



Consumer Participation Project

Prepared for:
NADA

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TABLE OF CONTENTS

ABBREVIATION	5
ACKNOWLEDGMENTS	6
EXECUTIVE SUMMARY	7
INTRODUCTION	11
BACKGROUND	13
EVALUATION FRAMEWORK	14
Development of an evaluation framework and evaluation measures	14
Survey measures	14
Qualitative measures	14
SURVEY COMPONENT	15
Methods	15
Measures	16
Survey items	16
Results from survey	18
Beliefs about why consumers do not engage in consumer participation in their AOD treatment facility	19
Complaint Procedures	22
Current levels of consumer participation in services	25
Views on Consumer Participation	26
Changes to services as a result of the Consumer Participation Project	27
Significant relationships	28
INTERVIEW COMPONENT	29
Methods	29
Consumer participant profile	30
Pre- and Post- training consumer interviews	31
Findings from consumer interviews	31
<i>Prior knowledge and previous experience with Consumer Participation</i>	33
<i>The model: perceived strengths and weaknesses of Consumer Participation</i>	36
<i>Outcomes and impact of the training, and ongoing initiatives</i>	38
<i>Barriers to Consumer Participation: what's needed?</i>	39
<i>Recommendations from consumer interviews</i>	41
Professional interviews	42
Professional participant profile	43
Findings from professional interviews	43

<i>Professional participants' role in the Consumer Participation project</i>	<i>44</i>
<i>Prior knowledge of Consumer Participation and the level of interest at their workplace</i>	<i>45</i>
<i>Strengths and weaknesses of the model.....</i>	<i>46</i>
<i>Outcomes and impact, including witnessed changes at their service.....</i>	<i>48</i>
<i>Barriers to Consumer Participation: what's needed?</i>	<i>51</i>
<i>Recommendations from professional interviews.....</i>	<i>51</i>
DISCUSSION.....	52
RECOMMENDATIONS	56
Advocacy	56
Sector Development and Support.....	56
Consumer supports.....	57
Limitations	57
References	58

ABBREVIATION

AIVL	Australian Injecting & Illicit Drug Users League
AOD	Alcohol and other drugs
NADA	Network of Alcohol and other Drugs Agencies
PAG	Project Advisory Group
TSU	Treatment Service Users
NUAA	NSW Users and AIDS Association

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We would like to acknowledge the hard work and input of the Project Advisory Group, the NADA Project Coordinator, co-facilitators, stakeholders and staff members of all five services who provided unwavering assistance to the research team. Their contributions assisted the researchers in accessing participants and ensured that this final report is a valuable resource for consumer engagement.

EXECUTIVE SUMMARY

The evaluation of NADA's Consumer Participation Project assessed the effectiveness of this project to provide to support treatment services that undertook to engage in consumer participation. Under the guidance of a Project Co-ordinator and supported by co-facilitators, the project involved training and relationship building with five AOD treatment services involved in the project and the development and implementation of unique consumer engagement models for each specific service. The evaluation comprised of both qualitative and quantitative arms. Eight-six participants completed the online survey, of which 36% had taken part in the consumer participation training delivered by NADA staff and consumer representatives. In depth interviews were undertaken with AOD service consumers, staff and stakeholders, to fulfil the qualitative component of the evaluation.

While consumer participation in decision-making about service planning is common in certain health services in Australia it is thought to be largely underdeveloped in drug treatment services. This evaluation, in line with existing literature and previous Australian studies, found that consumer participation activities exist in these services, however the existing activities were largely 'low'-involvement activities, often concerned with providing information to or receiving information from consumers. While the sector is seeing a slight shift toward higher-level consumer engagement initiatives, there is a persistent lack of awareness and understanding of both the theoretical and practical activities in relation to consumer participation and limited understand of the benefits of consumer engagement.

It was evident throughout the evaluation that both consumers and staff members are in favour of the idea of consumer engagement. However, a significant finding is the lack of knowledge among both consumers and staff about what consumer participation actually means and how consumers can participate in activities available to them. Concerns around the consequences of consumers participation on their treatment goals was evident, reflecting a strong need for guidance for consumers who require support to improve their knowledge and support their skill development in this area. These concerns and other challenges faced by consumers, such as being overburdened, concerns about working with some fellow consumers and the implications of where consumers are in the treatment experience, were echoed by staff members. However, participants who had engaged in consumer participation activities since the training, had more detailed and practical knowledge about consumer participation and its aims and benefits. This indicates that ongoing workshops supporting consumer participation and the and the implementation of practical, task driven activities could be a robust approach to integrating consumer participation into service provision.

A significant finding from the quantitative arm suggests that there is a strong relationship between staff attitudes and beliefs around consumer participation, current levels of consumer participation activities and beliefs around positive changes as a result of this project. Results from the surveys found that the more positive staff members' attitudes were towards consumers being involved in the service planning and delivery, the greater

their level of current consumer participation in the service and the more these staff members felt that their service would show positive changes as a result of participating in the current consumer participation project. Additionally, although the quantitative sample is small, there were some significant differences among those staff members who undertook the consumer participation training, suggesting staff developed a greater understanding and knowledge around consumers as a result of the training. This emphasises the need for continued, regular training that includes the positive benefits of consumer engagement, practical implementation and ongoing support for both staff and consumers.

Consumer participation, and its success, was thought to be highly contextual, with the culture of a service setting being described as influential. Consumer participation was perceived as thwarted at sites that were not considered collaborative or equitable. The structural, emotional, political and the current atmosphere for staff and consumers need to be considered and acknowledged in order for consumer engagement to operate effectively. However, consumer engagement initiatives should take advantage of the finding that training increased consumers' comfort in communicating with staff, their self-confidence and awareness of their rights.

Some consumers reported using the training to strengthen relationships with fellow consumers, with a view to transferring these skills to post-treatment scenarios. Consumers may require ongoing support and skills which engagement activities should acknowledge and provide for in the period post treatment. The benefits of the provision of such supports would include the opportunity for post-treatment consumers to act as mentors, ongoing supporters and advocates for the 'next generation'.

One of main barriers to consumer participation was seen to be lack of resources. Staff and consumers report being overburdened already. Additional resourcing must include payment not only for consumers' time but also to staff given specific roles and additional responsibilities. In addition, specific care should also be taken when promoting and advocating for consumer engagement initiatives as it was found that at times it was difficult to balance the expectations of consumers with limited service resources. Beyond limited resources, such a project also relies on the capacity and overall service commitment to implement engagement practices. This can easily lead to disappointment and unwillingness to participate in the future engagement activities. In addition, findings drawn from interviews with professionals tend to show an ambivalence or disappointment about how this project played out. Ongoing support for these staff would be advised to explore their support needs in order to prevent disillusionment. Professional participants who were not involved directly with the project, requested more detail about how the principles of consumer participation could be applied in practice, and that the training should be clearer in this respect. They also suggested greater clarity about the role that consumers might take, and that adequate support is provided to these consumers. Finally, while they had witnessed changes among consumers who attended the workshops, there seemed to be a lack of action post training, and some participants tended to be frustrated by this. It is possible that integrating a post-training procedure would counteract any service stalling,

and greater support for trainers would bolster their motivation levels and help them manage their expectations.

The evaluation of this project clearly shows the Consumer Participation Project was a worthwhile investment yielding positive results in the areas of consumer engagement, increasing knowledge and communication among consumers and staff. There was a strong sense of support for consumer participation throughout however service providers were less supportive of activities in which consumers would be involved in decision-making that relates directly to staff and expressed concerns about the practicality of operationalising such activities, the inadequacy of consumers' skills, consumers' lack of interest and the appropriateness of having consumers involved in such decision-making. To overcome these concerns, future training and engagement activities should include concrete examples of consumer participation in practice and additional recourses that include the benefits in moving from lower-level to higher level consumer engagement activities.

Recommendation for advocacy, sector development and support and consumer supports have been developed in consultation with NADA to provide a valuable resource for future consumer engagement projects.

Advocacy

1. More resources are needed to ensure longevity of consumer participation activities. Interruptions due to lack of resources reduce staff and consumer positivity and enthusiasm for the project.
2. Promotion of early engagement and commitment from all levels (Board, Management and staff) within organisations are necessary to prevent the start/stop nature of the project that can too easily lead to disillusionment and subsequently suspicion of consumer engagement initiatives in the future.
3. Increased advocacy needs to focus on consumer participation training being embedded in the delivery of treatment in order to raise awareness among consumers, whilst acknowledging and accepting that some consumers will not want to be involved.

Sector Development and Support

1. Develop a mentoring role for staff who have been employed for longer periods of time within organisations as data shows that they have a more positive attitudes towards consumer participation. Experienced staff members can be involved in ongoing staff training to share their knowledge and experience of consumer participation.
2. Consumer participation should be included in all areas of staff training with consideration to shorter training at more regular intervals. Such training could include practical/activity-based components and information about the positive benefits of consumer engagement.

3. The development of fact sheets and other resources on consumer participation targeting sector workers and consumers with consideration given to various levels of literacy.
4. Foster greater opportunities where staff and consumers can have more expansive discussions about what are important and relevant consumer participation activities.

Consumer supports

1. Improve consumers' awareness of consumer participation activities and better support opportunities for them to build advocacy skills over the long term.
2. Increase support and development for the co-facilitators role with considered thought given to selection, training, ongoing support, expectations and remuneration.
3. Give consumers capacity to navigate and successfully respond to stigmatising behaviour and work with them to feel positive about their involvement in consumer participation.
4. It is important to 'prepare the ground' in order to make sure that services can actually follow up on what is promised to consumers, otherwise consumers will be left disappointed and not trust future initiatives. Specific care should be taken when promoting and advocating for consumer engagement initiatives as it can be difficult to balance the expectations of consumers with limited service resources.
5. Timing the consumer participation training to an optimal stage in the consumer's treatment plan by exploring the opportunities with them and phasing their involvement at a time that would reduce the risk of participants being distressed or triggered by the group work style of the workshop. Consideration must be given to the type of treatment service (longer vs short stay) and the consumer's stages of treatment (early vs later) when designing consumer participation activities.
6. Increase the use of technology in future consumer participation models with particular application to questionnaires and evaluations.

INTRODUCTION

All health policy is clear about the importance of consumers informing their own care, with person-centred care recognised internationally as the best approach to delivering quality services. Yet, in the alcohol and other drugs (AOD) sector we have not seen this implemented in a planned and consistent way. Stigma and discrimination of AOD service users continues to play a limiting role in enabling consumers to inform the way their services are delivered. The growing recognition of the benefits of consumer participation combined with momentum from governing and accrediting bodies' means that this can no longer be the case.

