

2016

Principles & Best Practice Strategies for Consumer Engagement in the Alcohol and Other Drugs Sector in Western Australia

Summary of findings from Consumer and Other Key Stakeholder Consultations in 2016

Consultations were facilitated by a consumer consultant that was engaged by the Alcohol and Other Drugs Consumer Engagement Advisory Group (AOD AG). The Health Consumers Council established the AOD AG to develop Principles and Best Practice Strategies for engaging AOD consumers in W.A. through funding received by the Mental Health Commission in 2015.



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Health Consumers Council Western Australia
Alcohol and Other Drugs Consumer Engagement Advisory Group
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1. Acknowledgements

The Health Consumers Council Western Australia wishes to thank all of those involved in the development of the Principles and Best Practice Strategies for Consumer Engagement in the Alcohol & Other Drugs Sector in Western Australia, for their time, effort and expertise. We would particularly like to acknowledge the expert advice and input from the Alcohol and Other Drugs Consumer Engagement Advisory Group

1.1. Participants of the Advisory Group

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2. Glossary (Definitions and Acronyms)

Definitions: (Definitions are for the purpose of this document)

Consumer: Consumers are people who use or are potential users of Alcohol & Other Drug Services including their family and significant others or self-identify as a consumer

Family/Significant Other: Refers to a family member &/or significant who is impacted by an individual's use of AOD

Consumer Participation/Engagement: Participation and engagement are used interchangeably throughout this document. Consumer engagement or participation refers to any activity that incorporates consumer aspirations and needs into decision making at an individual, service, sector and systems level or 'Participation occurs when consumers, carers and community members are meaningfully involved in decision-making about health policy and planning, care and treatment, and the well-being of themselves and the community' (cited in Consumer participation in the Australian alcohol and other drug sector; ANCD page 13)

Acronyms:

AADS: Aboriginal Alcohol and Drug Service

AOD: Alcohol and other drugs

AOD AG: Alcohol and Other Drugs Consumer Engagement Advisory Group

ATSI: Aboriginal and Torres Strait Islander

COMHWA: Consumers of Mental Health WA

DAO: Drug and Alcohol Office

HCC: Health Consumers Council

MHC: Mental Health Commission

NSP: Needle Syringe Program

NSEP: Needle Syringe Exchange Program

WANADA: Western Australian Network of Alcohol and other Drug Agencies

WASUA: Western Australian Substance Users Association

3. Introduction:

3.1. Background

In 2014 the Drug and Alcohol Office (now known as the Mental Health Commission) contracted a consultant to research consumer involvement in the Western Australian Alcohol and Other Drug Service sector. The research aimed to look at:

- Current levels of consumer involvement
- Barriers to consumer participation
- How consumer participation activities could be improved

The research found that consumers mostly participated in lower levels of consumer engagement activities such as surveys and feedback forms and there were a number of barriers identified by both consumers and treatment service providers.

Following the research the Drug and Alcohol Office (DAO) in partnership with the Western Australian Substance Users Association (WASUA) and Western Australian Network of Alcohol and Other Drug Agencies (WANADA), held a forum in November 2014 of 70 consumers to discuss ways to improve consumer involvement in the alcohol and other drug (AOD) sector. The forum aimed to confirm previous research findings and determine priorities for implementing future consumer engagement strategies.

The forum supported the previous research findings:

- Consumers wanted more opportunities to participate in a range of activities including individual treatment, AOD service delivery, policy development and planning
- Support for consumers through training and peer support
- Barriers need to be addressed so consumers can provide meaningful, confidential feedback
- Ongoing consumer involvement at all levels of the AOD sector
- Strategies to reduce stigma associated with AOD use need to be developed

The following six recommendations were proposed as a way forward in working towards meaningful consumer involvement within the AOD sector.

1. Ensure ongoing consultation with consumers to progress strategies
2. Develop a common set of principles
3. Ensure appropriate support mechanisms to break down barriers
4. Develop training for consumers and service providers to participate in processes
5. Understand the current context
6. Work towards consumers being involved at all levels

In 2015 the Health Consumers Council (HCC) received funding from DAO/Mental Health Commission to further progress the work already completed (as outlined above). The funding required the HCC to:

- Ensure ongoing consultation
- Develop a common set of principles

- Outline best practice strategies to engage and support consumers to participate in activities at a range of levels throughout the sector

The HCC established the Alcohol and Other Drugs Consumer Engagement Advisory Group (AOD AG) in 2015 consisting of service providers and a diverse range of consumers contributing to at least 50% membership of the Advisory Group. The purpose of the Advisory Group was to oversee the deliverables of the project entitled “Improving Consumer Involvement in the Alcohol and Other Drug Sector”. The group met on a monthly basis.

3.2. Consumer Consultant

A consumer consultant was selected by the AOD AG to develop a common set of principles and identify best practice strategies to engage and support consumers to participate at a range of levels in the AOD sector, with consideration to strategies that address known barriers to participation.

A draft set of principles were developed and the AOD AG sought feedback through consultation with consumers and families/significant others and other key stakeholders regarding those principles, as well as identifying ways to improve consumer engagement at a range of levels in the AOD sector.

This document identifies the six principles developed, as well as strategies to improve consumer engagement in the AOD sector in WA. It outlines the consultation process that occurred with consumers and other key stakeholders and provides practical examples of using these principles in both the consumer consultation process and the establishment of the AOD AG.

The benefits of consumer engagement have been well researched and are seen as essential to improving quality service delivery, planning and review. Consumer engagement is becoming a standard reporting item for health and community services, as well as for accreditation purposes and is reflected in the National Standards for Mental Health Services, Standard 3: Consumer and Carer participation. There is however the risk that consumer engagement activity can become somewhat tokenistic and superficial, involving only those consumers already engaged, as well as endorsing already made decisions. For engagement to be genuine and meaningful, it needs to be grounded in key principles. This report identifies a common set of principles and strategies developed through consultation with key stakeholders, to further progress consumer engagement in the AOD sector in Western Australia.

3.3. Consumer Engagement:

Effective consumer engagement is embedded in an organisation’s culture and practice. It informs organisations about the needs of the people who use their services as well as potential service users, who may for various reasons, experience barriers to access. Consumer engagement can enable organisations to better plan, design and deliver services that meet the needs of the people who use them, to gather feedback about initiatives and reforms that will impact upon service delivery and to monitor the quality and safety of providers to deliver improved services for consumers and their family/significant others.

Consumer engagement is a key mechanism to build partnerships that can influence resources and enable services, consumers and communities to work collaboratively to achieve desired outcomes. It can also be used to empower consumers to work actively as partners in their own healthcare, contributing to more efficient and effective service delivery.

A Department of Health and Aged Care resource guide identified four reasons why health care organisations should have a strong consumer focus and be involved in enhancing and responding to consumer participation including: (page 1)

- Participation is an ethical and democratic right
- Participation improves service quality and safety and helps gain health service accreditation
- Participation helps improve health outcomes
- Participation makes services more responsive to the needs of consumers

3.4. Benefits of Consumer Engagement:

There is significant evidence both internationally and nationally regarding the benefits of consumer participation in individual healthcare and at a broader healthcare system level. Meaningful consumer participation creates many benefits for both consumers and health services and staff. Some of the benefits identified in the ACT Health Government document 'Consumer and Carer Participation Framework' include:

Benefits for consumers:

- receiving services that are more responsive;
- improved quality and safety of services;
- increased trust and engagement with health care professionals;
- improved understanding of conditions, treatments and options;
- increased capacity to self-manage and adhere to treatments;
- increased confidence, competency and sense of self-determination;
- improved health literacy and help-seeking behaviour;
- increased social inclusion
- improved long-term health outcomes

The benefits for Health Directorate and the broader health system:

- improved safety and quality of health services provided;
- improved health outcomes for consumers;
- improved responsiveness based on meeting consumer needs and community priorities;
- increased openness, trust and respect for consumers, carers and community;
- improved efficiency and cost effectiveness in how health services are provided;
- increased accountability to consumers and carers;
- increased consumer focus to drive quality improvement processes;
- inclusion of valuable insights from consumers and carers which may not otherwise be apparent, or may be significantly different to those held by health professionals;
- improved access to a diverse range of skills, experiences and knowledge;
- increased capacity to meet accreditation standards;
- improved job satisfaction, staff retention and morale;
- reduced conflicts, complaints, litigation; and absenteeism; and
- increased social capital towards a more inclusive community

(Consumer & Carer Participation Framework: ACT Health Government page 6-7)

3.5. Levels of Consumer Engagement:

Consumer engagement or participation can encompass a range of activities, with various functions or purposes, involving varying levels of consumer inclusion. For the purpose of this document the following definitions which are consistent with and reflect other state and national frameworks (Consumer and Community Engagement Framework, Health Consumers Queensland; Consumer, Family and Carer Engagement – Interim Policy Govt. WA, MHC 2014, Straight from the Source etc.) will be referred to. It is important to note that the framework recognises that there is no ‘one size fits all’ approach, supporting the development of tailored strategies to meet the purpose of consumer engagement activities. The principles developed within this report are to encompass consumer engagement activities across all levels and degrees of participation.

