Establishment of an AOD Consumer Peak
Think Tank

20 February 2018

Consumer Forum Workshop Report

- Facilitated by Joel Levin, Aha Consulting
- Hosted by the Health Consumers Council, WA.
- Funded by the WA Primary Health Alliance

Organised by the Transitional Alcohol and Other Drug Advisory Group

http://www.hconc.org.au/cce-consumers/consumer-engagement-projects/alcohol-and-other-drugs-advisory-group/

Introduction

On 20th February 2018, a forum was convened by the Alcohol and Other Drug Transitional Advisory Consumer Group. 55 people attended this forum, the majority of whom where consumers of some type of AOD service, others were representatives of various peak bodies and/or service providers.

The purpose of the forum was to:

- Overview the work completed to date on the establishment of a AOD Consumer Peak
- Discuss the purpose and values for a group of this kind
- Explore the types of involvement in this group people would like to have
- Map out next steps

Joel Levin from Aha! Consulting was the independent facilitator for this forum (session plan can be found on appendix 1) and what follows are the notes from this forum.

Is a consumer peak is needed?

After some discussion about the role and importance of having a consumer voice present in the design and delivery of AOD services, the group was asked if a consumer peak was needed.

The chart shows a unanimous agreement on the need for a group of this kind.

Note: One person (2%) said no, to show that the online polling system used was working.

Is some kind of AOD Consumer Peak needed?

When poll is active, respond at **PollEv.com/ahaconsulting**
Text **AHACONSULTING** to **+61 429 883 481** once to join

Yes	98%
No	2%
Unsure	

Total Results: 50
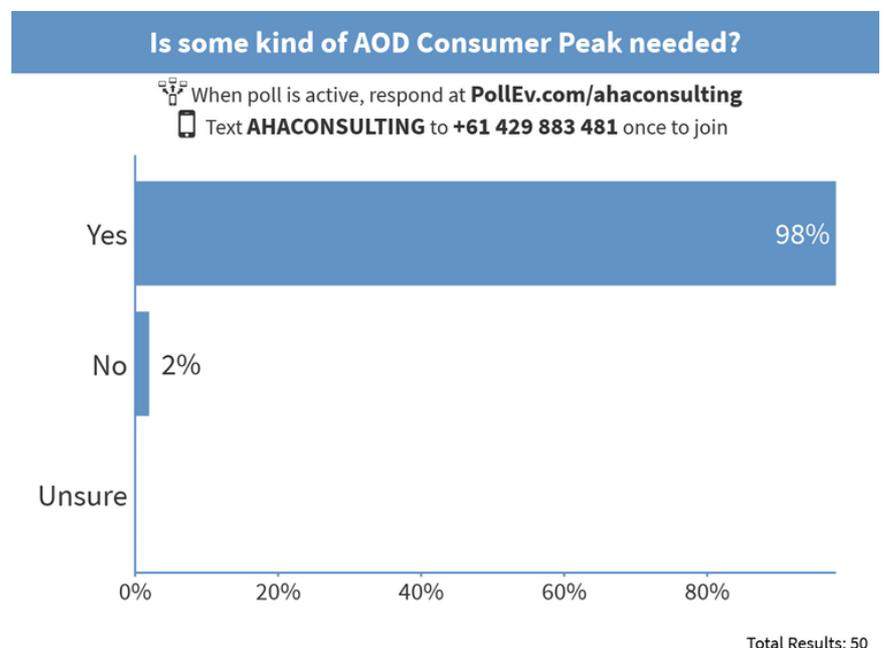
Purpose of a Consumer Peak Body

On confirmation of the need for a Consumer Peak body, the group explored the purpose of such a body. The feedback from the room was themed into four areas of activity presented below with the raw notes from each table provided in Appendix 2.

Policy	Advocacy
- Policy and law reform - Government policy - Drug register - Legal 'issues' - Policy research - Exploring services gaps - Families, Kids, Parenting - Medical - Co-morbidity - Informing sector and service planning and integration - Making service easier to navigate - Set 'umbrella' policies and description to develop/inform policies, standards, laws and guiding services - Conduct research including long-term	- Advocacy - Individuals - Service Gaps - Systemic - Support for carers, families and consumers - Consumer voice and support - Training - Internet - Representation - Influence within corrective services - AOD Sector and services accountability - Talking to politicians to influence change - Avenue for consumer feedback and help with issues
Education and Training	**Networking**
- Peer support and mentoring - Education and advertising to reduce stigma and increase people's awareness that they have a voice - Training - Consumer Representatives - Lived Experience - Peer Workers - Education - Education - Realistic information for schools especially inclusive for parents - Upskilling Organisations - Training - HR - Discrimination - Education, information and advocacy - Consumers - Community - Media - Government - Information classes, knowledge sharing – governing body	- Resources - Knowing what's out there - All in one place - Different formats - Central Hub - Information portal - Electronic option - Relevant info - Fact sheets - Directory - To include online, phone and mail options - Not just online – inclusive of homeless, casual users, families - Centralise info - Collection point for data - Central point of two-way information sharing - Streamline accessibility of information - Offering bereavement support for families and friends who knew people with addiction that did not survive

Values of a Consumer Body

The group was asked to consider the kind of values a group of this kind would operate by to ensure that is it both effective and credible.