The Network of Alcohol and other Drugs Agencies (NADA) is the peak organisation for the non-government AOD sector in NSW, providing quality evidence-based programs to reduce alcohol and drug related harms. The NADA Consumer Participation Project was funded by the Australian Government Department of Health to undertake a sector capacity building initiative. The Project was an innovative approach that enabled service providers to build the capacity of consumers to inform their own treatment at a range of different levels. It aimed to provide the collation and distribution of resources to support treatment services that undertook consumer participation and representation activities and provide intensive in-service support to a number of treatment services and their consumers. In October 2017, a Coordinator was employed, followed by the establishment of the Project Advisory Group (PAG). The Project was also informed through various sources such as Australian Injecting & Illicit Drug Users League (AIVL)'s Treatment Service Users (TSU) I and II, NSW Users and AIDS Association's (NUAA) the CHANGE Project and SHARC in Victoria. Five sites were selected through a detailed expression of interest submissions process with considerations given to existing consumer participation initiatives, management's overt commitment to the project, the service's capacity to undertake and support the project, and levels of consumer involvement in the application process and undertaking any potential project. Service location, size and model was also taken into consideration.

A consumer and a staff representative for each site were invited and funded to attend a training and information session at the NADA offices. Sessions covered the theory and practice of consumer engagement, impact of stigma and discrimination on consumer engagement and service access, and pragmatic consumer engagement implementation. Additionally, training participants were asked to focus test the draft NADA Consumer Engagement Audit Tool - this resource went through a separate development process and was launched in June 2019. The initial training, supported by the Project Coordinator, was followed by a period of networking, support and relationship building. The five services involve in the project were required to develop an action plan which was signed off by management. This was followed by the recruitment, training and support of co-facilitators

who - together with the Project Coordinator, on-site consumers and staff - were responsible for training and the development of these Advocacy plans.

Four consumers who had previously participated in Consumer Academy (NUAA's capacity building and empowerment initiative), and had recent experience with residential drug and alcohol treatment took on roles as co-facilitators. Together with the NADA Project Coordinator they participated in a 'Train the Trainer' styled workshop facilitated by NUAA to ensure that all participants were actively delivering the same content to workshop attendees. Co-facilitators were extensively supported by the Project Coordinator through ongoing formal and informal meetings, group and individual practice sessions and brainstorming initiatives. It was deemed imperative that not only were co-facilitators linked with and reflective of the relative services, but that they were in a position to demonstrate that their own lived experience was holistic and went beyond the treatment service. They were allocated a service which they engaged with and were supported to learn as much as possible about the service and reflect on how their individual experiences could enhance the training experience for staff and consumers.

This research aimed to evaluate NADA's consumer participation project and engaged in a consultative process with NADA and project partners to assess the effectiveness of the processes utilized, the training provided, the audit tools developed and the outcomes of the project. From October 2018 to May 2019, in depth interviews were undertaken with AOD consumers, staff and stakeholders and online surveys were conducted among staff members.

BACKGROUND

Closely connected to notions of consumer rights and citizenship, consumer participation in the health sector is broadly defined as ‘the process of involving health consumers in decision making about health service planning, policy development, setting priorities and quality issues in the delivery of health services’ (Commonwealth Department of Health and Aged Care, 1998). While the past three decades have witnessed a substantial growth in consumer participation within some areas of health, particularly mental health, its implementation within AOD has lagged conspicuously behind (Treloar, Rance, Madden & Liebelt, 2011; Hinton, Tasmani & Action, 2010). The international literature (Ti, Tzemis & Buxton, 2012; Fischer & Neale, 2008; Patterson, Weaver, Agath, et al., 2009; Patterson, Weaver & Crawford, 2010) highlights a number of perennial challenges and barriers: the deleterious impact of stigma and discrimination; unequal staff—service-user power relations; and the persistence of enduring stereotypes held by staff about people who inject drugs. The latter are themselves often underpinned by a ‘deficit model’ philosophy (Treloar & Holt, 2006): a perception that the person seeking drug treatment is necessarily deficient, defective or somehow lacking.

Important consumer participation initiatives such as AIVL’s Treatment Service Users (TSU) Project 1 and 2 and NUAA’s The CHANGE Project have provided valuable insights into the conditions, barriers and challenges within the Australian AOD context (Rance & Treloar, 2015; Australian Injecting and Illicit Drug Users League (AIVL), 2008, Wilson, Morris, Rance, & Treloar (2013). Notwithstanding the inevitable differences across geographic location (regional, inner urban, NSW, WA etc.), treatment modality (residential rehabilitation, opioid substitution therapy etc.) and individual organisational cultures, the findings from TSU1 and 2 and CHANGE confirmed many of the barriers and challenges identified in the international literature (above). These reports highlight the need for increased awareness and understanding of consumer participation among both staff and consumers; the need to explicitly acknowledge and better understand how ‘power’ and ‘power relations’ operate within AOD organisational contexts; and the imperative to make consumer participation ‘core business’ within services. Despite the considerable challenges facing consumer participation within the AOD sector, a number of positive outcomes from both TSU1 and 2 and CHANGE were identified. For service users, the opportunity to have ‘a voice’ began to disrupt the routine objectification or dehumanisation that consistently, if unintentionally, characterise the treatment experience. Having a voice, it seemed, was synonymous with being human, with having ones’ ‘humanness’ recognised (Rance & Treloar, 2015).

The NADA Consumer Participation Project built on these previous projects and included a thorough evaluation component to the project. The NADA consumer participation project aimed, with training and support, to enable service providers to build the capacity of consumers to inform their own treatment and treatment service at a range of different

levels. For the wider AOD field in NSW this project and the evaluation report will provide insight about the future pathways for consumer engagement.

EVALUATION FRAMEWORK

A team from the Centre for Social Research in Health (CSRH) submitted an expression of interest to evaluate NADA's Consumer Participation Project with the following proposed methods. As the evaluation developed the methods were adapted slightly to reflect service participation, practices and project implementation in the field.

Development of an evaluation framework and evaluation measures

The development of an evaluation framework was conducted collaboratively in consultation with NADA once the five pilot sites had been selected over the first few months of the project. The context and setting of the sites will determined how the Consumer Participation project and the concurrent evaluation were implemented. As requested, the assessment procedure contained scope for tailoring to individual sites. Additionally, clear aims and objectives of the project and the evaluation were established through this early consultation process prior to implementation of the evaluation in order to ensure that the methods developed addressed the research questions/aims of the project.

The measures used in the study were developed in consultation with NADA and the Project Advisory Group. Where relevant, each measure has been slightly tailored to the specifics of the treatment site. Measures will be borrowed from previous quantitative surveys that the evaluation team have conducted about consumer participations (see Bryant et al, 2008a; Bryant et al 2008b; Brener et al 2009, references 1-3). Specific measures have also been developed to assess consumer satisfaction and perceptions of the service.

Survey measures

A survey was conducted with staff at the sites where the consumer participation was rolled out. Initially attempts were made to engage staff prior to the start of the project with the aim of conducting a follow up survey 3-4 months into the project. However difficulties in data collection (see below) made this impossible and hence only one survey administration early on in the project was undertaken. The survey was brief and included measures used in our previous research assessing experiences of consumer participation (and other measures), including perceptions of the service, satisfaction with the service, attitudes towards staff, and treatment experiences.

Qualitative measures

Client interviews: Interviews were undertaken at pre and post implementation of the Consumer Participation project with clients and staff at all five sites. The interviews explored participant experiences and perceptions of consumer participation activities, including benefits, limitations, and experience and/or perceptions of changes. Participants were

reimbursed with a \$30 Coles Myer voucher to thank them for their time in participating in the interview.

Staff interviews: one or two key staff members at each site were undertaken to explore their perceptions of the implementation of the Consumer Participation service and the perceived benefits and limitations for the service, the staff and the clients.

Key stakeholders and trainer interviews: A number of stakeholders and trainers involved in the establishment of this project were interviewed in order to understand how the project developed. This information is used to frame an understanding of the perceived significance of the project as well as whether the aims of the project are being met through its delivery and implementation.

SURVEY COMPONENT

Methods

An online survey was conducted among the staff members of the five service organisations. All staff members, regardless of whether they had participated in the Consumer Participation Project training, were invited to participate in the survey through the email lists of the service organisations. A link to the online survey was incorporated into these emails. Once they clicked on the link, participants read detailed information about the study to ensure that they were eligible and comfortable to take part. In addition, descriptive information was provided about the purpose, the investigators and the funders of the study. The survey was anonymous, and it took approximately 10-15 minutes to complete. Contact details of the Chief Investigator was provided should further information or assistance be required. Eligible and interested participants gave consent by completing the survey.

The first email invitation was sent to services on the 16th of October 2018. The response rate was low which prompted a follow up invitation on the 24th October 2018. By 12th November 2018, only 12 persons had completed the survey. The response rate increased to 42 after another reminder was sent on the 11th December 2018. At the end of January 2019, two more emails were sent across the organisations to remind participants about the survey. By April 2019, a total of 76 responses were received. In a bid to increase the response rate, the research team sent paper copies of the survey to two organisations with the lowest response rates. Ten persons responded from one of these services, but no response was received from the other. This was largely due to the fact that a key staff member left the service and it was difficult to engage with the new person in this role, as a result we received no further surveys from this service. Overall, 86 people participated in the survey.

Measures

This survey was developed as part of the process of the evaluation of NADA Consumer Participation project and was conducted early on in the roll out of the Consumer Participation Project after staff members had undertaken the training. The survey was designed to assess staff views and understanding about consumer participation. Items were designed to elicit staff beliefs about consumer participation, including whether their service engaged in different types and levels of consumer participation activities. The aim was also to explore any differences between those staff members who were involved in the NADA consumer participation training and those who were not.

A definition for consumer participation was adapted from current relevant literature to assist with interpretation of data. A central feature is the recognition of varying degrees of consumer involvement: from low degree (such as information sharing or suggestion boxes), to mid-degree (such as active participation without decision making) to high degree (such as shared decision making in matters regarding staff recruitment, for example).

Survey items

Respondents were asked whether or not they had been involved in the consumer participation training delivered by NADA staff.

Questions included attitudes and beliefs around consumer participation and complaint procedures. The questionnaire included 11 items used to measure beliefs about why consumers do not choose to engage in consumer participation in their AOD treatment facility. Respondents were asked the extent to which they agreed or disagreed with the reasons why consumers do not engage in consumer participation; for example, “I believe that consumers do not choose to engage in consumer participation in their AOD treatment facility because they feel too vulnerable”. These questions were responded to on a 5-point scale ranging from strongly disagree (1) to strongly agree (5).

Several items were synthesised to form a scale. These scales provided information on attitudes towards consumer participation in service planning and/or delivery, current levels of consumer participation, high versus low levels of consumer participations, and measuring changes as a result of the consumer participation project. These scales are outlined in more detail below.

Scale for attitudes towards consumer participation in service planning and/or delivery

This is a six item scales used to measure attitudes towards consumer participation in service planning and/or delivery; for example, *I believe the following will happen if consumers are involved in the service planning and/or delivery - less burnout and stress for the staff of those services*. Responses were provided on a 5-point scale from strongly disagree (1) to

strongly agree (5), with higher scores indicating greater support for consumer participation. Three of the items were reverse scored. The scale showed good internal reliability ($\alpha=.75$).