Individual, service, sector, system

Consumer engagement operates at four levels including the individual, service, sector and system levels as below in table 1.

Table 1: Levels of Consumer Engagement

Level	Area	Explanation
Individual	Individual care	This level focuses on engaging with the consumer in their own health care, support, options, treatment etc.
Service	Program delivery Service delivery	This level focuses on engaging with consumers about the delivery, structure, planning and evaluation of a program or services at an agency or organisation
Sector	AOD sector and state-wide	This level focuses on engaging with consumers about the regional or state-wide AOD sector in terms of planning & evaluation
System	Local, State & Federal Government	This level focuses on engaging with consumers about policy, reform and legislation at the systems level across local, state and commonwealth jurisdictions

3.6. Degree of Consumer Engagement:

The degree of consumer engagement occurs along a spectrum and involves an increasing level of consumer participation from information through to empowerment (based upon IAP2). The degree of consumer participation is useful for understanding the level of power or influence that consumers have in various consumer participation activities. Table 2 below identifies the 5 degrees of consumer participation.

Table 2: Degrees of Consumer participation

Degree	Level of Power	Explanation	Purpose
Inform	nil	Information is given to consumers	Used to convey information e.g. facts, decisions to consumers e.g. websites, media release, fact sheet
Consult	Very low	Information is gathered from consumers	Two-way exchange to find out what consumers think about an issue e.g. focus groups, surveys, meetings
Involve	Some influence	Consumers are involved in the process	Shared decision making. Processes & outcomes are jointly owned e.g. workshops, panels, conferences
Collaborate	High Influence	Organisations and consumers work together in partnership	Consumers & other key stakeholders work together to develop solutions, decisions etc. e.g. Advisory Committees, networks etc.
Empower	Consumer Control	Consumers make decisions about solutions, ideas and initiatives, and feed this back to organisations	Consumers make the decisions which are implemented e.g. steering committees, boards, policy councils, strategy groups etc.

A consumer may be consulted about their individual care in terms of their preferred treatment option &/or support as well as consulted in terms of the type of services or programs an agency may deliver. Similarly, a consumer may collaborate with their treatment provider with regard to developing an individualised plan, as well as collaborate on a committee to develop a set of principles, as did the consumers on the AOD AG. It is important to identify the level and degree of consumer participation when developing appropriate strategies for consumer engagement.

3.7. Standards and Rationale for Consumer Engagement:

Consumer engagement is recognised as a fundamental component of policy development and service delivery in the Australian health sector yet there is limited reporting on the extent or outcomes of consumer engagement. The current health reform agenda provides significant opportunity for collaboration and partnering for better outcomes through the development of consumer engagement strategies. The National Standards for Mental Health Services 2010: Standard 3: Consumer and care participation. Consumers and carers are actively involved in the development, planning, delivery and evaluation of services; the Fourth National Mental Health Plan 2009-2014 and the WANADA Standards

on Culturally Secure Practice, all acknowledge and support the need for consumer engagement at a range of levels.

The Mental Health Commissions has a commitment to increase consumer engagement activities with “All Mental Health Commission (WA) funded organisations are required to meet the National Standards for Mental Health Services and these are evaluated through Independent Quality Evaluations in addition to an annual self assessment”.

(http://www.mentalhealth.wa.gov.au/mentalhealth_changes/quality_assurance/national_standards.aspx)

In the Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015 – 2025, it asserts the need for ‘Consumer, families, and carers are fully involved in co-planning, co-designing, co-delivery and co-reviewing of policies and services’.

“The changes place individuals at the centre of service planning, provision, review, and would deliver consistent high quality care reflecting national standards and frameworks.” Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015 – 2025, page 74).

Whilst these are robust statements supporting consumer participation at all levels, there is an ongoing disparity between support mechanisms for consumer engagement opportunities in the alcohol and other drug sector, in the absence of an AOD consumer carer and families advocacy peak body.

4. Consultation Process:

4.1. AOD AG:

The AOD AG was consulted throughout the process of developing the principles and strategies for the engagement of consumers. The group offered expert knowledge in terms of its ability to firstly represent a diverse range of consumers including:

- Consumers that have accessed a range of AOD services
- Current users
- Aboriginal and Torres Strait Islanders (ATSI)
- Range of alcohol &/or other drugs used
- Family/Significant others
- Range of ages
- Range of backgrounds (e.g. socio-economic, educational etc.)
- Peer workers
- Consumers with co-existing issues

And secondly, other key stakeholders with knowledge and experience including:

- Consumer Representatives
- Consumer advocates
- AOD treatment agency representatives
- Peer based services
- Agencies with Consumer Engagement strategies
- Funders

4.2. Principles:

Initially a review of national and international literature was undertaken leading to the establishment of a draft set of six principles. The draft principles identified, considered the findings from the DAO research and forum, relevance to the AOD sector and already existing principles from the Health (e.g. Mental Health, Disability, AOD) sector within Australia. These principles were initially presented to the AOD AG for feedback prior to the consumer consultation process.

4.3. Consumer Consultations:

Given various restraints including time and resources, it was initially decided that approximately 16 - 20 consumers would be consulted with regard to the draft principles and development of strategies to improve consumer engagement/participation. To consult with a diverse group of consumers including marginalised groups, small focus groups consisting of four people and individual interviews would be the preferred format for consultations. The AOD AG identified four consumer focus groups including:

1. AOD treatment service users
2. Current users including people accessing NSP's &/or pharmacotherapy programs
3. Patrols/Sobering Up Services
4. Family/Significant Others

Individual interviews were used for any consumer that may have issues or concerns about attending a focus group such as confidentiality, language/cultural barriers, mobility/transport etc.

Consumers consulted included people from a Culturally and Linguistically Diverse (CaLD) background, Aboriginal people, male and female consumers of varying ages and abilities, as well as a diverse range of substances used and experiences of alcohol and/or other drug use and services.

Members of the AOD AG took responsibility for promoting consumer consultations which included displaying a flyer at agencies and through social media. Consumers were offered \$70.00 for attending the consultation meeting and were provided with four documents to read at least one week prior to the consultation. Consumers were also provided with the consultant's phone number if they had any questions. The four documents included: (see appendices for a copy of the documents)

- **Background:** Identified as optional reading and provided an overview of the work that had already occurred to date
- **Barriers to Consumer Participation:** Optional reading that provided a list of barriers to consumer engagement/participation identified from the DAO research, forum and literature review
- **Principles for Consumer Engagement:** Required reading prior to attending focus group or interview. This document identified draft principles and a definition of the principles and was a condensed version of the original document. Consumers were offered the full version of the principles document upon request
- **Consumer Role Focus Group:** Consumers were required to read this document prior to attending. The document informed consumers of what would occur at the consultation, including the questions they would be asked, as well as how their feedback would contribute to the development of strategies

4.4. Questions for Focus Group Participants

Consumers were asked to provide feedback on the principles as well as consider the following two questions prior to participating: (as per 'The Consumer Role Focus Group' document):

1. What are some of the ways that services could support consumers to participate in decision making at a range of levels including:
 - Own individual treatment planning
 - Service delivery level
 - State-wide and sector policy and planning level
2. How can consumer participation be improved, what needs to change &/or what can help consumers overcome some of the barriers to participation? What would help you to attend more consumer participation activities?

