emotions.

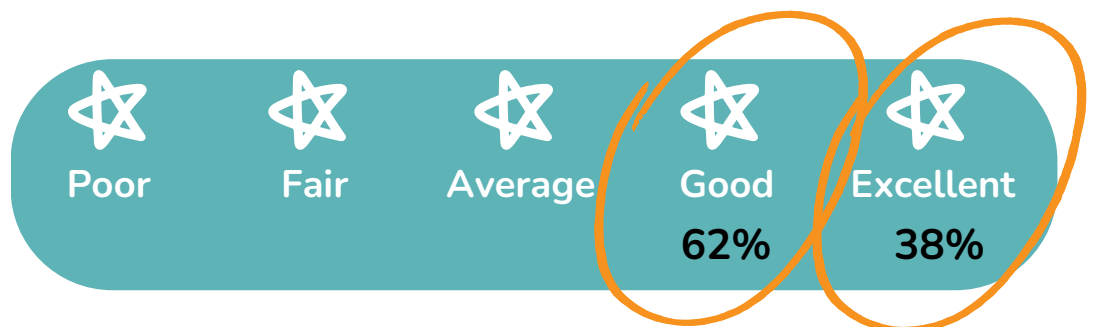
GR Member Voices

How many Reference Group meetings have you attended to date?

Respondents included a nice spectrum of term time and RG attendance.



From your experience and contributions made, how would you rate the AODCCC's advocacy work?



"I have attended a number of RG meetings and consultations, and the reports and submissions are good."

"Like anything in this world (not just advocate work) there is always room for improvement. I am proud to be a part of AODCCC because of the caliber of work being performed. The people I'm sharing my views with are genuinely interested and seem grateful for my participation."

"I felt that my perspectives, as well as the perspectives of others were considered, valued & represented accurately in the submissions that the AODCCC put together."

The AODCCC Reference Group works in accordance with the following values:



Inclusion

We acknowledge the legitimacy of everyone's experiences and provide a safe space for diverse views to be shared.



Collaboration

We look for opportunities to bring consumers, family, community, policy makers and service providers together for real change.



Accountability

We consult broadly and are open about our intent, activities and outcomes.



Leadership

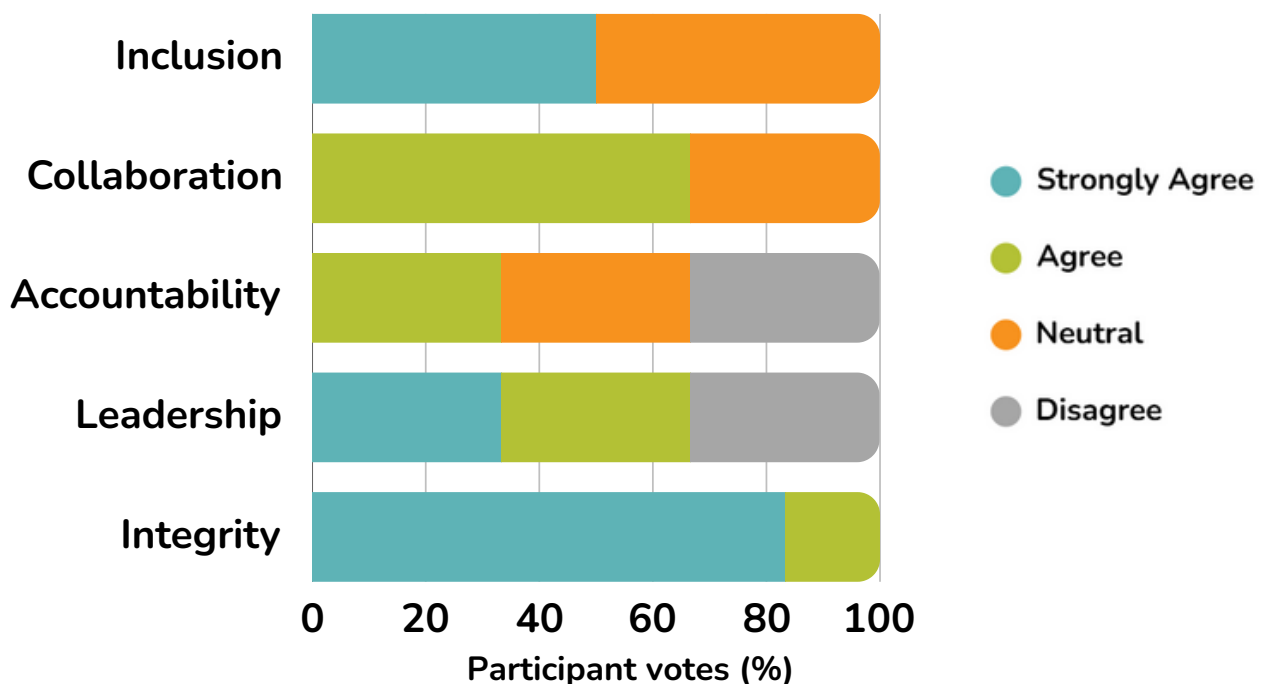
We share bold visions and take courageous steps towards what is needed in the community.