Scale for current levels of consumer participation

This scale is comprised of seven items used to measure current levels of consumer participation in their AOD facility. For example, *are consumers involved in the hiring decisions of your agency's staff?* and *Does your service sponsor events/forums that educate consumers about their rights and entitlements?* Responses were provided on a 5-point scale from never (1) to always (5) with higher score indicating a high level of consumer participation. The scale showed very good internal reliability ($\alpha=.822$).

Scale measuring beliefs around consumer participation

Nine items were used to measure the degree that staff members believed consumers should participate in their AOD service. For example, *Consumers should be involved in the planning and delivery of all staff education and professional development sessions* and *Consumers should always be involved in the evaluation and diagnosis of their presenting problem*. Responses were given on a five-point scale from strongly disagree (1) to strongly agree (5) with higher scores indicating a desire for greater levels of consumer participation in all areas of the AOD facility. Two items were reverse scored. The scale showed good internal reliability ($\alpha=.76$).

Scale measuring changes as a result of this consumer participation project

This scale comprised six items that measured feelings around how their service would fair if consumer participation was rolled out in their service for example *I think my service will implement a range of consumer participation activities as part of this consumer participation project* and *I think there will be only small improvements in client treatment outcomes as a result of implementing this consumer participation project*. Responses were measured on a five-point scale from strongly disagree (1) to strongly agree (5) with higher scores indicating more positive change as a result of this consumer participation project. Three items were reverse score. The scale showed good internal reliability ($\alpha=.78$).

Other questions

Participants were asked eight questions around complaint procedures. These items were dichotomous (yes/no) for example *Does this service have a suggestion box where clients can give feedback and ideas about services and programs?* There were also other questions around complaints, treatment responsibility, staff monitoring and consumer representatives such as, *What are the other ways for clients to make a complaint about services?* and *In most cases, where does the responsibility for deciding the goals of treatment usually lie?* Demographic data were also collected.

Results from survey

A total of 86 participants completed the online survey: 20 from Service 1 (23.3%), 20 from Service 2 (23.3%), 12 from Service 3(14%), 4 from Service 4 (4.7%), and 30 from Service 5 (34.9%). Even though 71% of staff members who completed this survey had held their current position for an average of two years or less, 59.3% had been working (paid or unpaid) in the AOD field for three years or longer. Almost three-quarters of the participants' (74.4%) work was reported to be in the field of service delivery. See Table 1 for further information on demographic and participant details.

Table 1: Participants' socio-demographic characteristics

Socio-demographic characteristics	(N=86)	Percentage (%)
<i>Gender</i>		
Men	40	46.5
Women	46	53.5
<i>Age group (years)</i>		
20-29	12	13.9
30-39	26	30.2
40-49	23	26.7
50 or older	25	29.1
<i>Highest attained educational level</i>		
Secondary school	2	2.3
Undergraduate/TAFE certificate or Diploma	34	39.5
Bachelor's degree	29	33.7
Post-graduate degree	9	10.5
Master's degree	10	11.6
PhD/Doctorate	2	2.3
<i>Employment Role</i>		
Full time (30-40 hours a week)	62	72.1
Part time	15	17.4
Casual or temporary	9	10.5
<i>Duration of work in current role</i>		
less than one year	32	37.2
1-2 years	29	33.7
3 to 5 years	15	17.4
6 to 9 years	4	4.7
10 years or more	6	7.0
<i>Duration of work in <u>any</u> AOD service role</i>		
less than one year	16	18.6
1-2 years	19	22.1
3 to 5 years	22	25.6
6 to 9 years	11	12.8
10 years or more	18	20.9

<i>Current Service Organisation of staff member</i>		
Service 1	20	23.3
Service 2	20	23.3
Service 3	12	14.0
Service 4	4	4.7
Service 5	30	34.9
<i>Role in the Current Service Organisation</i>		
Service delivery	64	74.4
Service development/ management	8	9.3
Administration	6	7.0
Governance	1	1.2
Other (e.g. counselling, nursing, support work)	7	8.1

Of the 86 participants who completed the surveys, 31 staff members (36%) took part in the Consumer Participation training delivered by NADA staff and consumer representatives.

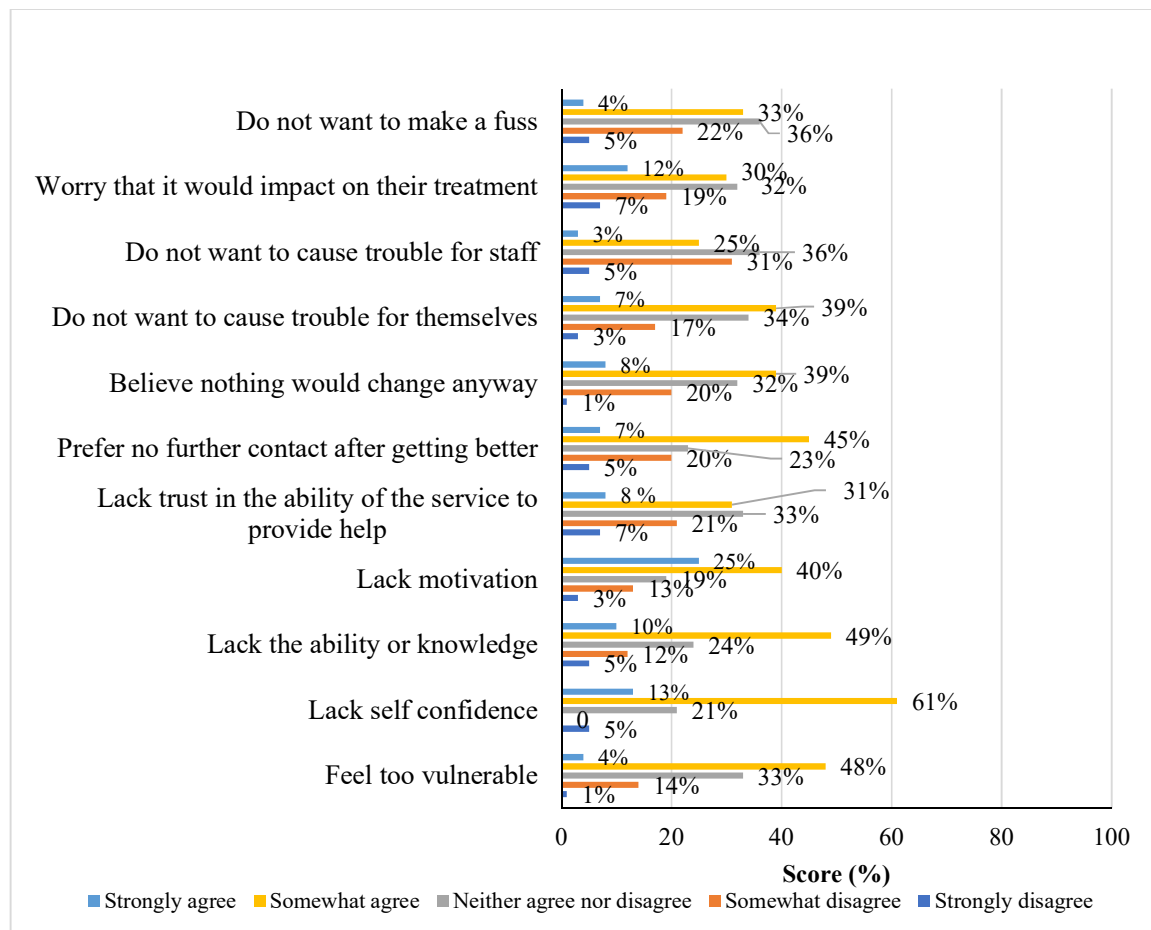
Staff members who had been working in their current positions for longer periods of time were statistically more likely to have taken part in the consumer participation training [$t(84)=-2.317$, $p=0.023$]. This suggests that staff who are more stable in the work environment are more likely to engage in consumer participation.

Of the 86 staff members who took part in the survey, 46% reported that they do not receive any mentoring in their current role while 29% receive group mentoring and 21% receive one on one mentoring. While the majority of staff members were unsure as to why they did not receive mentoring in their current roles, unfavourable work shifts (10%) and inappropriate supervisors (10%) were cited as the main reasons by the remainder.

Beliefs about why consumers do not engage in consumer participation in their AOD treatment facility

The survey assessed staff beliefs about why consumers do not or would not engage in consumer participation. The majority (74%) of the 86 participants felt that consumers do not engage in consumer participation in their AOD treatment facilities because they lack confidence. Other reasons commonly cited included lack of motivation (65%) lack of ability or knowledge (59%) and preferring no further contact after getting better (52%) (see figure 1). These reasons that are most frequently agreed upon appear to be more centred around the consumer as opposed to the actual service.

Figure 1: Bar Graph showing responses to statements about why consumers do NOT engage in consumer participation in their AOD treatment facilities



An independent samples t-test was conducted to compare beliefs about why consumers do not engage in consumer participation in their AOD treatment facility among those staff members who participated in the consumer participation training project against those who did not partake in the training. What is interesting to note is that participants who took part in the training were significantly more likely to believe that **consumers** do not choose to engage in consumer participation because:

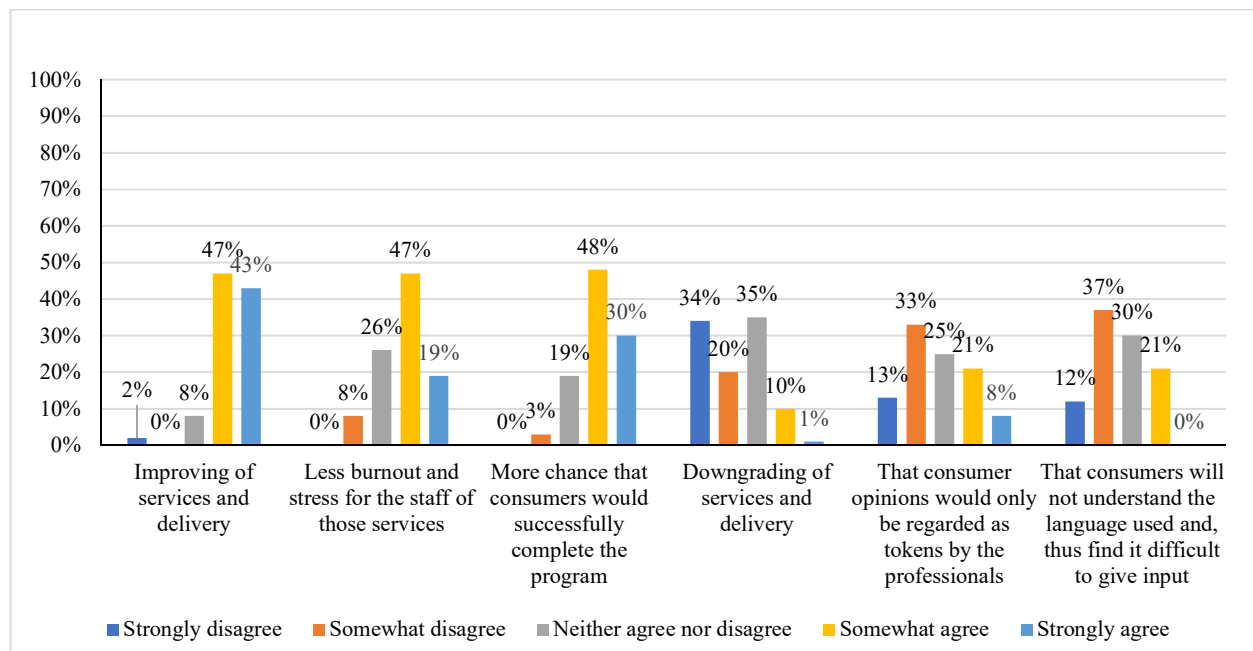
- 1) consumers lack trust in the ability of the service to provide help [t (74) = -2.113, p=0.038]
- 2) consumers believe nothing would change anyway [t(75) = -2.775, p=0.007]
- 3) consumers do not want to cause trouble for staff [t(75) = -2.747, p=0.008]
- 4) consumers worry that it would impact on their treatment [t(75) = -2.138, p=0.036]