5. Principles and Strategies for Consumer Engagement

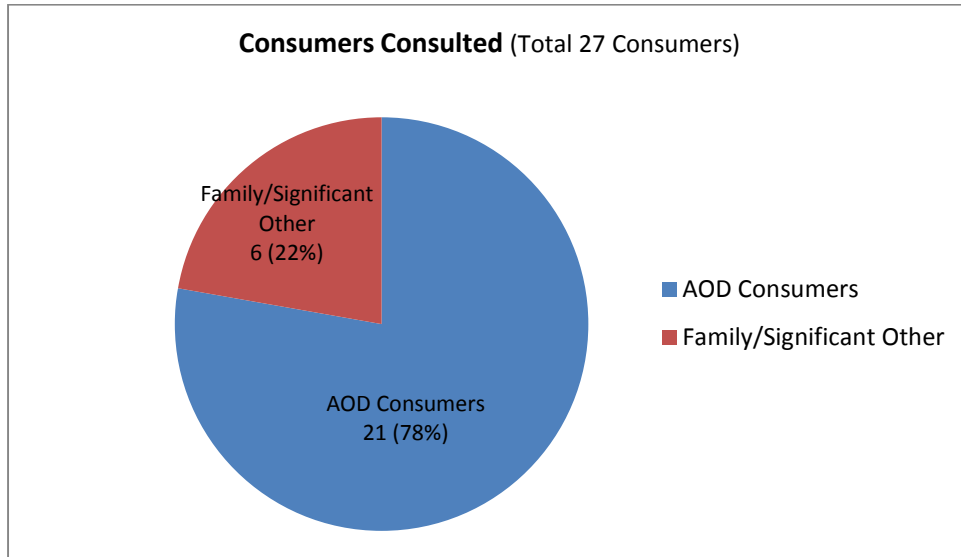
Principle	Description	Strategies
Participation	Consumers have the right to participate in decisions about their own health, well-being and welfare, as well the provision of services including planning, design, delivery, monitoring and evaluation and sector and state-wide policy, reform and legislation at the system level. A broad range of consumer participation strategies should be incorporated to ensure accessibility to a diverse range of consumers. The value of consumer participation should be recognised and respected.	<ul style="list-style-type: none"> • Develop a Consumer Engagement Framework strategy • Provide a range of participation options for consumers, recognising that consumers may want to participate at varying levels/degrees • Consumer participation opportunities are widely and broadly promoted e.g. newsletters, social media, websites, posters etc. • Ensure consumers are aware of their rights
Diversity	AOD consumers and their families/significant others are a diverse group. This diversity includes but is not limited to the type of substance used, patterns of use, legal status, social acceptability, drug related harms, as well as cultural, age, gender, ability etc. considerations. Given this diversity, consumer participation opportunities need to be accessible and inclusive, with flexibility and a range of options for consumer participation.	<ul style="list-style-type: none"> • Recognition that consumer and family/significant others are unique groups with unique issues and thus require specific representatives • Engage broadly using a range of strategies to address known barriers to engagement to increase access and inclusion from marginalised consumers • Services should recognise and value diversity, ensuring they are culturally secure and responsive to the varying needs and perspectives of a diverse range of consumers
Leadership and Support	Organisational culture supports and values consumer participation and maintains a culture of engagement through leadership, knowledge, skills and processes. Opportunities are provided for the ongoing support, training and education for consumers to assist in their effectiveness as consumer representatives. Consumer participation is resourced at an appropriate level within the agency and in recognition of the value, time and cost to consumers.	<ul style="list-style-type: none"> • Build organisational capacity for consumer engagement activities through policies and procedures, staff training, support and leadership • Build consumer capacity through ensuring consumers have access to appropriate training and support • Consumer engagement must be supported from the top and resourced so that participation is meaningful • Consumer time and input is recognised and remunerated accordingly including provision of practical assistance such as transport, childcare, access to the internet etc. to ensure consumers can participate

<p>Meaningful</p>	<p>All consumer participation opportunities are meaningful with regard to involving consumers at the earliest opportunity, clearly identifying and explaining the role of consumers, informing consumers of the purpose of their participation, including the decision making processes, the ability to influence outcomes and ensuring access to information and means to participate.</p>	<ul style="list-style-type: none"> • Provide information for consumers outlining their role and responsibilities, as well as the purpose of the engagement/participation activities • Information provided to consumers is clear, accurate, relevant and timely, recognising the different communication needs and wants of consumers • Allow sufficient time for meaningful engagement • Processes must be transparent to ensure participation is not tokenistic &/or rubber stamping already made decisions or outcomes • Consumer engagement processes are initiated as soon as practical and are open, honest, inclusive, appropriate and measurable.
<p>Accountability</p>	<p>Consumer engagement activities are transparent and accountable and establish clear and measurable criteria against which the influence and success of consumer engagement can be measured. The outcomes of consumer engagement processes are provided to consumers as well as how consumer engagement is measured. Continuous improvement processes are incorporated including ongoing and regular review and evaluation.</p>	<ul style="list-style-type: none"> • Develop Consumer Engagement policies, procedures and/or protocols • Each consumer engagement activity establishes clear and measurable criteria against which the success of the engagement can be measured. This will allow for continued improvement and ensure accountability against the objectives of each engagement activity • Provide feedback to consumers about how their contribution has influenced outcomes • Continuous improvement processes are incorporated with consumer consultation, including evaluation and review of consumer engagement processes • Consumer engagement strategies are guided by current best practice
<p>Respect and value</p>	<p>The needs of consumers and their families/significant others, benefits of consumer participation and consumer engagement processes are respected and valued. There is recognition of the impact of stigma and discrimination and the need for confidentiality, privacy and a safe environment for all consumer participation processes.</p>	<ul style="list-style-type: none"> • Engage with consumers in a respectful way that values the contribution that consumers bring to improving service planning and provision, monitoring and review as well as overall system outcomes • Build partnerships with consumers, through relationships, trust, openness and consistency • Recognise the impact of stigma and discrimination • Explanation of how personal information will be managed to ensure confidentiality, including the opportunity to remain anonymous • Provide a safe, secure and welcoming environment for consumer participation activities

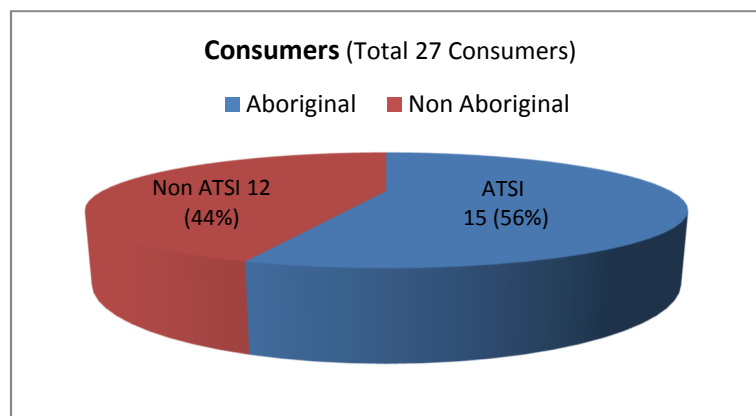
6. Consumer Consultation Findings

6.1. Consumers Consulted:

In total, 27 consumers were consulted, including 6 or 22% that identified as Family/Significant Other (several consumers identified as both AOD consumer and Family/Significant Other however have been identified as AOD consumer within this report).



24 consumers participated in the focus groups, with three individual interviews conducted. All individual interviews occurred at the consumer's place of residence and included one person from a CaLD background, an ATSI person and a non ATSI person that was unable to attend a focus group. Three of the four focus groups were held at the Health Consumers Council, with the Patrols/Sobering Up Service focus group being held at the Nyoongar Outreach Services in East Perth (which accounts for the over representation of ATSI people). Of the 27 consumers, 15 or 56% of consumers identified as ATSI.



12 or 44% of consumers were male, 15 (56%) female. Whilst there was no formal questionnaire regarding consumer demographics or drugs and services used etc., through discussion with consumers, there appeared to be a diverse and representative group of consumers (except for already mentioned over representation of ATSI people and no representation from young people – under 21 years or steroid users). Consumers were aged from approximately mid-twenties to late sixties and had

used a range of substances including alcohol, solvents, prescription medication and illicit substances. Most consumers reported having had some contact with an AOD service at some time including:

- Counselling
- Detoxification service
- Sobering Up Service
- Rehabilitation Service
- NSP or NSEP
- Aboriginal Service
- Women's Health Service
- Pharmacotherapy
- Women's Health Service
- GP/Medical Service (e.g. Cambridge Clinic, Street Doctor)
- Parent Support Group

Consumers reported being involved in varying levels of consumer engagement/participation activities, with most having filled in a consumer feedback form at some time. Only a couple of consumers reported being involved as consumer representatives on committees, with several consumers working as volunteers, as well as one person working in a peer position.