Integrity

We respect and value different perspectives and experiences of alcohol and other drug use.

From your experience, how would you rate the Reference Group's values performance?



The AODCCC will implement stronger boundaries and accountability tools to ensure that RG members continuously improve their perceived performance in relation to AODCCC Values. RG members will be given the opportunity to chair and lead the RG meetings to encourage a sense of shared leadership.



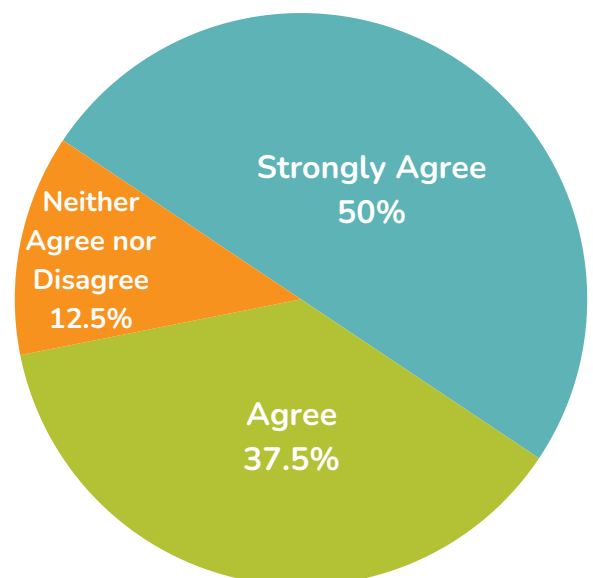
"I agree that the reference group meets all these values."

"I love how each of our versions of rehab or therapy is respected and we're still encouraged to share even though someone else might not have found success through a particular organisation. It has shown me how important it is to keep an open mind, and I love how that's respected by the AODCCC."

"I find the AODCCC doesn't penalise or remove members for swearing in the RG meetings. As trivial as that may sound, that's not the case in all groups. It's really hard to do justice on a subject while trying to heavily filter yourself."

"I enjoy that the leaders of AODCCC are approachable and come across as real people despite having what some consider a higher level of education. I half expected to be treated as "less than". That's not been my experience and I'm so grateful for this."

The Reference Group meeting agendas and required readings were achievable and appropriate?



Members indicated the importance of responsibility and consistency for all participants when preparing for the meetings, this includes pre-reading and preparation to contribute to agenda items. This allows for improved use of time in-session and creates a sense of equity in commitment and focus, leading to cohesion. This also displays a shared value for each other's time and work. If I.T. skills or competing priorities are impacting RG members ability to prepare or engage in the meetings, the AODCCC will respond with adjustments and tailored supports as needed.

"Sometimes it is a lot of reading - I don't like reading from a screen."

"It did not feel overwhelming for me."

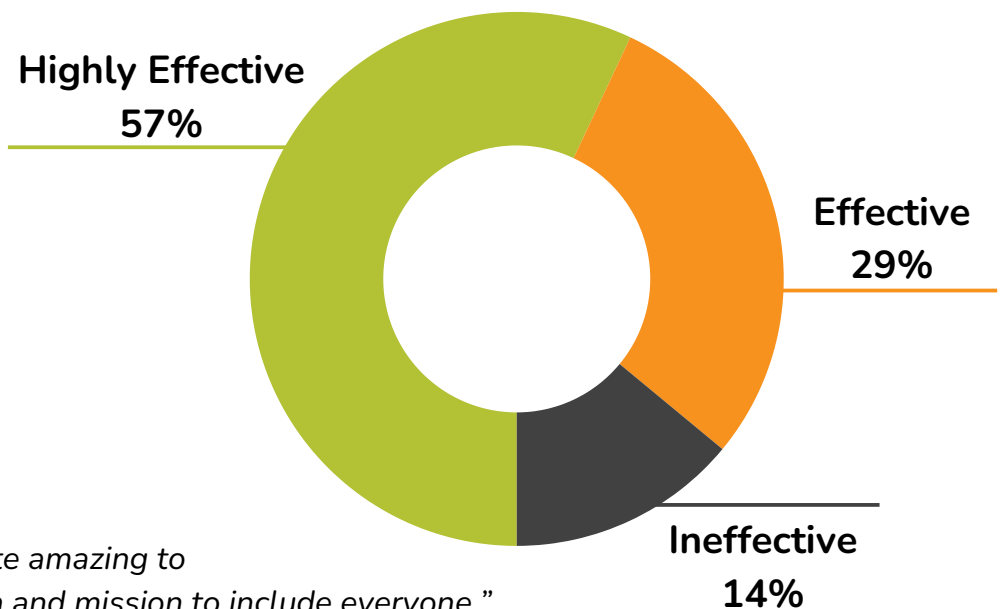
"For most weeks I'm not struggling to prepare/ complete what I need too."