The above four reasons as to why consumers do not or would not engage in consumer participation selected by those staff who had undertaken the training appear to be more

focused on issues related to the service and rather than on consumer related factors. This focus on issues relating to the service is in contrast to the staff who did not undertake training. In the case of the latter, these staff members tended to cite reasons for consumer non-engagement as related to the consumers themselves. This suggests that staff who have undertaken training develop a better understanding of and sensitivity towards consumers.

The survey included items assessing beliefs as to what would happen if consumers were involved in service planning and/or delivery. The majority of participants agreed that if consumers were more involved, it would result in an improvement in service and delivery (90%), there would be more chance that consumers would successfully complete the program (78%) and there would be less burnout and stress for staff (66%). See figure 2 for more details.

Figure 2: Bar Graph showing responses to statements about what is expected if consumers are involved in service planning and/or delivery

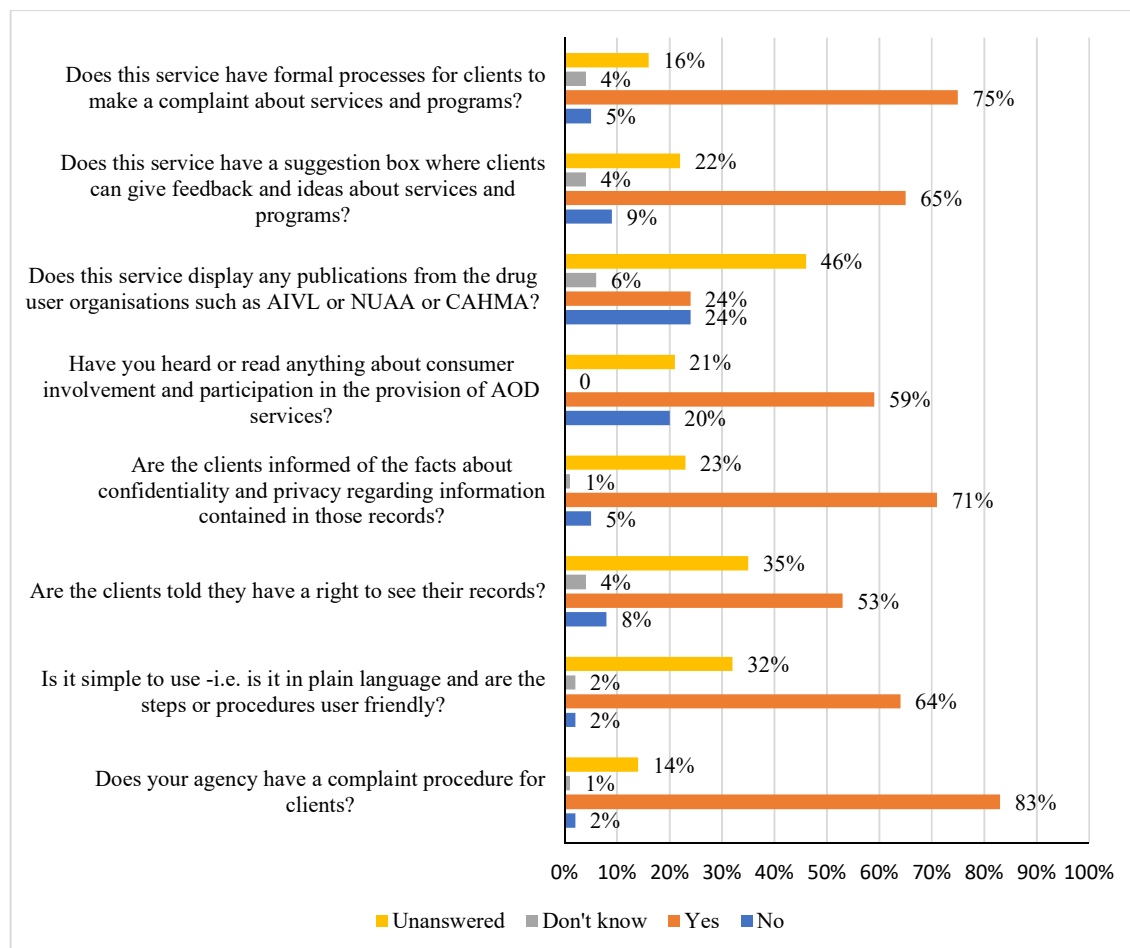


An independent-samples t-test was conducted to compare attitudes towards consumer participation in service planning and/or delivery among those staff members who participated in the consumer participation training project against those who did not partake in the training. Participants who took part in the training were significantly more likely to agree that consumer opinions would only be regarded as tokens by the professionals if consumers are to become more involved in the service planning and/or delivery ($t(74) = -2.220, p=0.029$). This may suggest some implied criticism of fellow colleagues whom staff members perceive to be cynical about consumer participation initiatives.

Complaint Procedures

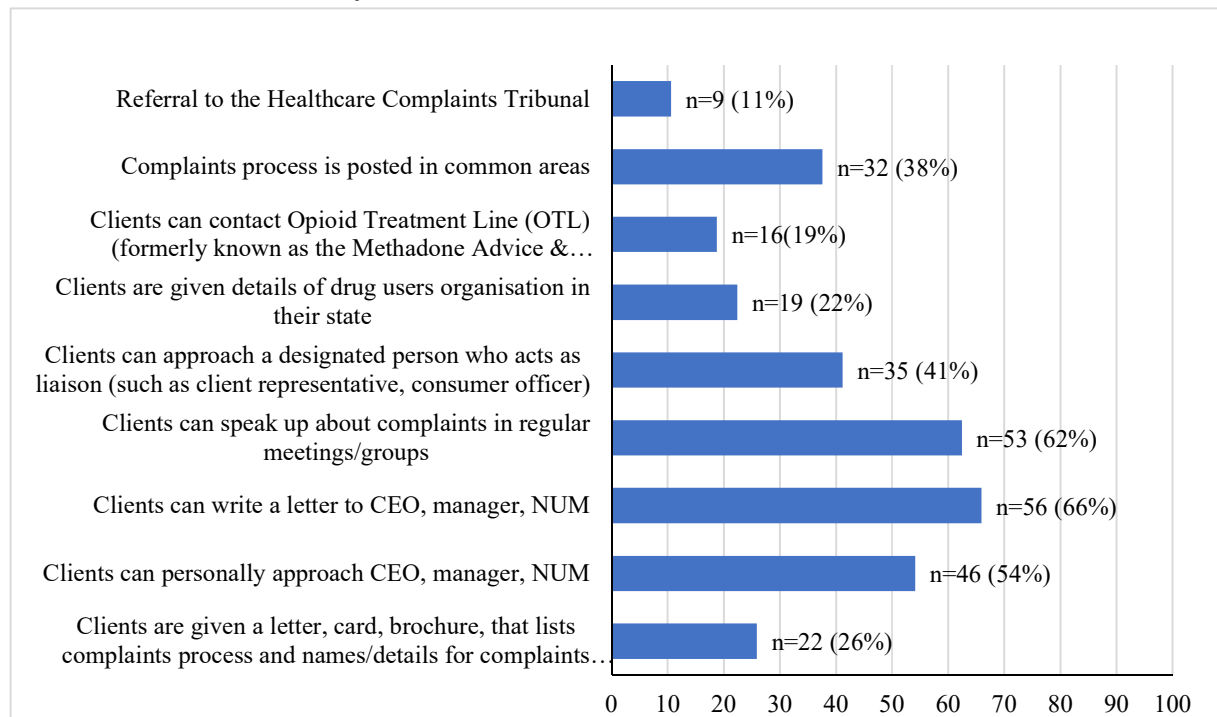
Respondents were aware that consumers had avenues to make complaints or raise concerns within their organisations. Staff were asked several questions around their knowledge of complaints procedures within their organisations. The majority of the sample (83%) knew their service had a complaint procedure for consumers, with 64% reporting that it was simple to use (see figure 3 for more details). However, it is worth noting that when participants were asked whether they had heard or read anything about consumer involvement and participation in the provision of AOD services, 20% of respondents replied *no* suggesting that some staff did not perceive complaints procedures as part of consumer participation. Staff members who had taken part in the consumer participation training were significantly more likely to have had heard or read anything about consumer involvement and participation in the provision of AOD services [$t(66)=-2.333$, $p=0.023$].

Figure 3: Bar Graph showing responses to general questions about complaint procedures



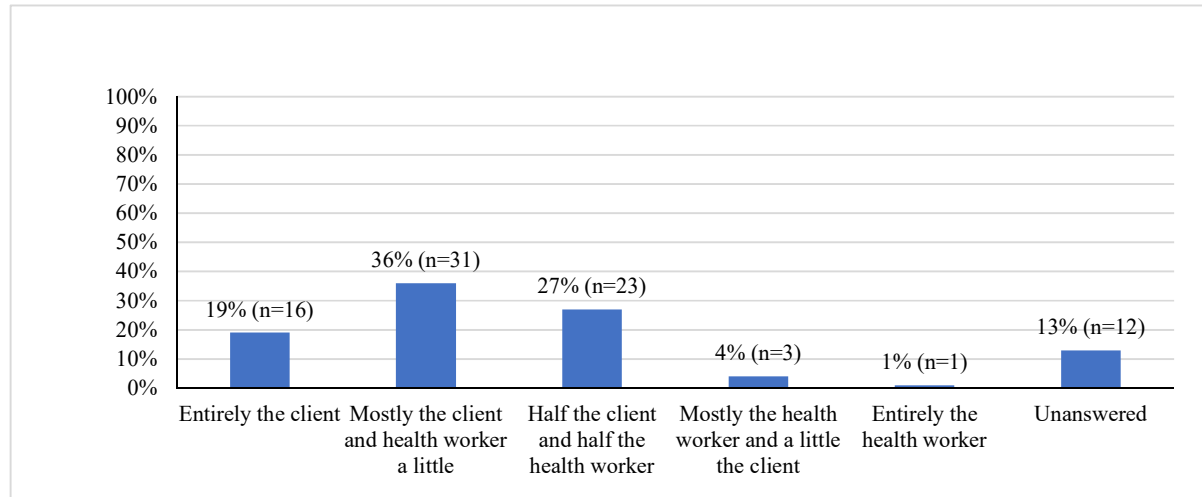
Participants were also asked about other ways that consumers can make a complaint about a service. Two-thirds of participants reported that consumers can write a letter to the CEO and 62% reported they can speak up about complaints in regular meetings or groups. Only 11% were aware of the option for a referral to the Healthcare Complaints Tribunal. See Figure 4 for more details.