6.2. Principles: (see appendix 5 for all consumer feedback)

Consumers were provided with the principles and a description prior to their interview/group. The purpose of the principles and the principles themselves were explained to consumers by the consultant.

Feedback suggests that consumers felt the principles were very thorough and comprehensive with general consensus from all consumers. There were however concerns raised by two of the focus groups and one individual interview that centred around how will the principles be applied in a practical sense and how can you monitor that agencies are following the principles, with a suggestion that there should be an external body to check that agencies are following the principles and not just ticking boxes. These comments appeared to reflect a general theme expressed by most consumers regarding scepticism about an agency's desire to act upon consumer feedback as well as develop genuine partnerships with consumers that involve equal power with regard to decision making.

6.3. Summary of Response to Questions: (see appendix 5 for all consumer feedback)

Consumers were asked the questions regarding ways to improve and support consumers to participate in decision making at a range of levels. All consumer responses were documented (see appendix 5) and have been recorded according to the principle most applicable. Best practice strategies developed to engage and support consumers to participate in activities at a range of levels throughout the sector has been informed by consumer response to the questions, findings from the DAO research and forum, consideration of strategies that address known barriers to participation and a review of the literature. Feedback has been mapped against the principles, and summarised on the following pages. This consumer feedback further validated and supported the DAO research and forum findings and literature.

Participation:

In general, all consumers want to participate in decisions that impact upon them. Consumers made the point that there should be a range of ways and degrees for consumers to participate, acknowledging that some may not be interested at all and this should be respected. Ways to contribute ranged from feedback forms to sitting on committees with equal decision making. All focus groups and consumers interviewed raised the issue regarding finding out about various ways or opportunities to contribute or participate. Most consumers were not aware of the various ways that agencies involve consumers in decisions regarding service delivery yet there was significant interest expressed by consumers. Consumers discussed the need to broadly promote and advertise opportunities including newsletters, flyers, Facebook and other social media options etc. so they could be informed and get involved. In terms of accessing particularly marginalised groups, consumers suggested flexibility in terms of days and times, as well as going to the consumer at a place of their choice would increase participation. Consumers should know their rights, was another theme that was raised, particularly in relation to complaints mechanisms and degree of power in decision making.

Diversity

All consumers acknowledged the diversity of AOD consumers, as well as the need for a separate voice for Family/Significant Other that were deemed to have their own unique issues. Recognition of issues such as culture was raised and the need to provide a culturally sensitive service, as well as have a good understanding of the various cohorts and their issues within the agency consumer group. Using a range of engagement strategies, engaging more than one consumer on a committee, and acknowledgement of different issues for different consumers were all strategies raised by consumers. Several consumers suggested the need to have a broad and diverse range of consumer representatives that were well trained and supported, particularly at the state-wide and sector policy and planning levels. The need to include current users and not just those in recovery or abstaining was raised by several consumers, as well as the need to include people that have used both legal and illegal drugs. Most consumers agreed that service providers need to have a better understanding of consumer issues and the diversity of consumer issues, with a not all one size fits approach. A number of strategies were suggested regarding engaging ATSI people including:

- Going to where consumers are e.g. day services, park
- Using Aboriginal workers to engage Aboriginal consumers
- Develop relationships with workers and consumers
- Having 2/3 Aboriginal consumers together
- Aboriginal people are not comfortable speaking out

Leadership & Support

The culture of the AOD agency was a prominent theme raised by consumers suggesting there needs to be:

- Agency cultural change to support participation
- Commitment to build agency capacity amongst staff through staff education and training, support, attitudinal change and skill development
- Developing partnerships with consumers through relationships based on trust and understanding, staff consistency and leadership
- The agency values and can demonstrate its commitment to consumer participation and continual quality improvement through appropriate policies and procedures, consumer engagement strategies etc.
- Consumer participation is supported at all levels of the organisation, from the top down

Consumers suggested that agencies should have an increased understanding of many of the issues that impact upon them, as well as staff having an awareness of the benefits of consumer participation and valuing consumer input.

One of the main and possibly most frequent responses was the need for appropriate training and support for consumers. There were several suggestions as to what should be included in the training as well as the need for partnerships and co-design with consumers to develop appropriate training. In terms of support, consumers mentioned peer support and support from other consumer representatives.

Support also included recognition for consumer's time and costs including transport, childcare and assistance with mobile phone and email access. Consumers felt that remuneration for their time would increase participation and demonstrate their contribution is valued. Providing food was another suggestion many consumers supported.

Many consumers felt they lacked the confidence and knowledge to effectively participate at levels other than their own individual treatment, with one consumer commenting that she did not want to feel unworthy or fearful when participating. Training was identified as a way to build confidence and reduce some of the anxiety and fears identified.

With regard to consumer representatives at the state-wide sector policy and planning level, consumer feedback suggested there should be well trained and knowledgeable consumer representatives and just being an alcohol and/or drug user is not enough to represent consumers at this level.

On several occasions, consumers suggested having a group of well-trained consumer representatives that were knowledgeable and had a good understanding of the issues, being able to represent a diverse range of consumers, as well as support consumer participation and advocate for consumer interests was raised. These comments support the development of a peak consumer advocacy organisation, independent of government and service delivery, to promote and support consumer interests and involvement, as already established in both the mental health and disability services sector in Western Australia. One consumer specifically identified the need for an AOD consumer peak

organisation, suggesting it was another form of systemic stigma and discrimination that there was not one for AOD consumers given mental health and disabilities have already established bodies.

Meaningful

As already mentioned, a number of consumers were sceptical about agencies intent to engage in meaningful consumer participation activities. Whilst most of the consumers acknowledged engaging in activities such as feedback forms, satisfaction surveys, questionnaires and suggestion boxes, these activities provide limited opportunity for meaningful feedback, with consumers having no idea about the outcome of these activities and/or the degree to which their feedback influenced service delivery. In general, consumers were wary of various consumer participation activities, feeling they may be tokenistic and necessary to retain funding and/or tick boxes for accreditation purposes, with no real intent to change things or take consumer feedback seriously.

There were a number of suggestions presented by consumers that could assist meaningful consumer participation activities including:

- Informing consumers of their role and responsibilities, as well as the purpose of the engagement/participation activities prior to commencement
- Information provided to consumers is clear, accurate, relevant and timely, recognising the different communication needs and wants of consumers
- Allow sufficient time for meaningful engagement
- Processes must be transparent to ensure participation is not tokenistic &/or rubber stamping already made decisions or outcomes
- Consumer engagement processes are initiated as soon as practical and are open, honest, inclusive, appropriate and measurable
- Informing consumers of the degree of influence of their feedback and how information would be used
- Do not involve consumers in any activities if they are not going to be taken seriously, or listened to or able to have any influence
- Including consumers in the development and co-design of agency feedback forms, questionnaires and staff training for example, to ensure that forms are relevant, easy to understand and/or 'user friendly'

One consumer got tears in her eyes as she informed that she has been involved in a number of consultations regarding consumer engagement and stigma and discrimination. She stated that she felt nothing had changed and if anything, community attitudes and stigma and discrimination was worse, not better. She concluded by saying

"Please don't involve us or ask us if nothing is going to change or you have already made the decisions. I am continually hopeful, only to feel disappointed once more when I hear the same issues are being researched or consulted on again. Surely they should have a fair idea by now about what we want. Treating us with dignity and respect and valuing our contributions would be a good start".

Accountable

Consumer feedback that relates to the accountability principle includes the need for agencies to demonstrate how consumer feedback has influenced change, with many consumers reporting that they want to see the outcome or results of consumer engagement activities.

It also highlights the need for organisational infrastructure to be in place including:

- Development of Consumer Engagement policies, procedures and/or protocols
- Each consumer engagement activity establishes clear and measurable criteria against which the success of the engagement can be measured. This will allow for continued improvement and ensure accountability against the objectives of each engagement activity
- Continuous improvement processes are incorporated with consumer consultation, including evaluation and review of consumer engagement processes

Consumers should be involved in the continuous quality improvement process regarding consumer participation and whilst it is not expected that agencies will immediately have consumers on the board, interview panels, committee's etc., there is an attempt to continually review consumer participation activities with the view of improving and increasing the degree, level and range of options that consumers may contribute.