"Some of the participants don't prepare anything before meetings or important tasks, when I've asked why, it's because they've learnt they don't need to in order to still get paid, that was frustrating to hear."

"Some have said they don't know how to find the links or don't get paid for reading time like other advocacy organisations. Technology isn't everyone's forte so I can see why everyone's level of participation varies..... some of us are not able to share to our full potential in a lot of areas because of the language used, difficulties finding or using some of the resources we're given. Not having things printed out or available in a different medium to best suit our needs. For me, when reading for example, I struggle with the overuse of abbreviations or when a passage of reading material has a lot of acronyms."

How effective is/was the Reference Group Facilitator?



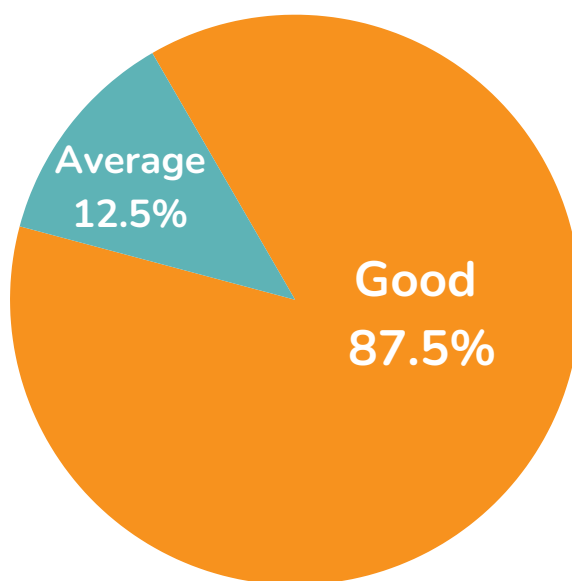
"Amazing work! It was quite amazing to witness the grit, dedication and mission to include everyone."

"I love the facilitator would be devastated to have someone replace them. They are patient and welcoming and do a fantastic job of making people feel at ease. I know I walked in feeling isolated and nervous and was immediately made to feel part of the group and that they valued my input. The facilitator does a wonderful job of helping me understand things I don't grasp the first time or in an email and doesn't make me feel stupid for asking."

“Onto it. Really quick with information gathering and understanding what all consumers are saying. Ask us always what we think.”

“The facilitator has the utmost consideration and care for the members. I love that they also have lived experience and draw on it and share that with members. Love the passion.”

How do you rate the Reference Group venue facilities?



“Plenty of space and great location”

“Compared to other peak bodies - the funding for comfort, inclusion of diverse needs e.g.: lighting/ seating, as well as catering budgets were well below what Mental Health advocate services provide.”

“Great room, comfortable chairs, love the nibbles and fresh fruit that been there lately. Technology surprised me when I first came as for whatever reason I thought the level of tech would be cheap or not a very extensive as AODCCC has. Location is great in respect to it being central for people north or south of the river. And zoom/teams is a great addition for those important rural communities/voices. And for me, the air conditioning being used is so important as I can’t regulate temps, so little things like that are huge for me and keep me coming back.”



What specific improvements or changes would you suggest to enhance the effectiveness and impact of our consumer Reference Group?

"Increase the size of the group. Increase the term time. More paid opportunities for the RG members."

"FUNDING! Outreach to increase diversity, an inclusive space that is not a sensory nightmare - also catering budgets."

"More than 12 sessions. They go so quickly, and it can feel like you've just got the hang of it and your time is up. I'd love more prep time for meetings where possible."