- Member informed governance structure
- Not another 'treatment service'
- Accessible
  - Equality of acceptance and access
  - Open to anyone who identifies the need for service
- Professional Conduct
- Evidence based, and data informed
  - Quality
  - Accountability
  - Legal Advice
  - Current
  - Etc.
- Inclusive
  - Any type of substance use / addiction
  - Open to all theories of treatment (Abstinence, Harm Reduction, Social)
  - Holistic, all inclusive, whole person
  - Inclusive of diversity
    - Treat everyone the same
- Confidential
  - Privacy of the individual accessing the service
- Safe
  - Providing a safe place
  - No discrimination or judgement
- Understanding and Respect
  - Valuing the peer experience
  - Positive and supportive of each individual and where they are at
- Accountability
- Integrity
  - Deliver what we say
  - Steadfast
  - Clarity
  - Transparency
  - Operates with clear expectations
- Compassionate approach
  - Empathy
  - Understanding
  - Caring
- Harness the culture of AOD

Appendix 1 – Session Plan

Time	What
10:30	**Welcome and Intro** • Welcome to Country • Introductions • Confirming session objective
10:50	**How we got to today** • Who is the advisory group? • How did they get started and what have they done to date?
11:10	**Is a strong consumer voice important in the AOD sector?** • What have you learnt as a consumer of AOD services about the need for a strong consumer voice?
11:30	**Purpose of a AOD Consumer Peak** • What could an AOD Consumer Peak do to support other AOD consumers and or consumer groups?
11:50	BREAK
12:10	**Purpose of a AOD Consumer Peak Continued…** • What could an AOD Consumer Peak do to support other AOD consumers?
12:30	**A credible and effective AOD Consumer Peak** • How would this AOD Consumer Peak operate to ensure it is credible and effective? (values)
1:10	BREAK
1:30	**Structure** • Does an AOD Consumer Peak need to be a standalone organisation or a group housed within another organisation?
2:00	**Moving Forward** 1. What training would be useful for consumer reps? 2. What involvement would you be interested in? - Formation of the AOD Consumer Peak - Running of the group once it is established - Volunteering on programs/services once established - Supporting and promoting the service in the wider community and online
2:10	**Next Steps** • What happens from here? • Thank you for your participation
2:30	**END**

Appendix 2 - Summary of Responses From Tables

Rather than reproduce each table's raw notes, meaning that further collation would need to be done, the following notes have been collated from each table and grouped into theme areas. The number of tables noting the same thing has been identified.

What could an AOD Consumer Peak do to support other AOD consumers?

- Advocacy (5 tables agreed)
  - Provide platform for individual's voices to be heard
  - Policy advice, inform policy, comment on policy and law reform
  - Political interaction, Inform govt decisions – proposals
  - Have an influence within the prisons
  - Lobbying for services/rights
  - Link and advocate for people with multiple/co-occurring issues – e.g. AOD & homelessness, mental health, HIV, Hep C etc.
  - Going into prisons – make sure access to 'hard to reach populations'
  - Drug register – who does it help –stops people accessing treatment
- Training and Education (4 tables agreed)
  - Consumers capable of sitting on panels of 'the powers that be'
  - Support and educate services and consumers
  - Upskilling, including harm reduction
  - Highlight the need for training that people in grassroots need
  - Need to make sure it includes families and supported, not just individuals
  - Have training available + "protections" available (e.g. when sharing their story)
  - Providing upskilling and education opportunities
  - Information classes/knowledge sharing (governing body)
  - Harm reduction messages and education
- Give consumers a voice (3 tables agreed)
  - Let consumers know that they have a voice
  - Increase real consumer voice, not tokenistic
  - Input on who represents
- Collection point for data – act as central platform or hub for networking (3 tables agreed)
  - Streamline accessibility of information for all consumers – electronic options
  - The Green Book (RUAH?)
  - Factual information/evidence/science/facts – provide a source of truth rather than the media hype – myth busting
  - Develop sense of community
  - Relevant to consumers – from whether they are at (e.g. different services types and treatments) – housing, jobs
  - Save having to find info individually/what is available
  - Point of self-referral – bypasses need to access GPs
  - Able to contribute to 'hub' – information development
  - Online forum – anonymity
  - One-stop shop