Value & Respect

As per the DAO research and forum, stigma and discrimination was identified as one of the greatest barriers to participation by consumers. Consumer feedback suggested that stigma and discrimination had the potential to impact upon whether someone chose to identify &/or disclose their consumer status given the negative attitudes, perceptions and community views on AOD issues. Several consumers suggested it was more acceptable (less stigma & discrimination) if the AOD use was in the past and the drug used was 'legal' e.g. alcohol &/or prescription medication. Consumer experiences with regard to stigma and discrimination was seen as having the likelihood of impacting upon consumer confidence, self-worth and self-esteem, as well as attitudes towards participation opportunities, particularly if consumers had prior negative experiences.

Confidentiality and the use of personal information were both raised, with a number of consumers reporting concerns about negative repercussions, particularly regarding individual treatment planning. Several consumers informed of times when they felt obliged to fill in consumer feedback forms at treatment agencies that were not confidential and able to be viewed by their individual worker. As a consequence, consumers reported filling in feedback forms in a manner that did not reflect their true feelings, particularly regarding satisfaction levels.

One consumer informed that her case manager walked into the full waiting room and suggested to the consumer that the reason her feedback was negative was because the consumer had personal issues with the worker and did not like her (worker had consumers feedback form in her hand). The worker then left the waiting room and returned with a urine sample bottle, demanding the consumer provide a sample in front of a full waiting room. The consumer felt so humiliated that she got up and left the building, knowing she would not have a new prescription for her methadone.

Consumers also reported not always being honest about their substance use, often informing it had decreased, again due to fear of negative repercussions. Several consumers agreed that agencies need to have a better understanding of relapse.

Consumers want to feel their participation is valued and respected, recognising the contribution consumers bring to improved service planning, provision and review. Communication should be open and honest with an attempt to develop quality partnerships with consumers. Consumers commented on staff consistency, with frequent changes making it difficult to develop genuine relationships.

Consumer participation activities should be undertaken in an environment where consumers feel safe, secure and welcome, confident that they are not being judged and their personal details are treated in a confidential and respectful manner.

Mention should also be made of several consumers identifying legal protection and support. Upon further discussion with consumers it appears this relates to consumers feeling anxious about repercussions and judgement if they are arrested or have spent time in jail, particularly if involved in consumer representation type roles.

7. Using the Principles: A practical example

7.1. Consumer Consultations: (Example of using the principles)

Once the six draft principles were developed, the AOD AG were keen to ensure the principles were upheld throughout the consumer consultation process and further considered in terms of their relevance and usefulness. Strategies used in the consumer consultation process, for the development of this document, have been outlined below according to the six principles.

Participation:

- Participation options included small focus groups and individual interviews. A phone interview would also have been offered if necessary or preferred
- Groups and interviews were offered at locations including the Health Consumers Council, other agency of consumers' choice &/or consumer's residence
- Consideration as to the start time of the groups
- Consumer consultations were widely and broadly promoted through flyers, social media, social/peer networks etc.
- Consumer consultation was promoted by a broad and diverse group of key stakeholders including a diverse range of consumers, all with their own networks

Diversity:

- Four specific diverse consumer groups were identified to consult with including marginalised, difficult to engage consumers e.g. Aboriginal people, Family/Significant Other, Current Users
- Family/Significant Other had a focus group specifically dedicated to them
- The Patrols/Sobering Up Services focus group was to be held at HCC with 4 people attending. No one attended on the organised day and time, so the consultant re-scheduled the focus group to a time and place as requested by consumers and agency, with 14 Aboriginal people attending. (flexible options, recognition of culture etc.)
- The Nyoongar Patrol staff who have already developed relationships with the consumer group were utilised to recruit and support consumer participants

Leadership & Support:

- All consumers were informed they could bring along a support person of their choice
- Information about parking, transport, location etc. was provided to consumers along with consultant's mobile number for any questions/assistance prior to attending
- Consumers were paid \$70.00 in acknowledgement for their expertise, time and costs
- Morning & afternoon tea was provided
- The consultant was a consumer and part of the AOD AG. The consultant informed consumers during the introductions that she was a consumer.
- The consultant had previous experience with consumer participation activities and was comfortable facilitating the consumer consultations

Meaningful:

- Information was provided to consumers outlining their role and responsibilities, as well as the purpose of the consultation, background etc. at least one week prior to the consultation
- The original draft 'Consumer Engagement Principles' document was re-written to ensure it was appropriate and accessible to a diverse range of consumers, as well as offering the original document to consumers if requested
- All information provided to consumers was clear, accurate, relevant and timely, recognising the different communication needs and wants of consumers
- Consumers were provided with the written information at least one week prior to consultations
- Two hours were allocated for each focus group and interview consultation, with extra time available if required/necessary
- Consumers were clearly informed that their response/answers to the questions would be the foundation and inform best practice strategies to engage and support consumers to participate in activities at a range of levels throughout the sector

Accountable:

- Consumers were informed that they can receive a copy of the final document including information on how their contributions influenced outcomes (majority of consumers indicated they would like to remain involved)
- Consumers were asked to provide feedback about the consultation process, including how it could be improved
- Whilst a formal evaluation process with measurable criteria was not developed, the success of the engagement can be considered in terms of the diverse representation of consumers consulted, degree of relevant feedback received and consumer interest in continued engagement

Value & Respect:

- Consumers were clearly informed that their identity would remain anonymous, with only first names used in introductions (consumers were not required to provide real name)
- Explanation of how personal information will be managed to ensure confidentiality, was explained to consumers, including who would have access to their contact details if provided
- Consumers were engaged in a respectful manner, acknowledging the expertise and value of their participation
- A consumer consultant was engaged who had a sound understanding of many of the consumer issues including stigma and discrimination
- An informal approach was used to engage consumers ensuring that language did not include jargon &/or technical terms unless required or relevant and explained.

7.2. Consumer Consultation Process:

At the end of each focus group, consumers were asked for feedback about the consultation process. Consumer feedback included:

- Small group size of similar people was good
- Consumers consultant and the informal approach encouraged consumers to talk more freely and honestly
- Receiving \$70.00 was great
- Information provided to consumers prior to the consultation received lots of positive feedback, with consumers suggesting it gave them a clear understanding of what was expected of them and what the consultation was about. One consumer commented that he was originally only attending for the \$70.00, but after reading the information he was now interested in the findings and outcome.
- Knowing how their feedback could influence the strategies developed, provided some consumers with a sense of ownership and achievement
- Consumers reported feeling somewhat invested in the project and want to see the final report, particularly given their responses will inform the strategies developed
- Consumers felt they were listened to and their feedback valued
- Consumers wanted to know ways that they could be further involved in the project as well as other consumer participation/engagement opportunities
- Consumers felt it was a positive experience to get together with other consumers and talk about issues that impact upon them

One consumer commented on expecting a 'formal research person' to be facilitating the group & felt that could have been intimidating. He said "having a consumer facilitate the group helped us relax, be honest and talk more about how we feel. You (meaning the consumer consultant) understand what we are talking about, it's so much easier" – with nods of agreement from that particular group.

7.3. AOD AG: A Collaborative Approach

The role of the AOD AG must be mentioned given its role in the consultation process, providing feedback at all stages and guiding the consumer consultations (e.g. suggesting focus groups should consist of 4 consumers instead of the proposed 8 consumers), development of the principles, strategies, recommendations and final document. The AOD AG supports recommendation 1 from the forum report: 'Ensure ongoing consultation with consumers to progress strategies', and its ongoing future should be positively considered to further progress consumer consultation and recommendations regarding consumer engagement in the AOD sector.

The establishment and ongoing meeting of the AOD AG used strategies that support the principles and is a good example of a collaborative consumer engagement activity, with organisations and consumers working together in partnership, with equal decision making power.