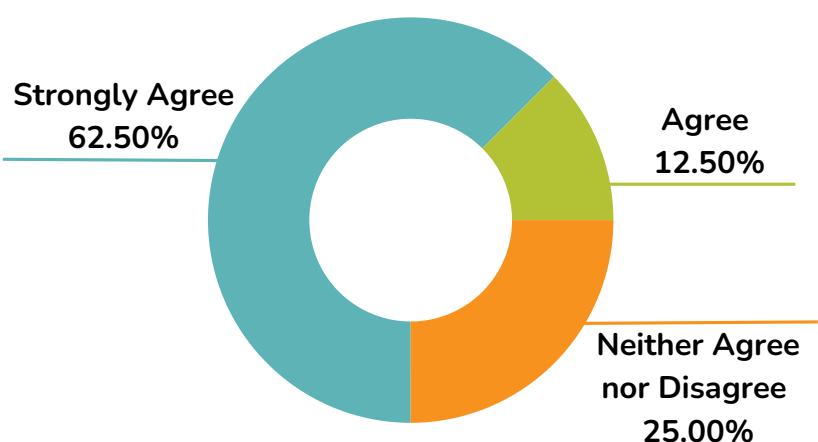
I'd love to be able to do more, so having more opportunities that don't even pay me would be great. Not just upskilling workshops but coming along for some of AODCCC speeches and getting a better feel for the reception would be nice. Sometimes people with past or present drug experiences can find it hard to relate to professionals or successful people. I've found often drug users listen to other drug users even if the same exact thing is being said by a dr or other professionals, like recognising like etc. So even tagging along would allow more people to feel comfortable engaging and asking questions afterwards."

"Longer term, 18 months."

"Longer term for members."

The Reference Group aims to build the capacity of its members through experience, opportunities and training.

From your experience do you believe your consumer representative skills and capacity has improved?



“Not only is the improvement noticeable to me, but others around me. And this isn’t just in my consumer rep skills, but all things advocacy related. Across the board my interpersonal skills and relationships have improved dramatically.”

“My capacity for communication and understanding has increased significantly and I’m able to recognise my contributions for what they are, valuable and needed.”

“My ability to relate to others has increased greatly and I felt I’d always been a very accommodating and empathetic person already, but through my participation in the RG my abilities and yearning for more work in this field have grown exponentially. I’d love to contribute more. And I went into this as a reserve and potentially just filling in for an absent person.”



What has been the highlight of your Reference Group participation?

“The highlight was working with a wide range of people who shared much in common while also being a very diverse group.”

“Meeting other people who want to stop the stigma around drugs.”

“Finding my voice, making friends for the first time since becoming an adult out of high school. My passion for helping others who are affected by things related to AOD is being recognised and is growing with me. This is monumental for me. I’m earning my own money which for me and as a woman is very important. I’m learning a ton of new things I can’t begin to fully explain about myself on a personal level up to being a living/lived experience advocate.”

“Being a part of helping change or assist WA’s AOD sectors is phenomenal for me. Seeing things that I’ve talked about or brought up, later featured in newsletters or even on the AODCCC Instagram or Facebook page.”

“Understanding that there are other people experiencing issues with drugs and alcohol who are genuinely concerned about improving the lives of others who may not yet feel comfortable coming forward.”

“Learning that I’m not bad at communicating as I was led to believe. This has been a journey of self-awareness and discovery, despite how cliché that may sound. I’ve gotten out of my comfort zone/bubble and learnt that despite the anxiety I feel I can accomplish things. I’ve gotten out of the house. This is an area I struggle in greatly and may not be significant to others or their growth, but it is a massive step for me and my agoraphobia.”

“Another highlight is the admiration from friends and family for my participation in such important work. They are proud of me. And as someone that’s had a lot of drug issues, having people be proud of you is often a new feeling. I’d be happy to share these thoughts and experiences in talking with others that you wish to join or to share with potential new members.”



Do you have any further final constructive feedback that we could use in relation to the AODCCC reference group?

“Keep on keeping on.”

“We should be paid for our reading time.”

“I wish you all luck - you don’t have the resources- I have always advocated for agitating inclusion with COMHWA - that is where the money is, it is also where about 50% of our community is - they are the unmet needs and instead of sector siloing - fight for our representation within the finances of the well-funded.”

“Meaningful engagement & experience. Thank you. I would love a longer term.”