Figure 4: Bar Graph showing percentage of participants who were aware of other ways consumers can make a complaint about services



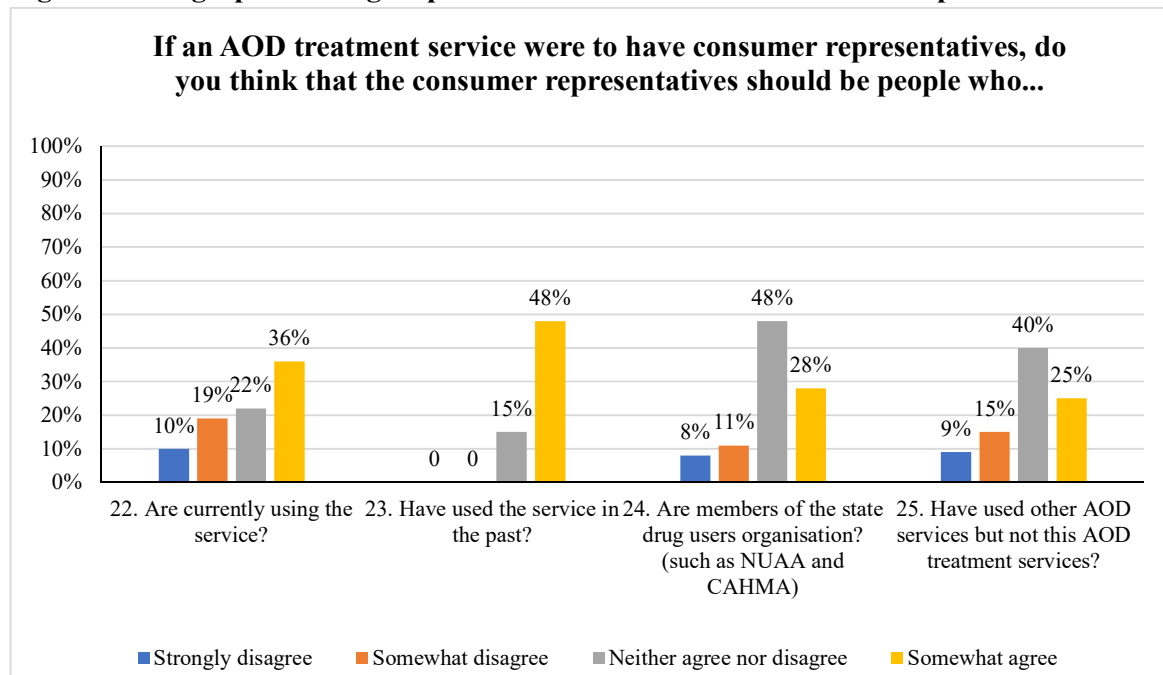
Participants were asked a question around where the responsibility for setting treatment goals lies: with the consumer, health worker or both? Over one-third (36%) of participants reported that this responsibility lies with the consumers and a little with the health worker. Only one participant reported that the responsibility lies entirely with the health worker (see Figure 5 below). The amount of flexibility around goal setting is generally laid out in a service's guidelines. A positive sign of consumer participation is that consumers are permitted to set their own goals for treatment, however it is important to be aware of the flipside in that consumers may be seen as "responsible" when they fail to achieve their goals.

Figure 5: Bar graph showing where responsibility for deciding the goals of treatment lie



In order to assess staff participant feelings about consumer's suitability as consumer participation representatives in AOD treatment, participants were asked who they felt should represent consumers in an AOD service. Forty percent of participants felt that the consumer should have used the service in the past and 36% felt the consumer should be currently using the service (see Figure 6). Participants who had taken part in the consumer participation training were significantly more likely to agree that consumers should have used the service in the past [$t(73) = -2.173, p = 0.033$].

Figure 6: Bar graph showing responses to statements about consumer representatives



Current levels of consumer participation in services

Current literature generally classifies consumer participation along a continuum from ‘low’ degree involvement (such as information provision) to ‘high’ degree involvement (such as decision-making). This survey included seven items asking respondents about different consumer participation activities that their service offers. Responses to these items were provided on a 5-point scale (from never or rarely, to sometimes or always) with higher scores indicating greater participation. These activities have been classified according to the degrees of consumer participation. For the purpose of the table below, participants who responded *Every once in a while*, *Sometimes* and *Always* were grouped together to represent *consumer participation activities offered by the service*. Participants who responded *Never* or *Rarely* were classified as *activities not offered by the service*. Within all five services there was variability in the way that staff members within the same service responded to each item, indicating either a lack of knowledge among staff members of the various ways consumers are involved in the service or information around consumer involvement not being shared among all staff. See Table 2 for details on consumer participation activities offered by services according to degree of involvement.

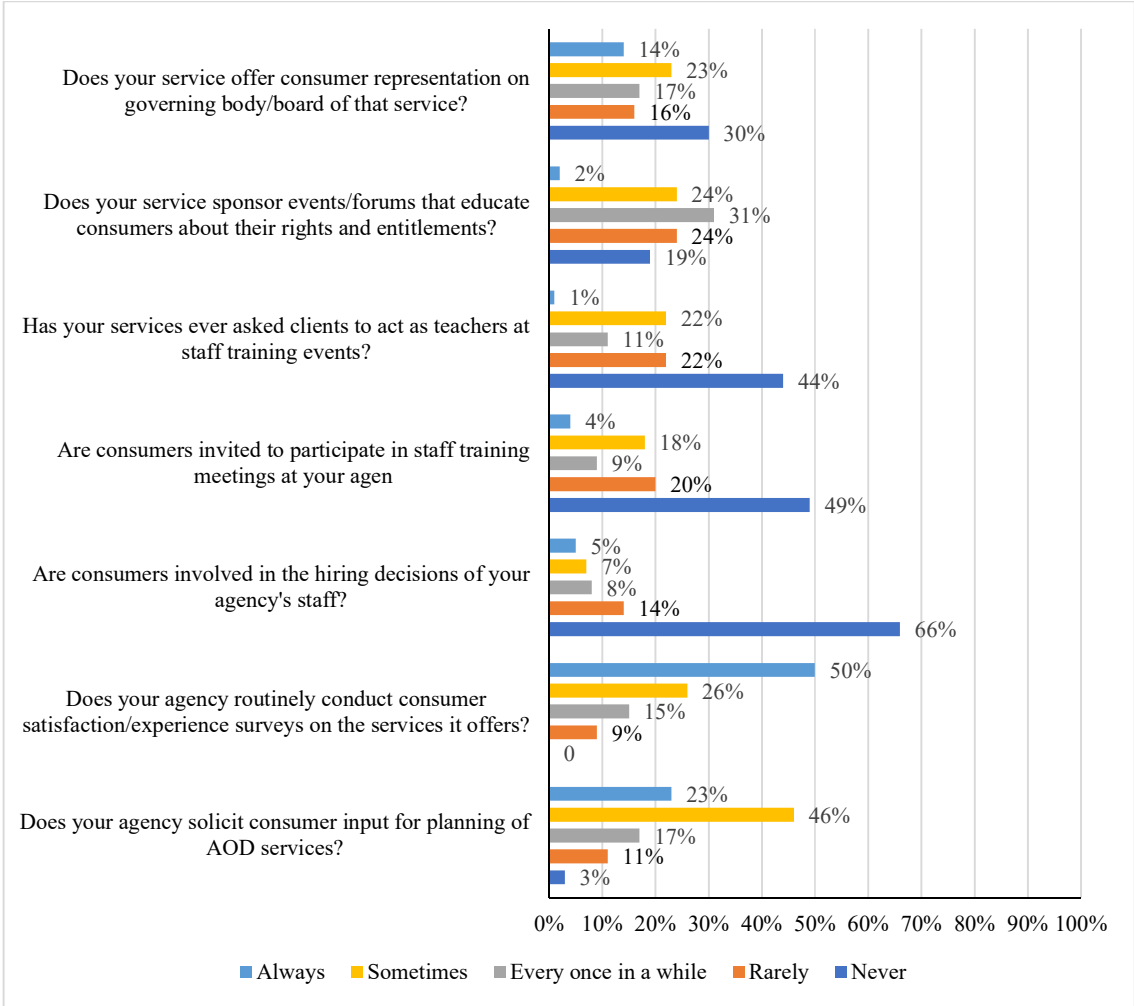
Table 2: Consumer participation activities offered by services

Degree	Type of activity	Example	Activities offered by services n (%) n=74	Activities NOT offered by services n(%) n=74
High	Activities in which consumers play a decision-making role	Representation on governing body	38(54.3)	32(45.7)
		Hiring of agency staff	15(20.3)	59(79.7)
		Solicits consumer input for planning	65 (86.7)	10(13.3)
	Activities in which consumer play a non-decision-making role	Act as teachers at staff training	25(34.2)	48(65.8)
		Invited to participate in staff training meetings	23(31.1)	51(68.9)
Low	Activities concerned with providing information to or receiving information from consumers	Consumer forums	42(56.8)	32(43.2)
		Surveys	67(90.5)	7(9.5)

The above findings suggest that services generally tend to offer “lower” level consumer participation activities such as surveys and consumer forums. This finding is consistent with the literature (Bryant et al., 2008; Hinton 2010; Treloar et al.,2011) which suggests that while consumer participation activities are relatively commonplace in AOD services they are

largely “low” involvement activities concerned with providing information to or receiving information from consumers. Importantly, however, our study did demonstrate some good support for some “high” involvement activities. For example, soliciting consumer input for planning — generally considered to be a high degree involvement activity — was well supported by services, with 86.7% responding positively and over half the sample indicating their service’s willingness to offer consumer representation on their governing body or board. Findings in relation to these particular services suggests there has been a slight shift over the past decade from only low involvement activities to activities that include consumer representation in the decision-making processes. See Figure 7 for more details.