Some of the strategies used include:

- Consumers were involved right from the start of establishing the AOD AG, making decisions about the development, membership, terms of reference etc. of the group
- Consumers make up at least 50% membership of the group, with a quorum requiring 50% consumers present at any meeting
- A diverse range of consumers and key stakeholders were identified to ensure marginalised consumers were represented
- Consumer family/significant other were represented
- At least two ATSI consumers were identified and participated
- Times, days and dates for meetings were identified to suit all members
- Consumers were remunerated for their participation at meetings (\$70.00)
- Depending on the meeting time, either lunch or afternoon tea was provided
- Consumers were in the role of chairperson and shared minute taking at meetings
- Information was provided to consumers in an appropriate manner, with any jargon or acronyms used explained
- Consumers were involved in discussions regarding contract deliverables and were aware of their role and the purpose of the AOD AG
- Consumers have equal decision making power
- Trust and value is demonstrated through open and honest communication with all group members being involved in all decision making
- Consumers have information and are aware of the degree of influence they have on outcomes as well as the provision of the report to demonstrate that influence
- Support flexibility around participation given the personal circumstances of attendees

Possible indicators of the effectiveness of the AOD AG could include:

- AOD AG meetings were well attended by consumers on a regular basis, with dominant representation at meetings. The meetings were chaired by a Consumer member.
- Consumer representatives were engaged in discussions and decision making
- A diverse group of consumer interests were represented

When informally asked about the AOD AG, consumer representatives suggested:

- They felt comfortable talking at meetings
- Their input was valued and respected
- Meetings and participation was not tokenistic
- Whilst it was somewhat intimidating coming to their first meeting, consumers very quickly felt accepted, and were able to understand and contribute to what was going on
- Informal approach made it easier to contribute

One consumer representative said she felt a real comradeship with all the other consumer representatives even though they were all so different.

“It is great to not be the only consumer representative on a committee, others have an understanding of the issues and I don’t feel judged. I don’t need to explain everything as people get it. What I say matters. This is a really good model that other agencies should look at using.”

8. Summary/Discussion

The Principles and Strategies for Consumer Engagement were developed through an extensive consultation process with consumers, service providers and other key stakeholders, and support findings from the DAO research and forum, as well as national and state literature. The principles identified are consistent with other health and alcohol and other drug consumer engagement frameworks and policies.

Whilst most consumers acknowledged participating in information gathering and consultation through feedback forms and suggestion boxes, this was mostly at the individual treatment and service delivery level, the number of consumers that reported opportunities of involvement and collaboration were minimal, with no consumer reports of input into state-wide and sector policy and planning.

Consumers clearly confirmed that they want to participate in further consumer engagement activities, however barriers such as knowing about opportunities, having the confidence, knowledge and skills to participate (gained through training and support), agency culture and the impact of stigma and discrimination were identified as issues that impede upon consumer ability to contribute.

It is important to recognise that consumers choose how and when they will engage. This may depend on the nature of the activity, the consumer's perception as to the intent or perceived meaningfulness of the activity and whether the activity will improve outcomes important to the consumer. It is therefore important that agencies provide meaningful opportunities for consumer engagement that facilitates access, recognises known barriers to engagement and demonstrate how opportunities will contribute to better outcomes for the consumer and their family/significant other.

The need to build the capacity of consumers and service providers to effectively participate in consumer engagement activities was over whelming, with consumers wanting to collaborate in the development and co-design of training. The development of partnerships between consumers and service providers was identified as a necessity to further progress consumer engagement in the AOD sector at all levels and would require attitudinal change, equal power in decision making and a range of strategies to ensure the diverse nature of AOD consumers is represented.

While some questions were raised by focus group participants regarding the practical application of the principles, the AOD AG demonstrated the use of the principles throughout the consultation process for this project, clearly identifying strategies to ensure the principles were upheld. These principles were developed as a result of a recommendation from the forum report: 'to develop an agreed set of principles upon which to base activities for progressing consumer involvement in the AOD sector in WA'. The six identified principles of consumer engagement should contribute to enhanced service delivery and reflect current state and national health reforms.

As with other sectors, a consumer body could provide representation and a voice for consumers at a range of levels including broader sector planning and policy, as well as contribute towards increasing consumer capacity to participate at an individual level and further progress strategies to increase consumer opportunities in service delivery. The development of a peak body for AOD consumers would also further support strategies proposed within the Western Australian Mental Health, Alcohol and Other Drug Services Plan 2015 – 2025 (page 74) including:

- autonomy, self-determination and choice;
- co-designing of individualised plans;
- the involvement of those with lived experience (such as through the employment of peer workers), families, friends, culture and community;
- social inclusion, and the challenging of stigmatising attitudes and discrimination; and
- consumers to become advocates such as through participation in working groups, forums, advisory councils, boards; and in the development of new policies, programs, initiatives and legislation

The principles and strategies identified within this report are a start towards addressing some of the issues and barriers raised by consumers. It is obvious that consumer engagement in the alcohol and drug sector in Western Australia has a long way to go, and it is only through the development of meaningful and accountable opportunities and partnerships, where consumers feel respected and valued, will consumers contribute in an open and honest manner. Whilst there is a need for ongoing consultation with all key stakeholders the recommendations offer a way to further progress the work already undertaken and demonstrate the commitment necessary to move towards the development of increased and meaningful consumer participation in the AOD sector.

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Appendix 1: Consumer Consultation Handout

Background (optional reading)

In 2014 the Drug and Alcohol Office (now known as the Mental Health Commission) contracted a consultant to research consumer involvement in the Western Australian Alcohol and Drug Service sector. The research aimed to look at:

- Current levels of consumer involvement
- Barriers to consumer participation
- How consumer participation activities could be improved

The research found that consumers mostly participated in lower levels of consumer engagement activities such as surveys and feedback forms and there were a number of barriers identified by both consumers and treatment service providers.

Following the research the Drug and Alcohol Office (DAO) in partnership with the Western Australian Substance Users Association (WASUA) and Western Australian Network of Alcohol and Other Drug Agencies (WANADA), held a forum in November 2014 of 70 consumers to discuss ways to improve consumer involvement in the alcohol and other drug (AOD) sector. The forum aimed to confirm previous research findings and determine priorities for implementing future consumer engagement strategies.

The forum supported the previous research findings:

- Consumers wanted more opportunities to participate in a range of activities including individual treatment, AOD service delivery, policy development and planning
- Support for consumers through training and peer support
- Barriers need to be addressed so consumers can provide meaningful, confidential feedback
- Ongoing consumer involvement at all levels of the AOD sector
- Strategies to reduce stigma associated with AOD use need to be developed

The following six recommendations were proposed as a way forward in working towards meaningful consumer involvement within the AOD sector.

1. Ensure ongoing consultation with consumers to progress strategies
2. Develop a common set of principles
3. Ensure appropriate support mechanisms to break down barriers
4. Develop training for consumers and service providers to participate in processes
5. Understand the current context
6. Work towards consumers being involved at all levels

In 2015 the Health Consumers Council (HCC) received a small grant from the Mental Health Commission (MHC) to further progress the work already complete (as outlined above). The grant required the HCC to:

- Ensure ongoing consultation

- Develop a common set of principles
- Outline best practice strategies to engage and support consumers to participate in activities at a range of levels throughout the sector

The HCC established the Alcohol and Other Drugs Consumer Engagement Advisory Group (AOD AG) in 2015 consisting of service providers and a diverse range of consumers contributing to at least 50% membership of the committee. The group have been meeting on a monthly basis. A consumer consultant was engaged to develop a common set of principles and identify best practice strategies to engage and support consumers to participate at a range of levels in the AOD sector, with consideration to strategies that address known barriers to participation.

A draft set of principles have now been developed and the AOD AG is seeking feedback through consultation with consumers and families/significant others regarding those principles, as well as identifying ways to improve consumer engagement at a range of levels in the AOD sector.

Appendix 2: Consumer Consultation Handout Barriers to Consumer Participation

(Optional Reading)

Barriers to consumer participation in the Alcohol and other Drug sector have been well researched and documented, including within the research and forum referred to in the background document. The following is a list of known barriers as identified by consumers:

- Stigma and Discrimination
- Views remaining confidential
- Not knowing how information provided by consumers was going to be used
- Fear that feedback could negatively impact upon treatment
- Feelings that nothing would change as a result of feedback/participation
- Staff changeover and a lack of consistency
- Illegal nature of drugs and 'outing' yourself either as a current or ex-user
- Information is difficult to understand e.g. use of jargon or technical words
- Lack of confidence
- Services being unreceptive to consumer feedback – not listening
- Power imbalance between consumers and service providers
- Not knowing about consumer participation activities
- Personal circumstances – can include how your feeling, not having money to attend e.g. bus fare/petrol, other commitments etc.
- Information overload or not enough information to effectively participate
- Cultural barriers for Aboriginal consumers and people from other cultures
- Feeling like you aren't heard
- Feeling like participation is tokenistic
- Not having the skills to participate

The above barriers may assist you to think about ways to increase and improve consumer participation opportunities.