Recommendations / Actions

The AODCCC has a shared commitment alongside our members to act on the findings of our RG evaluation:

Member's Voices	AODCCC Response / Action	Date Implemented
Request to be paid for required reading and preparation time.	Budget reviewed. RG members to be paid for 3 hours per meeting, allowing 1 hour paid preparation.	May 2025
AODCCC should be more explicit of their intent and of any outcomes, in relation to their Systemic Advocacy work.	AODCCC acknowledges that outcomes are meaningful to the community and imperative for sustaining relationships with members. The AODCCC will continue utilising diverse methods of communication to ensure timely dissemination of outcomes. The AODCCC team agreed to communicate and map outcomes on the website in relation to Systemic Advocacy.	January 2025

Member's Voices	AODCCC Response / Action	Date Implemented
There is a broad variation in RG members' contributions and engagement in meetings.	<p>The AODCCC have reviewed and updated the RG meeting Minute template to include action tasks to help motivate members to contribute to highly productive and engaging meetings.</p> <p>The Systemic Advocate will navigate the group dynamics with care and balance empowerment with respectful boundaries.</p>	February 2025
RG members indicated they don't always see their contributions.	<p>The AODCCC to implement an Action Log included in the monthly Agenda. This will be maintained monthly. Outcomes will be acknowledged and celebrated accordingly.</p>	August 2025
RG members indicated that they would like to 'shadow' the Systemic Advocate at presentations, events and meetings.	The AODCCC team to consider the establishment of a volunteer group to include shadowing.	Ongoing

Member's Voices	AODCCC Response / Action	Date Implemented
Continued.	<p>RG members are encouraged and given the opportunity to apply for grants to attend conferences alongside AODCCC Team.</p> <p>RG members to have the opportunity to be paid when helping promote the organisation at conferences and events.</p>	Ongoing
RG members indicated participation in the group goes beyond 'payment' and the process involved to become an RG member is important.	<p>RG and Systemic Advocate to create an onboarding package for new RG members to engender immediate trust and safety – factoring in time for genuine meet and greets and social time for group members to bond.</p> <p>RG provided input to onboarding content at February 2025 Meeting.</p>	To be finalised September 2025
RG members indicated that participation in RG has built their capacity and confidence in all aspects of their lives.	AODCCC recognises that capacity building within RG enables members to gain skills and knowledge through experience, opportunities, and training.	

Member's Voices	AODCCC Response / Action	Date Implemented
Continued.	The AODCCC will review the existing co-designed Lived and Living Experience Representative training package to ensure that it is current, with best-practice content, and will also develop and include suggested new relevant content.	To be finalised October 2025.
RG members commented on the ambiance of the facilities both positively and negatively.	The AODCCC strives to create safe and inclusive spaces. We will continue to ensure healthy snacks are budgeted and air conditioning is utilised when needed. Adjustable lighting has been installed in the meeting room.	Ongoing June 2025
Many RG members voiced their desire to have a longer-term period, beyond 12 months.	The AODCCC believes in providing its members with varied ongoing opportunities. It is important to allow new members the ability to access the RG and ensure that new voices are heard within our advocacy work.	

Member's Voices	AODCCC Response / Action	Date Implemented
Continued.	The Terms of Reference for the RG meetings was adapted to allow RG members to attend 12 sessions, not literal months, before their term is finalised.	January 2025.
RG members voiced their appreciation of communication being delivered in plain language and unfiltered.	<p>The AODCCC will continue developing and delivering communications in plain language.</p> <p>Clear, engaging, and transparent materials, with tailored messaging, and diverse sampling will be prioritised in all processes.</p> <p>Reviewing the website, pamphlet and poster in conjunction with the RG.</p>	<p>Ongoing</p> <p>June 2025</p>
RG recognised that the AODCCC works within a smaller budget compared to other larger more established organisations.	The AODCCC will engage with research to measure our social impact. We will continue to collaborate to build alliances and co-design partnerships that leverage Lived Experience where possible.	Ongoing

Conclusion

The RG fosters authentic collaboration and relationships with the community by listening to genuine conversations. This membership-centered approach respects members' needs and experiences and helps ensure accessible, inclusive practices.

The AODCCC understands that systemic change is a long game and is committed to continued community engagement, even if it does not immediately result in policy or legislation outcomes, by actively listening to and understanding the needs of consumers and communities. The AODCCC understands that sustainability requires both intention and reflection.

The AODCCC extends its gratitude to all past and present RG members for their time, wisdom, and willingness to share their lived and living experiences with AOD and we look forward to continuing our journey to enhance connectedness, empathy and insight within the AOD sector.

When you share your valuable insights and living/lived experiences it helps shape our activities and projects and influences our advocacy efforts to help our communities to move beyond stigma. Thank you.

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