- o Caution about starting another service – need for it to upskill consumers and facilitate their voices
  - Seeking funding
- o Peer support
- o Encourage a network – create a sense of community
- o Independent voice/platform to raise issues
- o Help people find a service by acting as central access point for info on services
- o Show the range of options that are available – "there is not one way"
- o Show examples of the diversity and level of problem
- o Encourage early intervention
- o Be the go-to place for advice from government
- o Should we be collecting stats and evidence? Collect info?
- o Bring to the table what's helpful or not?
- o Making sure people can see their input is being put to good use
- Support for carers, families and consumers (3 tables agreed)
  - o More approachable support services for families
- Marketing (2 tables agreed)
  - o Help consumers know where to go
- Collaboration with consumers (2 tables agreed)
- Mentoring (2 tables agreed)
- Networking (2 tables agreed)
  - o Agencies – e.g. homelessness, MH
  - o i.e. Self Help Addiction Resource Centre (SHARC) – self-help, alliance, resource
- Help reduce stigma and discrimination/shame (4 tables agreed)
  - o Legitimises experiences – most stigmatism
  - o Provide advocacy support
  - o Understanding culture for AOD consumers
- Produce and distribute resources and information
  - o Facts on laws/fact sheets
  - o Current, up-to-date and salient facts
  - o Distribute information on legal rights
  - o Accessible resources – not just online e.g. Green Book
  - o Integrated Resources
    - NGO, Govt, etc.
  - o Let people know what's out there
  - o Policy and research analysis
  - o Gather statistics – e.g. on use
  - o Identify and explore gaps
    - E.g. services for children and families
  - o Awareness of drugs
    - E.g. research chemical/'bath salts'
    - To support consumers/not to replicate services available
    - Represent/have a voice
    - Raise awareness of relevant events/opportunities to participate
  - o Promotion of what is available
  - o Provide another avenue for kids to know how to get help

- Collaboration and keeping people at the centre of service planning (not funding)
  - Hard to put it all together because services are siloed
  - Provide feedback to AOD organisation
- Show an example that treatment and support can work
  - Provide positive stories and examples of people in recovery
  - Good news stories – success stories
  - Before & after stories
  - Lived experience – share stories
- Soft entry point to engage services
- Set out parameters and minimum standards i.e. what is a consumer, what training should a peer worker have?
- Agenda switch (from service providers to consumers)
- Role modelling
- Mediation and support
  - To navigate the system
  - Direct to available services
  - Peer support
  - Mutual support
  - Openness of experiences as a positive
- Improve services
  - Provide feedback on services
  - Help to develop new services
  - Help develop services that are post treatment
    - E.g. to get skills and tools to re-integrate into community, get a job etc.
  - Referrals – services (consumer friendly)
  - Given diversity, ensure no one falls through the cracks – services for all
  - Keep services consumer focused and friendly "not to us, with us"
  - Needs to stay relevant while valuing experience
  - Services staffed by consumers
- Anonymous Q&A
  - Creating a safe place
  - Non-judgement of providers
- Build relationships between services
- Informing sector planning and service delivery
  - Media evidence – 'epidemic' vs experience of what works – combat negative, promote positive
- Input into 'who' represents consumers
  - Needs to be independent
  - Compassion – 'for us', 'with us' not 'to us'
- Awareness raising amongst health professionals
- Accountability
  - AOD sector accountability
  - Accountability to media
- Help lower the gap post treatment – still need support after rehab

How would an AOD Consumer Peak body operate to ensure it is credible and effective?

- Inclusive – families/support/friends
- Legal advice – legal obligations
- Based on data – evidence based
- Non-judgemental across use and services access
- Compassion based on personal experience – respect
- Individualised – individual issues and approaches
- Clear expectations/real
- Not another 'service'/treatment/clinical
- Value peer experience
- Quality – standards/accountability
- Member informed governance structure

Does an AOD Consumer Peak need to be a standalone organisation or housed within another organisation?

- Housed within another org
  - Role modelling
  - More information feasibility options
    - Timeline
  - Incubated
  - Phased
  - Compatible values?
    - Negotiated
- Stand-alone organisation
  - Consumer led
  - Independence
  - Sensitivity
  - Develop Charter
  - Crowd sourcing
  - Social enterprise
- Mutual benefits. Co-relationship.

Appendix 3 – What training would be useful for consumer reps?

- Cert IV in AOD
- How the health system works
- Explain the 'AOD Sector' (2)
- IT Training
- Doing grant applications (2)
- Duty of Care
- Story-telling (lived experience sharing)
- Specific AOD Consumer Rep training
- Leadership
- Grant writing and meeting procedure
- Training for the services and programs offered
- Difference between committees and boards
- Overview of acronyms, different services
- Information on commitment to boards – how to read/understand board papers
- Meeting procedures
- Assertive Communication
- Social Media
- Promoting and Marketing
- Boundaries
- Board Governance
- Advocacy
- Co-production

Appendix 4 - Register of people interested in the next steps of a AOD Consumer Peak

Attendees were given the opportunity to self-nominate their interest against these criteria below. The names of people have been recorded and will be managed by the AOD Advisory Group as the project continues to develop.

It was a very encouraging response, with many names against each of the areas. In the interests of privacy, these names have not been published.

- Are you interested in supporting the running of this group once it is established?
- Are you interested in supporting the formation of this group?
- Are you interested in volunteering on different services/programs?
- Are you interested in supporting this group by promoting it in the wider community and online?

Feedback from the day

We provided a paper-based survey and received 51 responses on the day about the forum. The feedback was overwhelmingly positive and a summary of the responses to the questions appears on the following pages.