Figure 7: Bar Graph showing participants views about some general questions

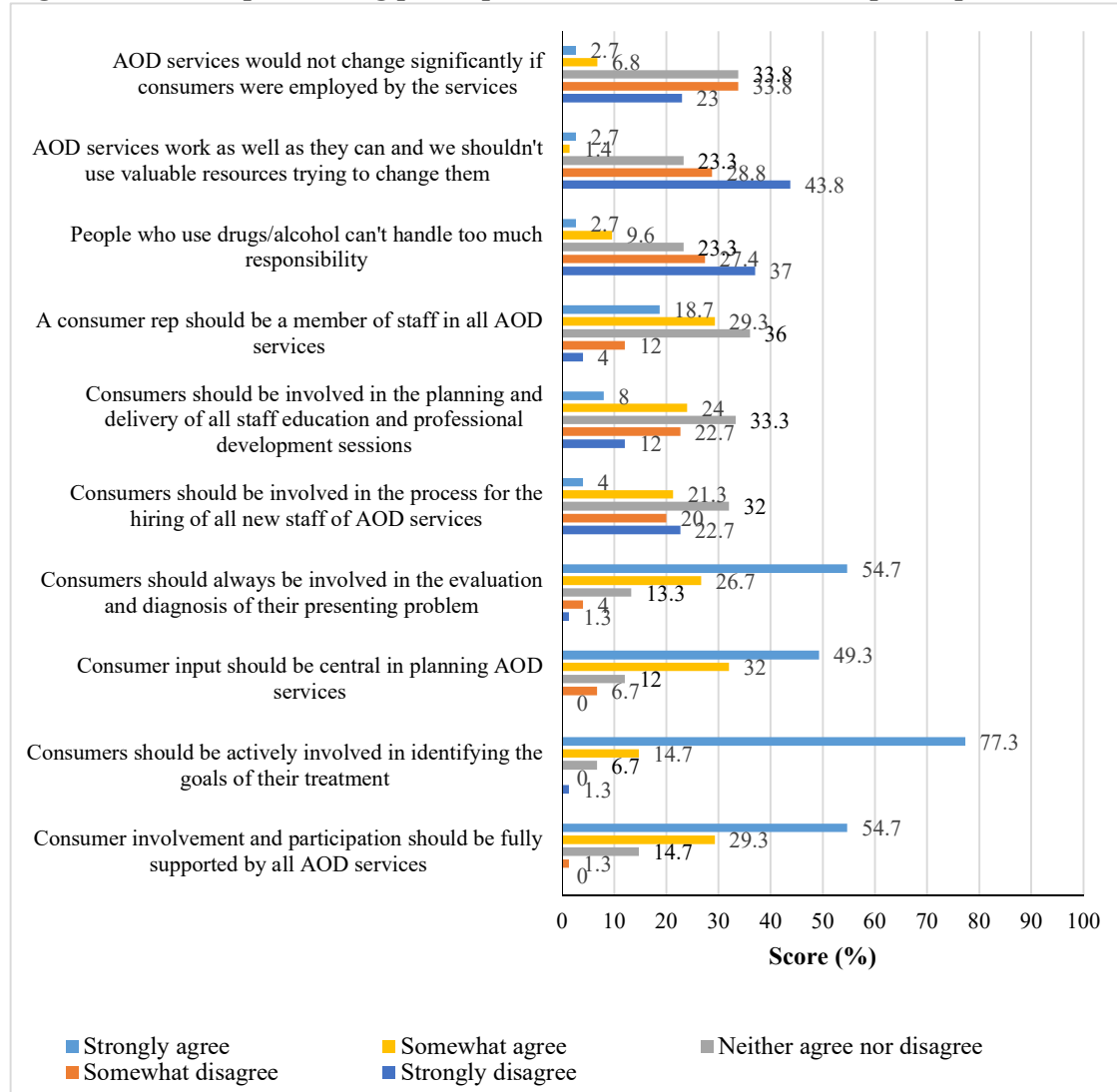


Views on Consumer Participation

Participants were asked their views around consumers’ involvement in AOD services. The majority of participants agreed that consumers should be actively involved in identifying the goals of their treatment and should always be involved in the evaluation and diagnosis of

their presenting problem. Only 12% of participants agreed or strongly agreed that people who use drug or alcohol can't handle too much responsibility. In addition, less than 10% of staff members felt that AOD services would not change significantly if consumers were employed by the service and only 4% agreed that AOD services work as well as they can and that valuable resources shouldn't be used to try and change them (see figure 8 for more details). There were no significant differences in opinions between those staff members who had taken part in the training and those who had not.

Figure 8: Bar Graph showing participants views around consumer participation



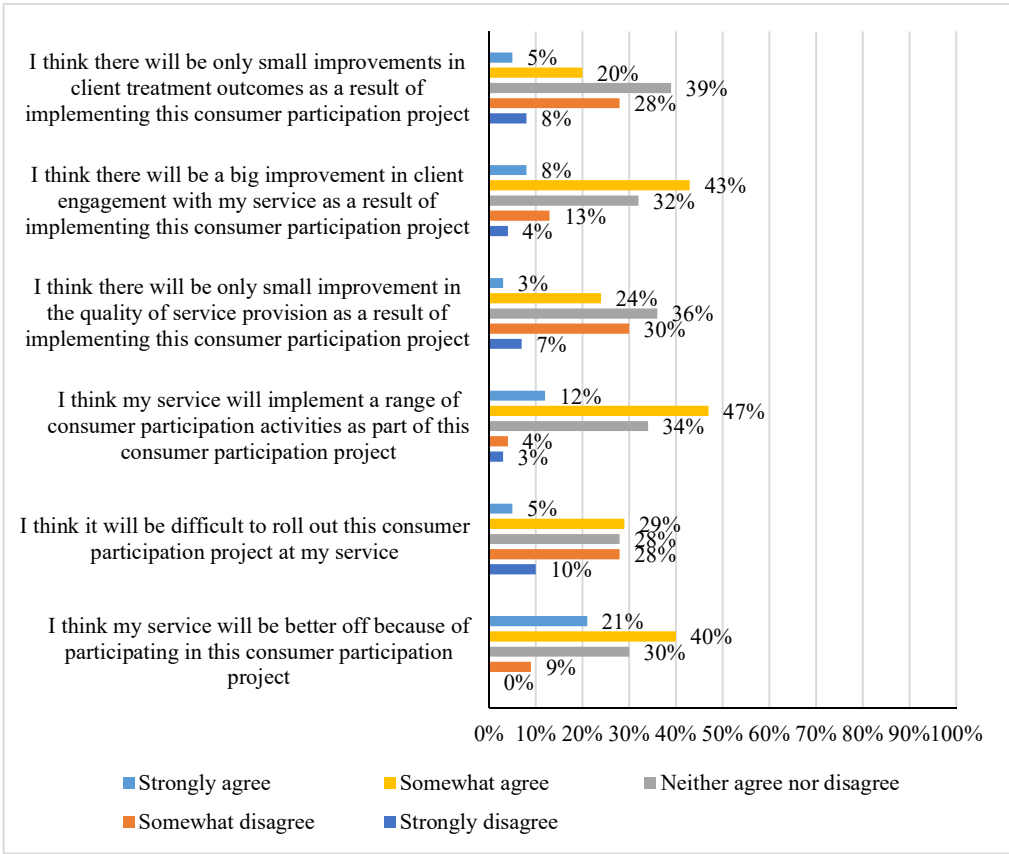
Changes to services as a result of the Consumer Participation Project

Participants were asked how they felt AOD services would change if consumers were involved. Twenty-eight staff members (36.8%) believed that AOD services would improve a lot if consumers were employed by the service to represent consumers concerns and 38

staff members (50%) felt that services would improve a little. Only 3 participants (3.9%) reported that they felt services would worsen a little as a result of consumers being employed to represent consumer concerns. Ten staff members did not answer this question. The majority of the sample (86.9%) felt that AOD services would improve if consumers were involved in the planning and/or delivery of those services.

Fifty-nine percent of staff members believed that their service would implement a range of consumer participation activities as part of this consumer participation project. More than half of all the participants (51%) felt that there would be big improvements in consumer engagement with services as a result of having implemented the Consumer Participation Project. There was no significant difference in opinions between those who had taken part in the consumer participation training and those that had not.

Figure 14: Bar Graph showing participants views on changes as a result of the Consumer Participation Project



Significant relationships

To investigate the relationships among the four scales (attitudes towards consumer participation in service planning and/or delivery, current levels of consumer participation, beliefs around consumer participation and changes as a result of consumer participation

project) correlations were conducted. As can be seen in table 3 below there were significant relationships between staff members attitudes towards consumers being involved in service planning and/or delivery, current consumer participation in their services, beliefs around consumer participation and changes that would result from this consumer participation project being rolled out in their service. Hence what this analysis indicates is that the more positive staff members' attitudes are towards consumers being involved in the service planning and delivery, the greater the level of current consumer participation in the service and the more these staff members feel that their service would show positive changes as a result of participating in the current Consumer Participation Project.

Table 3: Correlations between consumer participation scales

	Attitudes towards consumer participation in service planning and/or delivery	Current levels of consumer participation	Beliefs around consumer participation
Current levels of consumer participation	.329**		
Beliefs around consumer participation	.472***	.336**	
Changes as a result of consumer participation project	.506***	.342**	.601***

** Correlation is significant at the 0.01 level (2 tailed)

*** Correlation is significant at the 0.001 level (2 tailed)

INTERVIEW COMPONENT

Methods

From October 2018 to May 2019, in depth interviews were undertaken with AOD Service consumers, staff and stakeholders, to fulfil the qualitative component of the evaluation. Interested consumers were directed to the researcher who made contact to arrange a convenient time, date and process for the interview (telephone or face to face) and to explain the consent and privacy protocols. A list of potential staff members and stakeholder recruits was prepared by NADA, and then contacted directly by the researcher through an open email invitation. Interviews emulated a conversation and were designed to be a warm and non-judgmental forum through which respondents could describe their treatment experiences, prior knowledge of consumer participation, and any information they viewed as pertinent. The interviews with consumers were undertaken pre- and post-training, and our sample includes five people who undertook an interview at each time point. We also

sought interviews with consumers who would not attend the training workshop, to gauge their perceptions. In the post training interviews, the questions were repeated to ascertain participants' experience of the training session and any noted changes in service delivery. These data complement survey responses, and provide qualitative detail about the training and treatment experience from the perspectives of those with lived experiences and 'insider' knowledge.

Interviews were transcribed verbatim, checked and de-identified. For the consumer interviews, pseudonyms replace real names. The staff sample is small, which presents risks for their confidentiality, so numbers are used to denote their quotes when we present their interview data. The interviewer read and re-read the transcripts to generate preliminary topics (codes) across the data set, both in relation to the interview schedule and more broadly, and to look for expressions of consensus and dissonance. This coding frame was shared with the broader research team to check for salience and relevance to the overall research questions. The approved coding frame was then applied to the entire data set. Ongoing analysis sought to generate themes relating to the key questions. Using Interpretive Description (Thorne, 2006), analysis is sensitized by the research questions and practical needs of the service. The foreknowledge of the researchers is also used to interpret the findings so that the content of this report is applicable to practice settings. Approval for the conduct in the study was provided by the UNSW Ethics Committee.