Appendix 3: Consumer Consultation Handout

Principles for Consumer Engagement (please read)

Principles

Six principles have been identified

1. Participation
2. Diversity
3. Leadership and Support
4. Meaningful
5. Accountable
6. Value and Respect

Definition of Principles

Principle	Definition
Participation	This principle refers to a consumer's right to participate in decisions that impact upon them. This includes decisions about their own health, wellbeing and welfare, as well as service delivery and sector and state-wide policy and planning. It also refers to consumers participating in various ways such as surveys, committees and forums for example, recognising that consumers want to be involved at varying levels. The value of consumer participation should be recognised and respected.
Diversity	This principle refers to the diversity of AOD consumers and their families/significant others. Diversity includes the type of drug used, the way it is used, the legal status of a drug, drug related harms, etc., as well as different types of drug users according to gender, culture, age, ability, sexual preference, religion etc. One consumer cannot represent the interests of all AOD consumers and families/significant others.
Leadership and Support	This principle refers to an organisation supporting and valuing consumer participation through staff training and leadership. It also refers to supporting consumers to participate through training, support and providing information about consumer participation activities. Consumer participation activities should be appropriately resourced and remunerated.
Meaningful	This principle refers to informing consumers about their role and purpose of participation, including how their participation will change things and/or influence decision making. Communication should be open and honest, consumers are listened to and heard, information is provided in a way consumers can understand and make informed decisions.
Accountable	This principle refers to organisations measuring the influence and success of consumer engagement activities and informing consumers of the outcome of these activities. It also refers to reviewing and improving all consumer engagement activities.
Value and Respect	This principle refers to valuing and respecting the benefits of consumer participation. It includes recognising the impact of stigma and discrimination and the need for confidentiality and a safe environment for consumer participation. It also refers to valuing and respecting consumer needs and preferences and building trust with consumers.

Appendix 4: Consumer Consultation Handout

Consumer Role – Focus Groups (please read)

You have received this information as you have been invited to attend a focus group at the Health Consumers Council (HCC) on either the 11th or 13th October 2016. Each group will have 4 consumers participating with the consumer consultant. There may also be a consumer support person if a consumer has requested this. The group will be for 2 hours and all your responses will be confidential. During the two hours, the consultant will ask you to provide your opinions and any feedback on the 6 Consumer Engagement Principles. We have provided you with a copy of the 6 Principles which we would like you to read prior to attending the focus group.

You will also be asked the following questions during the two hours:

3. What are some of the ways that services could support consumers to participate in decision making at a range of levels including:
 - Own individual treatment planning
 - Service delivery level
 - State-wide and sector policy and planning level

4. How can consumer participation be improved, what needs to change &/or what can help consumers overcome some of the barriers to participation? What would help you to attend more consumer participation activities?

Prior to attending the focus group, could you please think about some responses to the above two questions? Your responses to these questions will be recorded and documented and will form strategies to increase consumer engagement.

We have provided you with a number of documents to assist you in participating in the focus groups. Your input will influence the final principles as well as identify best practice strategies to engage and support consumers to participate in activities at a range of levels throughout the sector. You will receive a copy of the final document if you are interested. Documents provided to you include:

1. Consumer Role – Focus Groups
2. Principles for Consumer Engagement – Consumer Handout
3. Background
4. Barriers to Participation

If you would like the full version of the consumer principles for engagement including the considerations, please contact the HCC or the consumer consultant as per the flyer.

Appendix 5: Consumer Consultation Feedback

Consumer Feedback

Three individual interviews and four consumer focus groups (4 consumers per group) with various consumers (as below) were interviewed regarding the 6 Consumer Engagement Principles as well as two questions regarding improving consumer engagement and participation. Below are the responses from the interviews and focus groups.

1. Treatment Services
2. Harm Reduction Services & current users
3. Sobering up/Patrols
4. Families/Significant Others

Consumer Engagement Principles: Opinions and any feedback on the 6 Consumer Engagement Principles. Consumers were provided with the principles and a description prior to their interview/group. The purpose of the principles and the principles themselves were again explained to consumers by the consultant.

Overall there was not too much feedback about the principles.

- Valid
- Covers it
- Very thorough
- Comprehensive
- Will this apply to complaint processes?
- How will the principles be applied in a practical sense?
- How can you monitor that agencies are following the principles?
- There should be an external body to check that agencies are following the principles and not just ticking boxes
- Family/Significant others have different issues than consumers
- Consumers should speak on their own behalf
- There should always be more than one consumer on a committee
- I don't think I could add anything, nothing comes to mind

Consumer Responses according to Principles

Consumer responses to the questions have been organised according to the principle they best support.

1. What are some of the ways that services could support consumers to participate in decision making at a range of levels including:

- Own individual treatment planning

Principle	Consumers Response
Participation	<ul style="list-style-type: none"> ➤ Options/choices in terms of days and times for appointments (Flexibility) ➤ Consumers know their rights ➤ Flexible service delivery ➤ Barriers to getting to places on time and making contact ➤ Mobile services ➤ Flexibility
Diversity	<ul style="list-style-type: none"> ➤ Groups and services for parents need funding ➤ Flexible times as parents/family work ➤ Aboriginal people are not comfortable speaking out
Leadership & Support	<ul style="list-style-type: none"> ➤ Assistance with childcare, parking and taxi vouchers if in the evening ➤ Continuity of treatment and worker ➤ Policies to support consumer participation ➤ Staff training ➤ Providers encouraging and supporting consumers to be more involved in decision making about their own treatment ➤ Staff need to be educated ➤ Consumers need education ➤ Consumers should have access to good training ➤ Service provider training should include harm reduction ➤ Training for pharmacy staff ➤ Have access to an advocate ➤ Bringing someone along to support consumer ➤ Mentors/support person ➤ GP's have significant training and are unlikely to want to share decision making ➤ GP's should have more knowledge regarding various AOD and other services
Meaningful	<ul style="list-style-type: none"> ➤ Consumers should be encouraged to work in the sector ➤ Be taken seriously ➤ Listen and form relationships with consumers ➤ Fear of repercussions
Accountable	<ul style="list-style-type: none"> ➤ Knowing there will be no negative consequences to individual treatment ➤ Doctor's see themselves as the expert and therefore make the decisions

	<ul style="list-style-type: none"> ➤ Assist to develop own treatment plan ➤ Good complaints procedures
Value & Respect	<ul style="list-style-type: none"> • Confidentiality ➤ Need to recognise relapse and past strategies for coping and not suffer punitive consequences ➤ Recognise the impact of stigma and discrimination ➤ Recognise trauma ➤ Develop trust with service providers ➤ GP's should be more respectful of consumers and their ability to make decisions ➤ Consumer experiences should be acknowledged and respected ➤ Continuity of care so you get to know and feel comfortable with provider ➤ Judgemental ➤ Recognise that most people's experiences have been very negative ➤ Decision making is frustrating with GP's
Treatment Issues (not a principle)	<ul style="list-style-type: none"> ➤ Options/choices of service provider and actual worker ➤ Gender/Age of worker ➤ Qualifications of worker ➤ Increase treatment options ➤ Decision making about the types of services ➤ Holistic treatment ➤ AOD treatment should be included and part of a mental health plan ➤ Increased treatment options and treatment matching ➤ Increase intervention options instead of just pharmacological and medical ➤ GP's shouldn't prescribe Valium and codeine when consumers are trying to abstain ➤ Doctors should be referring more and sooner to counselling ➤ How can a non-peer or young person with no life experience help me ➤ It would help if I knew that the counsellor had their own experiences of AOD issues as they have a better understanding ➤ Provide follow-up after leaving rehab ➤ Host employers for people getting out of jail