Question 1: I feel well informed about what's been done so far by the AOD AG

Response	Number of responses	Percentage of total responses
Strongly disagree	1	2%
Disagree		
Neither agree nor disagree	3	6%
Agree	30	59%
Strongly agree	17	33%
Total respondents	51	100%

I feel well informed about what's been done so far by the AOD AG

- Strongly disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree
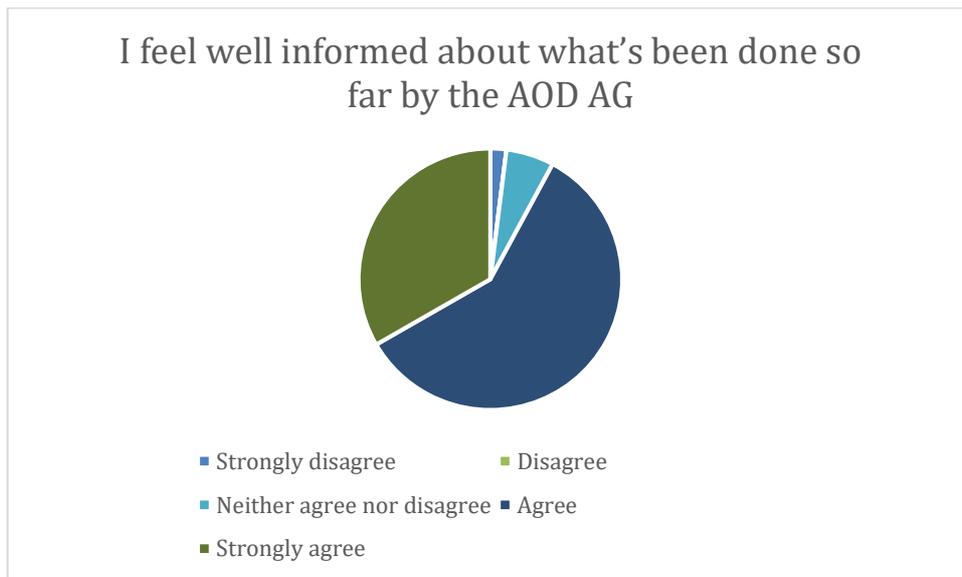
Question 2: I had a chance to contribute to the purpose of the AOD Consumer Peak

Response	Number of responses	Percentage of total responses
Strongly disagree	1	2%
Disagree		
Neither agree nor disagree		
Agree	34	67%
Strongly agree	16	31%
Total respondents	51	100%

I had a chance to contribute to the purpose of the AOD Consumer Peak

- Strongly disagree
- Disagree
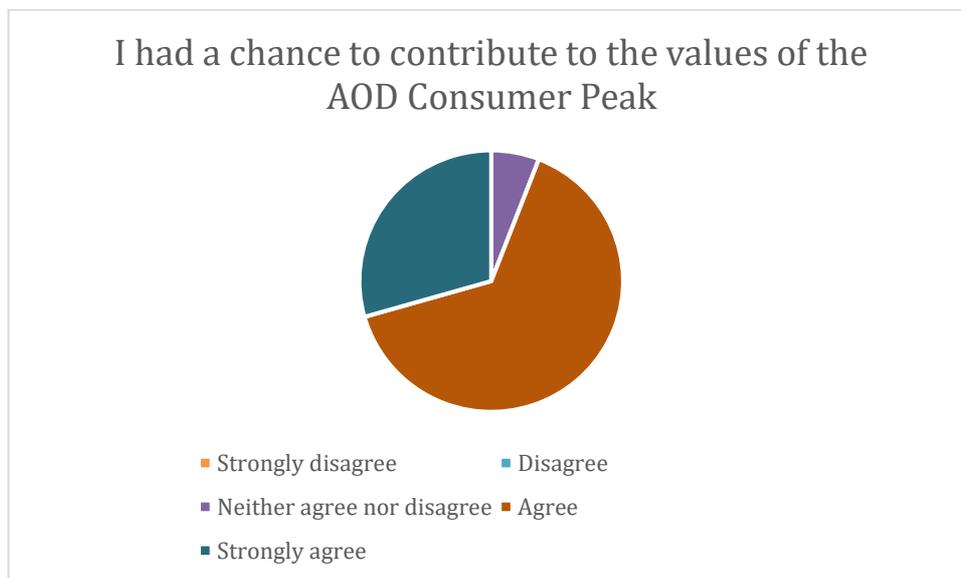- Neither agree nor disagree
- Agree
- Strongly agree
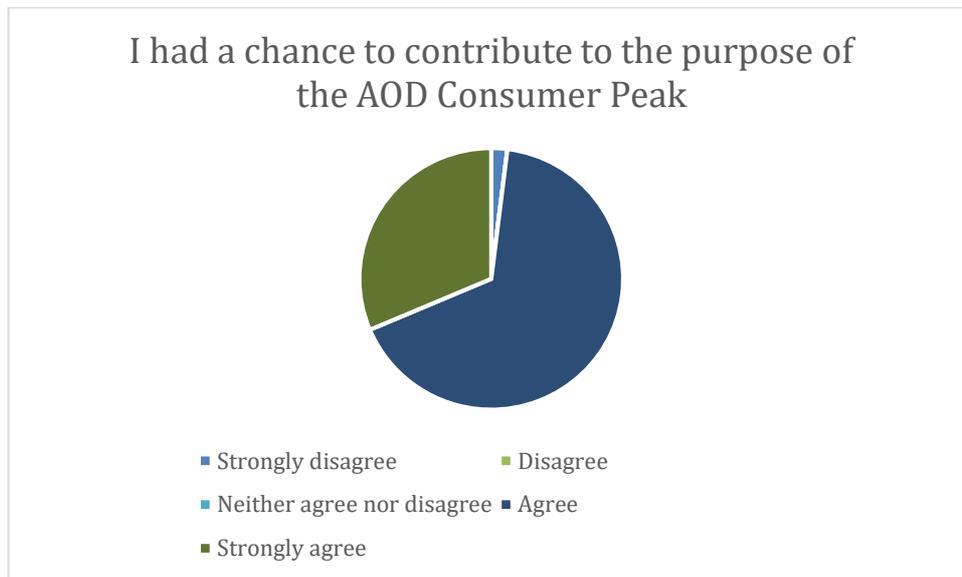
Question 3: I had a chance to contribute to the values of the AOD Consumer Peak