In this section, we describe the broad demographic categories of participants, before outlining the findings. We have separated the consumer data and professional data, and provide an outline of the professionals in that latter section. An overview of these findings will be discussed at the end.

Consumer participant profile

In all, 27 consumers undertook an interview. Thirteen participants provided an interview at the pre-training time-point, and 14 undertook an interview at the post-training stage. Of these, five participants were interviewed twice, before and after training. Most of the participants had undertaken multiple treatment episodes with only three participants attending an AOD service for the first time. As such, participants provided information about these various experiences and were able to compare their experiences at each and how this intersected with Consumer Participation perceptions and experiences.

The majority of participants were male (n=15). Most were in the 39-45 age range (n=11), with participants ranging in age from 26 years to their mid-60s. When asked about their cultural heritage, most described themselves as an "Anglo-Australian" (n=21), but two participants identified as Aboriginal, one as a Torres Strait Islander, and one participant identified as "Pacific Islander". The sample also includes participants who described themselves as Lebanese and Polish. Participants were asked about their current

employment status and their previous professional experiences. The majority were unemployed at the time of the interview (n=19) and others were casually employed (n=2) or working as an unpaid carer (n=2). One participant was studying at TAFE. The unemployed participants had often taken a leave of absence prior to entering treatment, and three were collecting a Disability Support Pension. Prior to entering treatment, most participants had worked in low paid employment, or insecure physically demanding work such as line marking (road work) and abattoirs. Two had had professional careers in the civil service or a clerical position.

Ultimately, data collection from each cohort was challenging and took longer than expected. While consumers tended to communicate directly with the researcher, to arrange their input, making contact with these participants required an in-service intermediary to broker contact. This was hampered by a lack of email and phone contact, high staff turnover within some workplaces, or significant structural change at one key service (which led to significant challenges in contacting staff and consumers at the post training time point). In some cases, delays related to the postponement of the training itself. In other cases, the researcher was required to recruit and interview trainees at very short notice due to the training schedule and the need to capture pre-training data, which is highly time sensitive. In one service, the researcher was able to communicate directly with a key professional and negotiated a field trip to collect interviews in person. The researcher was allocated a room and could invite and interview interested parties on site. This was particularly efficient, and where booked participants did not attend, alternative participants could be sourced at short notice. This also seems to reflect the experience of the trainers and project coordinators, in that, onsite tasks required the collaboration of staff members based on site.

Pre- and Post- training consumer interviews

In what follows, we report on findings that relate to the key research questions for this study: prior knowledge and experience of consumer participation; the perceived strengths and weaknesses of the model; outcomes including the witnessed changes as a result of the training, and descriptions about consumer participation activities at their location; the impact the training had on those involved, including their descriptions of the capacity building effect of consumer participation; perceptions about the barriers, risks and threats to consumer participation, including any opinions about what resources are needed for optimal functioning of the model; and, finally, any recommendations participants made for future implementation. This section includes findings from consumer interviews at the pre- and post-time point.

Findings from consumer interviews

Consistent with findings from a comparable study, implementing consumer participation within AOD settings involves negotiating a series of complex and competing factors (Wilson,

Morris, Rance & Treloar, 2013). While services volunteered to take part in the project, and the associated evaluation, uptake by individual staff onsite was highly variable and often limited. As such, these findings support those of the previous evaluation in that the attitudes and perceptions of key staff are highly influential. In this study, participants tended to view the communication styles as important to consumer participation. Where a participant perceived this communication as functional, they saw little need for consumer participation training. “Communication” remained a key theme in pre and post training interviews. Post-training, however, participants described communication differently and tended to perceive consumer participation as valuable. This seems to be due to low levels of knowledge about what consumer participation is and the forms it can take. Once trainees had undertaken the workshop, their sense of possibilities was expanded.

As with the report by Wilson and colleagues (2013), this evaluation found that prior to the training, consumers had low levels of knowledge about consumer participation, and that knowledge had increased post training. The relationships between consumers and staff were also perceived as improved. While study participants viewed the cash incentive as playing a large role in motivating consumers to take part in the training (and the evaluation activities) a proportion of trainees embraced the model and expressed a desire to continue. Overall, participants interviewed at the pre-training stage used the concept of a feedback loop to describe consumer participation. At the post-training stage, participants felt that feedback from consumers to staff is important. They also felt, however, that their “voice was important” and that their comfort levels with providing feedback had changed. Indeed, some felt that staff had greater respect for them, post training. This was invigorating for participants, and one interviewee requested that her details be forwarded to the consumer participation coordinator at NADA so that she could be formally involved. The model and its training activities seem to foster relational changes within the services, and trust and empathy seemed to increase. Our findings also suggest that relationships between fellow consumers improved, and that consumers used the training within an overarching agenda of self-improvement and skills acquisition.

Participants also discussed the culture of their AOD service setting, and the ways in which this affected their relationships with fellow consumers and staff. The lack of personal space and the often strict or rigid application of rules were challenging for some participants, and this affected their motivation to attend what they perceived to be additional demands on their limited personal time, such as the consumer participation workshops. For others, the power differentials between consumers and staff, and the perceived stigmatisation of “alcoholics and addicts”, was influential and led to low levels of confidence in the model. Those in attendance at the training, however, were heartened by the additional knowledge they gained about their fellow consumers and case workers, and enjoyed the sense of cohesion and mutual empathy this engendered. Feedback about the training and trainers was largely positive.

When reflecting upon the specific shortcoming of the implementation of the Consumer Participation Project, or changes that had or had not occurred as a result of the training, there was a perception there had been a lack of follow up and no concrete activities post-training. Participants struggled to describe additional consumer participation activities or mechanisms taking place, but did seem to be better able to define consumer participation and articulate the benefits for consumers and program designers. Ultimately, participants understood consumer participation to be grounded in communication between consumers and staff and to facilitate feedback loops. This was thought to empower consumers and provide a forum through which they could influence service design so that it would be better quality and regarded well. In what follows, we describe these findings in detail, using interview excerpts, before discussing the implications for future implementation.

Prior knowledge and previous experience with Consumer Participation

Participants seemed to have low levels of knowledge about consumer participation. They often used statements like “I know nothing” or “none whatsoever” when presented with questions about their prior knowledge or experience of the model. This was even the case for a participant who had undertaken a consumer participation workshop in past treatment episodes. For example, Liam (pre-training) said he knew “not a great deal. I did a workshop at IDAT before.” The lack of prior knowledge about consumer participation seems to be due to a lack of exposure but also a lack of knowledge retention for people who had undertaken different training in past settings. Shane (pre-training) was signed up for the training and was not confident about what to expect, but he guessed, and his speculations included the benefits he might experience for his ongoing treatment and aftercare:

I really don't have any understanding about what tomorrow is about, I would say, it's probably about people that need to get resources and how I can obtain them that kind of thing, that's kind of how I participate in the community and with other services: rehab, drug and alcohol, housing, like that's kind of how we deal with the outside world, kind of thought that must have been what it was, being an addict. I'm not sure.

Similarly, Aaliyah (pre-training) said she had “no knowledge” but speculated about what might be involved. These excerpts suggest that these participants value learning how to communicate effectively with professionals in a service network, so they can access the services they need:

It's basically they teach you how to communicate with somebody and [...] you learn how to take the right steps in life to get to where you want to get [...] they explain to you like when I first came, they explained to me that this is what's basically expected of me as a participant you know.

Their answers also reflect speculation about what is expected of them as community members, both of the service and more broadly. Along with clear and consistent

communication about relational boundaries and service rules, participants valued the capacity building benefits of the workshop. The primary aim, however, of having greater input in to their AOD service delivery, seems to be missing from these responses, as though consumers anticipated the workshops to be part of their “rehabilitation” rather than about their participation within their AOD service. Indeed, Aaliyah’s quote also indicates the ways in which the model might be conflated with other more treatment-oriented activities. Possibly, promotion of the training workshops could be revised so that potential participants are clear on the aims of the training.

A few participants had a better understanding of the aims of the model and its training program. Opal (pre-training interview) said, “Okay, so its people who use the service getting involved in the programs that they provide” and Jade (pre-training interview) said “it’s just a way to grasp short comings in programs and facilities and to gauge [...] how well or not a particular program is doing.” Participants tended to assume that consumer participation was a formal process that enabled a feedback loop between consumers and program providers. This was seen as important. Joel, who had a corporate background, perceived customer feedback as valuable for quality control and program innovation. He said in his pre-training interview:

It’s an opportunity for businesses and/or entities like [NADA] to get a feel of what can be done differently, better, or changes... You get a base line so you don’t just get to the individual, you get, people who have been through it.

In another interview, Wyatt (pre-training interview), a very experienced consumer of AOD services, said:

To be honest, I’m not quite sure what it means as in a definition, but I think it’s about being involved in giving feedback and information about the service and what sort of things I think would be appropriate that aren’t there and what is appropriate that is there, what I think is good, what I think is bad...

Similarly, Mac (pre-training interview) thought that consumer participation “is like a survey, a general consensus of the public about a product or a service... to get a more accurate assessment.” While these responses indicate varying levels of pre-training knowledge about consumer participation, which is arguably to be expected, they also indicate some of the motivation participants held when they signed up. For example, Lola wanted “just to listen and learn and maybe pick up a bit of knowledge I haven’t got.” She often described the training as part of her desire to develop her skills and improve her post treatment outcomes. Having said this, most of the participants stated that they were interested in the training but the cash incentive had been particularly influential in their decision. Indeed, Nigel had used the cash incentive to encourage others to attend “well, for a start, I told them, you get paid” and told fellow consumers that they had nothing to lose in attending.

In post-training interviews, these self-development themes were also evident. Aaliyah reiterated her goals in her second interview and when asked what her interest was in consumer participation now that she had done the workshop, she said “my interest is just to get better.” She seemed to perceive that any training opportunity would facilitate her treatment but did not have any plans to get more involved. Participants who had engaged in consumer participation activities since the training, unsurprisingly, had more detailed and practical knowledge about consumer participation and its benefits and aims. Nigel (post training interview) was attending one service at the time of the interview, but had also been involved in consumer participation groups at another service. He said:

I’m active in one now. [...] the consumer participation group should be ... have the input of whatever the people are asking right? Give them the questions and tell them how we find the services that you supply and how they could be bettered you know? And stigmas, places we know where people get treated better, things like that, helping out others.