- **Service Delivery Level**

Principle	Consumers Response
Participation	<ul style="list-style-type: none"> ➤ Advertise promote consumer participation activities through newsletters, website, social media, posters, noticeboards etc. at a range of places including services, pharmacies, newspaper etc. ➤ Consumers on boards, job interview panels etc. ➤ Recognise that some people are not interested in participating ➤ Increase flexibility in programs ➤ There are only feedback forms and should be more options ➤ Instead of the consumer go to the service, the service comes to you ➤ Knowing rights and options ➤ Invitation to provide feedback/participate ➤ A lot of consumers are too busy, chaotic and just not interested in participating ➤ Go to places where consumers are already attending e.g. Ruah ➤ Flexibility
Diversity	<ul style="list-style-type: none"> ➤ Support by other consumer reps ➤ More than one consumer on a committee or board ➤ Develop a group of consumer representatives that are trained ➤ Consider obstacles to employment such as Police clearances ➤ Difficult to participate if homeless ➤ Service providers should increase their understanding of consumer issues ➤ Should include current users, not just those in recovery or abstaining ➤ Unique issues for parents ➤ Parents issues are different to consumers ➤ Parents should not speak on behalf of consumers ➤ Recognition of where parents are coming from ➤ Going to where consumers are e.g. day services, park ➤ Using Aboriginal workers to engage Aboriginal consumers ➤ Develop relationships with workers and consumers ➤ Recognition of different issues for different consumers ➤ Legal and illegal drugs ➤ Having 2/3 Aboriginal consumers together
Leadership & Support	<ul style="list-style-type: none"> ➤ Training and support ➤ Training including the role of a board, advocacy, media, meeting processes, presentation skills, computer training ➤ Individual tailored support to assist consumers to fore fill their role whatever that may be ➤ Support by other consumer reps ➤ Assistance with childcare, parking and taxi vouchers if in the evening ➤ Payment ➤ Staff training ➤ Assistance with internet connection and mobile phone ➤ Legal protection and support ➤ Policies to support consumer involvement

	<ul style="list-style-type: none"> ➤ Develop a group of consumer representatives that are trained ➤ Financial remuneration and costs reimbursed (e.g. train, petrol, parking etc.) ➤ Increase motives to participate including financial ➤ Service providers should increase their understanding of consumer issues ➤ Awareness of how consumer involvement can improve service delivery ➤ Training should not be too long or early in the morning (people may have to dose, rely on public transport etc.) ➤ Transport to the venue ➤ Having confidence to participate ➤ Understanding of meeting procedures ➤ Not feeling unworthy or fearful ➤ Any training and participation should be recognised as ‘work for the dole’ activities ➤ Training should be recognised ➤ Staff consistency ➤ Being provided with a mug map of services ➤ Information and questions from provider ➤ Provide food
Meaningful	<ul style="list-style-type: none"> ➤ Agency culture recognises what consumers can contribute ➤ Not punished if busted or jailed ➤ Employment opportunities ➤ Get to know service providers ➤ Don’t ask consumers to be involved if they are not going to be listened to ➤ Develop trust ➤ Allow enough time for consumers to be involved and ask questions ➤ Appropriate language used that doesn’t include jargon ➤ Providers should sit down and walk consumers through all the information required to make informed decisions ➤ Have access to someone with knowledge ➤ Service providers should increase their understanding of consumer issues ➤ Awareness of how consumer involvement can improve service delivery ➤ Consumers been taken seriously ➤ Forms should be simple and short ➤ Information provided beforehand including expectations (like what has been provided to us for this focus group – was originally coming for the money but after reading everything am now really interested in the work) ➤ Not tokenistic ➤ Informal language and a friendly reception
Accountable	<ul style="list-style-type: none"> ➤ Policies to support consumer involvement ➤ Inform consumers of how they have influenced decision making ➤ Provide feedback to consumers after participation ➤ Follow-up including minutes and actions taken

	<ul style="list-style-type: none"> ➤ Not knowing how information is going to be used
Value & Respect	<ul style="list-style-type: none"> ➤ Confidentiality ➤ Recognise the impact of stigma and discrimination ➤ Recognise that most people's experiences have been very negative ➤ Recognise trauma ➤ Service providers should increase their understanding of consumer issues ➤ Consumers been taken seriously ➤ Feel valued ➤ Fear of loss, anxious ➤ Difficult to talk about your private business ➤ Safe environment ➤ Doesn't take too much time ➤ See consumers in the morning before they get too intoxicated ➤ Go to where people feel easy

- **State-wide and sector policy and planning level**

Principle	Consumers Response
Participation	<ul style="list-style-type: none"> ➤ Provide a number of ways for consumers to comment on legislation e.g. phone, talking to someone etc. ➤ How do you find out about these opportunities ➤ Consumer representatives on research committees ➤ Recognise that some people are not interested in participating ➤ Advertise and identify consumer representative opportunities ➤ Promoting and advertising opportunities e.g. Facebook, newsletters etc. ➤ Options with regard to how to participate or provide feedback, not everyone wants to sit on a committee
Diversity	<ul style="list-style-type: none"> ➤ Broad and diverse range of consumer representatives ➤ More than one consumer representative ➤ Develop a group of consumer representatives that are well trained and supported ➤ Diverse group of consumers including current users
Leadership & Support	<ul style="list-style-type: none"> ➤ Want well trained and knowledgeable consumer representatives at this level ➤ Just being an alcohol and/or drug user is not enough to represent consumers at this level ➤ Assistance with childcare, parking and taxi vouchers if in the evening ➤ Payment ➤ Assistance with internet connection and mobile phone ➤ Training and support ➤ Individual tailored support to assist consumers to fore fill their role whatever that may be ➤ Support by other consumer reps ➤ Legal protection and support ➤ Sector knowledge ➤ Transport provided to attend
Meaningful	<ul style="list-style-type: none"> ➤ Employment opportunities ➤ Ensure it is not tokenistic ➤ Consistency
Accountable	<ul style="list-style-type: none"> ➤ Inform consumers of how they have influenced decision making ➤ Feedback
Value & Respect	<ul style="list-style-type: none"> ➤ Recognise the impact of stigma and discrimination ➤ Recognise that most people's experiences have been very negative ➤ Confidentiality

How can consumer participation be improved, what needs to change &/or what can help consumers overcome some of the barriers to participation? What would help you to attend more consumer participation activities?

Principle	Consumers Response
Participation	<ul style="list-style-type: none"> ➤ Finding out about various opportunities ➤ Advertising and promoting opportunities ➤ Flexible meeting times ➤ Having a variety of ways to participate
Diversity	<ul style="list-style-type: none"> ➤ More than one consumer
Leadership & Support	<ul style="list-style-type: none"> ➤ Training ➤ Support and mentoring ➤ Recognition of time and costs ➤ Having the knowledge and confidence to participate ➤ Confidence and knowledge ➤ Assistance with transport and costs ➤ Staff consistency
Meaningful	<ul style="list-style-type: none"> ➤ Not tokenistic ➤ Knowing the purpose of participation ➤ Knowing that feedback and participation will improve things for consumers ➤ Having an informal or down to earth person or consumer facilitating (We thought this was going to be very formal but it is easy to speak to you) ➤ Ongoing opportunities
Accountable	<ul style="list-style-type: none"> ➤ Feedback about the outcome/s
Value & Respect	<ul style="list-style-type: none"> ➤ Agencies valuing consumer contributions rather than seeing it as something they have to do for funding or accreditation ➤ Agencies valuing consumer feedback/participation ➤ Confidentiality ➤ Developing relationships and trust ➤ Services recognising the trauma, stigma and discrimination consumers have experienced

Consumers were also asked about the list of barriers that were provided e.g. Is there any more? Does this cover it? etc. Feedback confirmed it was a thorough list and there was general agreement about the barriers to participation

Consultation Feedback:

At the end of each focus group, consumers were asked for feedback about the consultation process.

Consumer feedback included:

- Small group size of similar people was good
- Consumers consultant and the informal approach encouraged consumers to talk more freely and honestly (one consumer commented on expecting a ‘formal research person’ to be facilitating the groups & felt that could have been intimidating)
- Receiving \$70.00 was great

- Information provided to consumers prior to the consultation received lots of positive feedback, with consumers suggesting it gave them a clear understanding of what was expected of them and what the consultation was about. One consumer commented that he was originally only attending for the \$70.00, but after reading the information he was now interested in the findings and outcome.
- Knowing how their feedback could influence the strategies developed, provided some consumers with a sense of ownership and achievement
- Consumers reported feeling somewhat invested in the project and want to see the final report, particularly given their responses will inform the strategies developed
- Consumers felt they were listened to and their feedback valued
- Consumers wanted to know ways that they could be further involved in the project as well as other consumer participation/engagement opportunities
- Consumers felt it was a positive experience to get together with other consumers and talk about issues that impact upon them