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree		
Neither agree nor disagree	3	6%
Agree	33	65%
Strongly agree	15	29%
Total respondents	51	100%

I had a chance to contribute to the values of the
AOD Consumer Peak

- Strongly disagree - Disagree
- Neither agree nor disagree - Agree
- Strongly agree

Question 4: I was able to give feedback on what training I would like

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree	3	6%
Neither agree nor disagree	7	14%
Agree	28	55%
Strongly agree	13	25%
Total respondents	51	100%

I was able to give feedback on what training I would like

- Strongly disagree
- Disagree
- Neither agree nor disagree
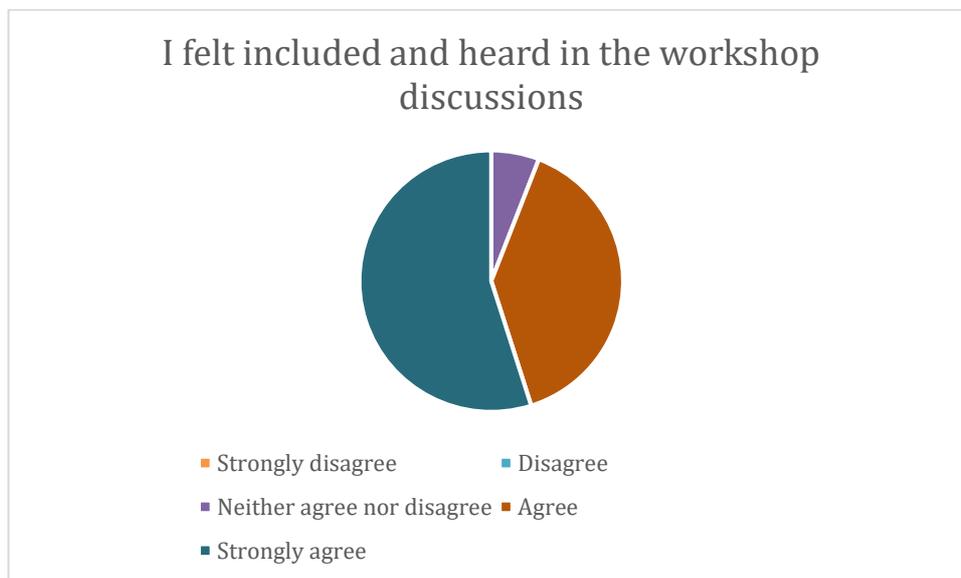- Agree
- Strongly agree

Question 5: I was able to give feedback on how much involvement I would like going forward

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree		
Neither agree nor disagree	2	4%
Agree	27	53%
Strongly agree	22	43%
Total respondents	51	100%

I was able to give feedback on how much involvement I would like going forward

- Strongly disagree
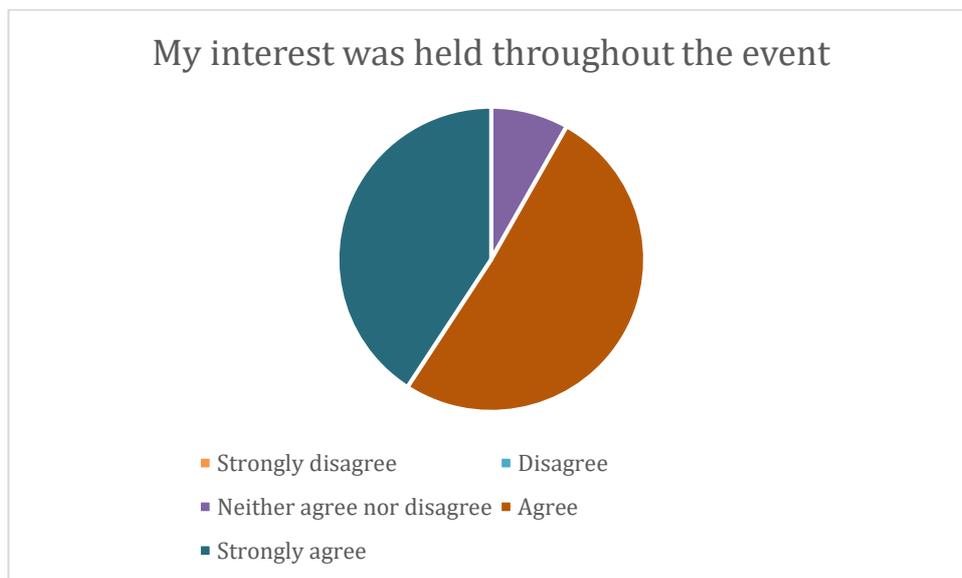- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree
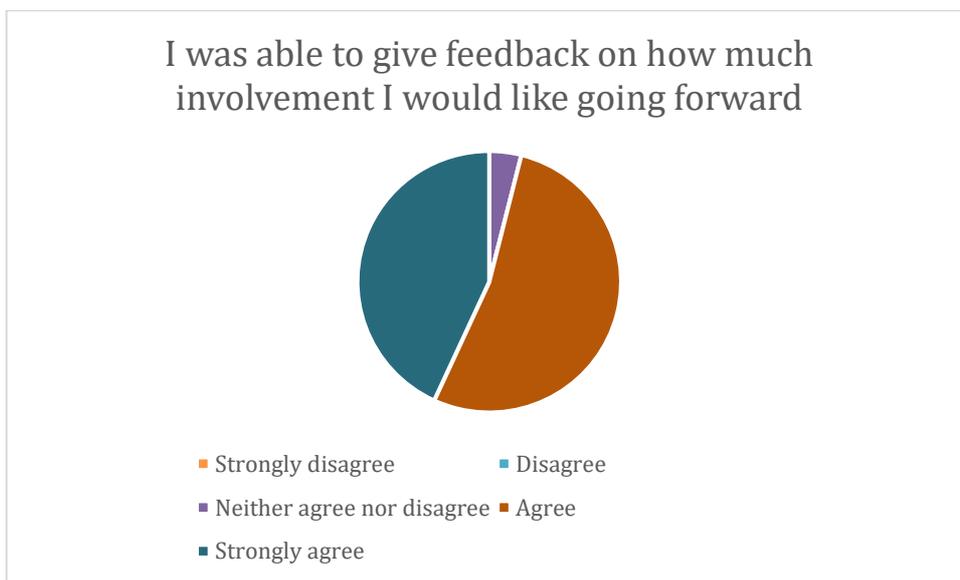
Question 6: I felt included and heard in the workshop discussions

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree		
Neither agree nor disagree	3	6%
Agree	20	39%
Strongly agree	28	55%
Total respondents	51	100%

I felt included and heard in the workshop discussions

■ Strongly disagree   ■ Disagree

■ Neither agree nor disagree ■ Agree

■ Strongly agree

Question 7: My interest was held throughout the event

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree		
Neither agree nor disagree	4	8%
Agree	25	51%
Strongly agree	20	41%
Total respondents	49	100%

My interest was held throughout the event

- Strongly disagree ▪ Disagree
- Neither agree nor disagree ▪ Agree
- Strongly agree

Question 8: There were opportunities to build my network

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree	2	4%
Neither agree nor disagree	8	16%
Agree	25	49%
Strongly agree	16	31%
Total respondents	51	100%

There were opportunities to build my network

■ Strongly disagree   ■ Disagree
■ Neither agree nor disagree ■ Agree
■ Strongly agree
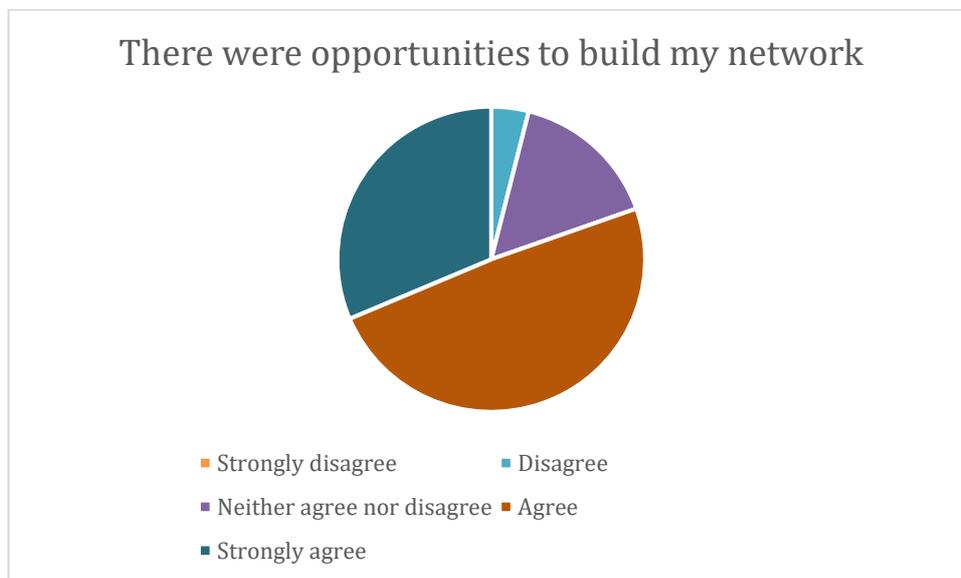
Question 9: The venue was appropriate and comfortable

Response	Number of responses	Percentage of total responses
Strongly disagree		
Disagree		
Neither agree nor disagree	1	2%
Agree	23	45%
Strongly agree	27	53%
Total respondents	51	100%

The venue was appropriate and comfortable

- Strongly disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree
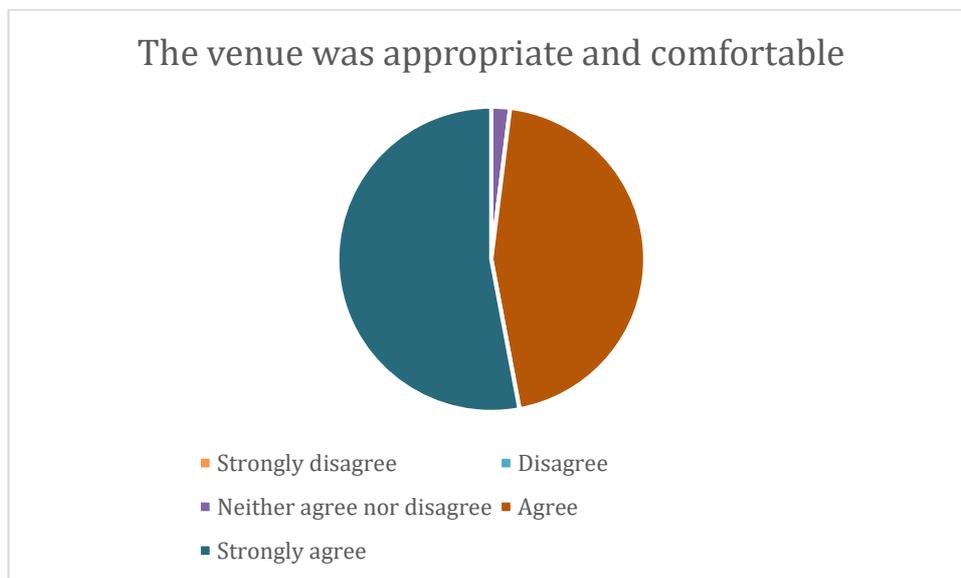
Question 10: The food was well presented and suitable

Response	Number of responses	Percentage of total responses
Strongly disagree	1	2%
Disagree		
Neither agree nor disagree	1	2%
Agree	22	43%
Strongly agree	27	53%
Total respondents	51	100%

The food was well presented and suitable

- Strongly disagree
- Disagree
- Neither agree nor disagree
- Agree
- Strongly agree
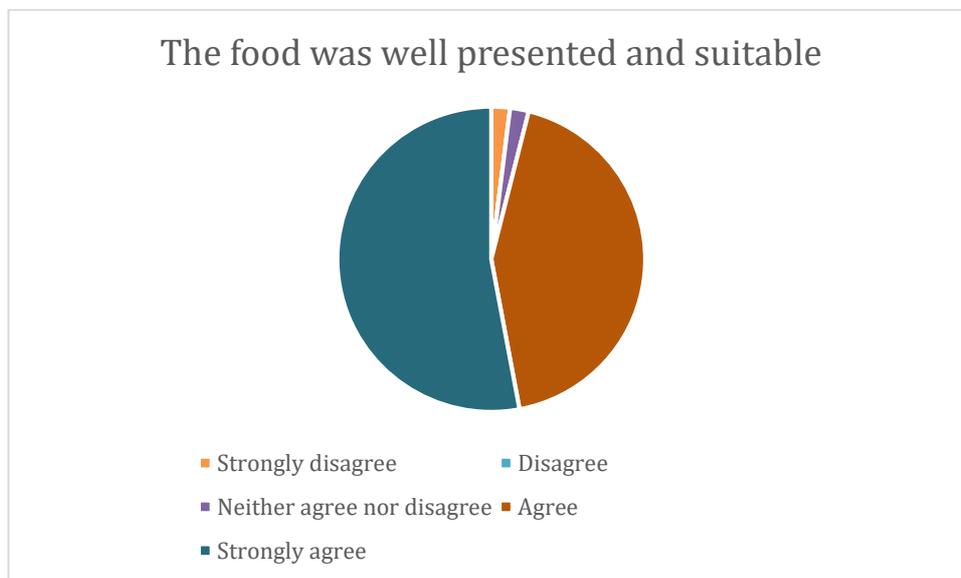
Question 11: Which part of the event did you think was most useful? Why?

- Establishment of AG/networking
- All of it
- Feedback from participants
- Audience participation
- How it was run (facilitated)
- The group discussions as got a heap of great ideas
- The group discussions (fruit salad) and the gallery at the end
- I think it was very inclusive, I liked the open feedback
- The discussion on consumer peak
- Group discussions
- Collaboration and sticky notes to view group purpose and values
- History/small group discussion
- The second question. And the multiple options to become further involved
- General camaraderie comfortable with each other
- Brainstorming and passion support
- Bringing everyone together in a community venue
- Being heard from a family perspective
- The purpose of this Peak Group
- Having a valued input into "grass roots" establishment of AOD project/committee moving forward
- The variety of consumers and backgrounds
- All the group participation
- Inclusion and diversity of AOD sector involving consumers
- Butchers paper, fruit salad, sticky wall
- Amazed about everyone getting on
- families, users, non-users
- Input from a diverse group of people
- The breaks – I was thirsty and hungry
- Contribution to the purpose of the AOD Consumer Peak
- Asking people to move around/sit on different tables
- The purpose brainstorm. Such a diverse range of opinion
- The lot
- The chance to give input as there was a wide variety of people here
- The pin up board with purpose and values
- Individual opinions/input
- Discussion on values
- Broadened both my knowledge and understanding
- The open forum discussions
- Collaboration and facilitation - all able to be heard and to hear
- Open discussion on topics.. Most transparent
- Brainstorming ideas

- I like the whole thing
  - The money for making sure I came and showing everyone's commitment
  - The whole concept
  - Excellent day, well facilitated - enjoyed it all
  - Hearing from different representatives in the industry
  - Bullet point, very visual
  - The whole lot as this was my first meeting
  - The display wall relating to the values and morals - why - because it showed common goals
  - Everyone was able to have a voice

Question 12: Which part did you think was least useful? Why?
- E.O.I process difficulty
- The standalone section
- Some of the open conversations/comments between group discussions
- Nil (9)
- Values (all already on same page)
- Was all good – seemed too short
- Discussion surrounding how it housed. A bit vague and became slightly stagnant
- Food
- Whether the Peak Group was 'standalone' due to financial issues
- Nil – loved the "healthy" respectful debate…
- The discussion on Housed or standalone
- N/A all relevant
- Time wasted on nit-picking around language/booze
- The breaks
- Would be interesting to see what training will be offered to consumers
- Not sure
- I was impressed and thought it was all useful
- Whole day
- Some of the people were personal agenda driven
- Not sure
- There was not enough time to flesh out training
- Phone business
- The day was too short. Longer would be better
- I think it was all useful
- All [awesome]
- The last question was a bit rushed

Question 13: Any other comments?

- Good initiative, well organised, Good venue, Great facilitator, Good representation of stakeholders, Thank you & Namaste
- Thank you for the work you have done
- Great to meet people whose hearts are in the right place
- I thought most people gave intelligent and incisive remarks about this very difficult problem
- People struggled with some of the questions – answering the question without getting ahead of themselves – clearer explanation of the questions to start with may have helped…
- Great day
- The facilitator was great. Awesome energy in the room. I'm feeling very optimistic about the future of the consumer peak and look forward to being involved
- Lunch was good, maybe something to drink would have been nice
- No. Thanks for day! 😊
  - As far as food, should be [grateful] it's not a major part
  - It's hard to cover for time. Think [there] was little time to network, i.e. longer day more breaks to do so
  - Good facilitator – keep people on line/track
- I feel the environment created here was excellent. In comparison to other forum[s] I've attended the ease I felt in sharing ideas was excellent
- I was personally having trouble with concepts of information
- Was great to be a part of it, was challenging and interesting. I'm impressed and inspired with what's been done so far.
- Well done and thank you
- Good day. Thank you
- Was wondering where the 'significant other' voice was in terms of presenting? It would have shown that this group is serious about it, in terms of really bringing it in which is important as I personally didn't always want 'them' in but do now
- Still felt mental ill health was not on a 50/50 basis with this forum and it is so much a part of the whole
- You are all amazing! Never give up
- I'm glad to see so many consumers wanting to have a voice and thank the team on the work that's been put into this
- Please keep us informed on where this is going and further development
- Thank you for opportunity
- It would be handy to be put on randomly allocated tables to ensure people don't stick just with people they know. Also, OMG! The bereavement stuff is SO IMPORTANT and I can't believe we didn't think of it sooner! 🙂 See you soon 😊
- Great forum, a lot of goodwill and passion in the room
- Don't like being involved with alcoholics – most hate users
- Looking forward to seeing the Consumer Peak develop and move forward 😊
- Wonderful. Looking forward to hearing and seeing more of AOD Consumer Peak 😊

- I am glad I was part of this. I look forward to future involvement. Facilitator was smooth and did well
- Felt a bit rushed
- I really enjoyed being a part of this group
- Well-presented and it's quite encouraging seeing how many people are and want to be supportive
- Thank Joel and AODAG
- The subjects were spoken about and the agenda items were kept moving
- The conversation was fluent and kept moving
- Loved the welcome to country story - highlighted the innate perspective of people to be 'for' or 'against' to see similarities and want to build up and fly with vs differences (tear down)
- "Your qualification today is being you". flip the switch from frustration vs curiosity 😊
- As an addict I really appreciate what's happening here! Thank you 😊
- I STRONGLY believe more consideration/discussion needs to be given to whether we are a drug users body or a drug related body. SERIOUSLY. VERY SERIOUSLY.
- Needed more research for input decision
- Great to be involved with like-minded people
- It was great that the organisers were floating around listening and participating
- I am very glad to be part of this group, and having feedback
- I would like to continue to come to these things
- Please don't lose momentum
- I really feel this is an opportunity to make an impact positively
- I enjoyed and appreciated the welcome to country - it was lovely