For Nigel, consumer participation was one part of a broader set of activities and experiences which enable consumers to be more proactive and engaged in their services. His descriptions of his role were practical, task driven and active. As such, his interview indicates that ongoing workshops and the implementation of practical, task driven activities is a robust approach to consumer participation. His response also demonstrates the potential benefits of experienced fellow consumers relaying information about consumer participation back to trainees. He can draw upon both knowledge and experiences about consumer participation when defining the model to others. Indeed, compared to other participants, Nigel indicated that he really owned the model and was motivated to undertake its associated tasks. In contrast, Jade (post-training interview) felt that consumer participation had not taken off in her service due to the lack of concrete planning after the workshop. She said “I suppose they do get a little bit of consumer’s feedback you know? Us letting them know things that aren’t working, but not hugely, no. I think we need to have a plan implemented.” It seems advisable, then, that additional mechanisms for consumer participation are set up during or soon after the workshop to capitalise on trainee engagement to solidify momentum. This finding is consistent with findings from the CHANGE Evaluation (Wilson et al., 2013), and suggests that if workshops and discussions fail to translate into meaningful actions, it risks seriously undermining not just this specific consumer participation project, but the concept of consumer participation (among both staff and consumers). For staff opposed to the idea of consumer participation, it simply confirms their opposition, including confirming stereotypes about AOD consumers. For consumers, it also risks confirming the doubters, as well as disillusioning the consumer participation advocates.

The model: perceived strengths and weaknesses of Consumer Participation

Participants were also asked to reflect upon the perceived strengths and weaknesses of consumer participation, and its workshops/training. As above, participants tended to respond that the “trainers were really awesome” (Jade, post training interview). In some cases, participants who had been ambivalent about attending were motivated by a respected fellow consumer, or were attending because of the positive reputation of the project coordinator.

Another finding relating to its perceived strengths and weaknesses, related to consumer feedback. Akin to her input outlined in the previous section, Jade (pre-training interview) perceived consumer participation to be positive because:

Staff [members] should be made more aware of what’s lacking in the program and also because when they are not here, they are only looking from the outside in, so they can’t be expected to have knowledge on it. Yeah, I think it’s really crucial for them because they can’t make change without anyone giving them ideas you know.

Similarly, Liam felt that consumer participation would enable consumers to join in their advocacy activities and be more impactful through providing feedback as a group. He said:

I don't know [what consumer participation is exactly], but people who are in the program, if a lot of them have consensus on there is a big problem, like you know some particular aspect of the building or the way it’s being run, I guess, you can all get together and get a chance to you know talk up about it to the powers that be and what not.

As with Joel and Wyatt’s responses, Jade and Liam felt that consumer feedback would enable service improvements and such insights could be used to improve the service and its reputation. Likewise, Aaliyah (pre-training interview) felt that consumer participation was well aligned with the supportive and collaborative approach already evident in her treatment program. When asked about what she viewed as a strength of consumer participation, she said:

One of the good things is that even [other consumers] are there to help you. Just help you through all the hard times and push you through and give you words of wisdom and if I have realized anything that this recovery journey you are not alone.

While consumer participation tends to focus on the potential for positive changes to consumer and staff relations, the potential for mutual support among consumers can be an unintended but positive consequence.

Similarly, Rhonda (post training interview) had had a positive experience at her workshop and was heartened by the level of collaboration and inclusion she witnessed at her session. She said:

Yeah, it was quite interesting... I thought it was good that we done a group one. We got other people's opinions and bit of brainstorming with other people.... there was a man there that was helping me and he'd suffered himself with ... I am pretty sure it was mental illness and I just thought that you know, it was good how that they were involving people that were ... and I wouldn't have known that they had people like that involved if we hadn't done it at "[consumer] participation"

Given that Nigel (post training interview) had had such a positive experience with consumer participation groups previously, he "put the word out" and encouraged other consumers to attend. For other consumers, working with fellow consumers was considered a weakness or threat to the model, and could make these initiatives more challenging. For example, fellow consumers were understood to be at different stages of the program. Tash (post training interview) felt that consumers in the early stages of the program were difficult to train with, and could be potentially triggering to other consumers. She said:

Challenges would be about trying to be in recovery and still dealing with people that are coming in as addicts. I know that's hard for me to see people who are still off their head and stuff, so once you are at the point where you would be working sort of you are mentally strong and equipped to handle that.

For Tash, the workshops should be provided to consumers who are stable with their drug use or no longer using, or alongside consumers who are in a position to manage feelings of temptation when viewing intoxicated consumers. Participants tended to perceive the strength of the model as related to providing a forum through which consumer feedback could be shared. It is also related to the tenets of AOD treatment services, with the emphasis on fellow consumer support. The perceived weaknesses of the model are that consumers were perceived to be distressed and in "turmoil" within AOD settings, and this would make it harder to get the practical aspects of consumer participation underway. Indeed, Rhonda (post training interview) stated that she was finding the other consumers difficult to live with and craved personal space. As such, more tasks involving other consumers were unattractive to her. The communal and collaborative approach to consumer participation training seems to be a double-edged sword and can attract or repel different consumers. For some consumers, the prospect of engaging with fellow consumers may well be repellent. However, consumer participation does not necessarily require an increased involvement with other consumers. The definition of consumer participation as 'the process of involving health consumers in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery of health services' (Commonwealth Department of Health and Aged Care, 1998) implies it is ultimately about creating structures & practices within services that fundamentally re-orientates how they operate and not simply about consumers having a greater role in supporting one another or improving communication. It is possible that providing the

training and follow up activities in a range of mechanisms, such as individual online modules alongside group forums, could enable greater access without the communal approach.

Outcomes and impact of the training, and ongoing initiatives

Participants were invited to reflect on any training outcomes and consumer participation activities they were aware of, both pre- and post-training. The most common example was increased and more effective communication between consumers and staff, and between fellow consumers. Before the training, Rhonda said:

We have a house meeting once a week where we are allowed to express our ideas and what may be beneficial to you know, changes made and that. I find it all pretty good. I don't really know what could be done or needs to be done [with this training].

Similarly, Mitch felt that current feedback loops were sufficient and was not convinced that increased opportunities to participate were warranted. He said in his pre-training interview:

There is already a pretty good format for providing feedback. So, we have like a house check in every morning and every night in which you can bring up issues to do with the service... There is a suggestion box."

In contrast, post-training interviews indicated an increase in interest in consumer participation as a model, and a greater comfort level in communicating with staff about the service. After the training, Jade said "I felt more comfortable giving feedback to staff. Gosh, it was such a long list!" Lola also experienced greater comfort levels in talking to staff, post-training, she also noted an increase in her confidence, and felt that her communication was better with her fellow consumers too. She said "I still go red sometimes, [...] but I'm starting to feel comfortable with everyone and I can just talk to them." RJ also felt that he was satisfied with the consumer participation training and also noticed an improvement in his relationships with fellow consumers. He said:

I was satisfied in a lot of ways. I mean, occasionally people are always going to rub you up the wrong way, but that's just you know same in here or outside. [...] I'm learning assertiveness, how to handle conflict, but having said that I can always learn more but. I am not the type of person who really needs to go into those classes but I am finding it interesting, but I see how many people don't have these skills. It's extraordinary.

When asked if she thought that her relationship with staff was different since the training, Jade said "yes, I do. I mean, they are all very nice people but yeah, they just treat me differently." Since the training, then, participants reported an improvement in their relationships and/or communication with staff. They also described an increase in their self-confidence. Some have used the training to strengthen fellow consumer relationships, with a view to transferring these skills to post-treatment scenarios. They also seem to have greater appreciation for consumer participation as a principle, and were more likely to view it as useful and beneficial. Indeed, Aaliyah speculated that the training indicated to

consumers that the staff members were interested in them, and that this enhanced consumer engagement in treatment. She said:

If [consumers] feel like [staff] are like interested in them a little bit then they are going to want to participate [in the program]. You know, they've taken the time to understand a little bit about me. I am going to actually participate and do it fully with what I have".

Tash also felt that since training, consumers were more comfortable and trusting of staff:

Some of the consumers think that staff are out to get them and, you know, stuff like that. But you know [...] [through the workshop] I got to know them, I realize that they care and they are here to help us.

Lola was also more positive and trusting of staff post-training, when asked what she thought had changed, she said "it is good here. I like the staff, they are great." Heidi was more likely to view the staff as "great." RJ enjoyed sharing his appreciation with staff and providing positive feedback about his treatment "It's good. Yeah, I gave them my feedback." Tash said, "they are lovely, particularly my caseworker, lovely." Participants tended to reflect on their relationships with staff and fellow consumers, when describing their service experiences post-training, when describing any outcomes or changes they had experienced. Finally, in addition to outcomes relating to the model, such as improvements to intra-service relationships, a few participants described a series of other outcomes they had experienced. As hoped, Tash had gained "more people skills, communication, being empathetic." While observations regarding effective communication should be welcomed as establishing the foundations for more substantive change and offering improved opportunities for genuine communication between consumers and staff, we still need to be mindful that consumer participation is far more than effective communication. It is possible that future communication about the model, when inviting services to take part, could be enhanced by highlighting these benefits for previous trainees. In the next section, we build on these findings to share consumer accounts of what might be needed to facilitate consumer participation models underway at AOD services in NSW.

Barriers to Consumer Participation: what's needed?

Discussion with participants about the perceived barriers to the consumer participation initiative, prior to training, tended to reflect their concerns about the communal and social nature of the model. Before entering the workshop, some consumers expressed trepidation about working with their fellow consumers, and how it might be during moments of disagreement or conflict. In her pre-training interview, Aaliyah felt that strong emotions or histories of trauma could make discussion difficult for some consumers:

I think some barriers for participants - is that they are afraid to get in touch with their emotions especially being in addiction for so long. I was in addiction for so long and I numbed all my feelings with it and all my pains from my domestic violence and everything like that and when I first started here, I found it difficult to trust people [...]

and when you start getting clean you feel the emotions a lot more and it does put this barrier on you where you don't want to go on anymore and some people actually turn away and walk out those doors and it's only when you are fully ready are you able to come back and commit to this program.

Akin to comments in previous sections, Aaliyah perceives early stages of treatment to be a distressing or tumultuous time and that this could be a barrier for some consumers taking part. Opal also perceived this to be a barrier in her pre-training interview:

If you are not feeling great that day, and you are having difficulties with whatever their journey is, then that will put [consumers] off from participating.

Likewise, Lola (pre-training interview) felt that potential participants might be hindered in attending due to challenges relating to their treatment:

I think some people might be too early on in recovery and too medicated to actually have the capacity to think or be aware of their surroundings.

What is positive about this concern (and others like it above) is that it is not about the essential 'deficiency' of AOD consumers, but rather an acknowledgement of the specificities of treatment time and place. Shane, Joel and Robbo raised their concerns that their health or mental health conditions would make it harder for them to participate. Robbo has chronic pain from a back injury, and is occasionally hampered by discomfort or high doses or pain killers that make him sleepy. Indeed, he felt that he might miss meetings that he cannot walk to due to his chronic pain. Future workshops would be advised to promote their efforts in accessibility and work with trainees to time the training in to an optimal stage in their treatment plan. When talking with participants, it sounds like trainees were not screened for these issues. Rather than excluding their participation, it is possible that phasing their involvement at a better time would be an equitable approach that could also reduce the risk of participants being distressed or triggered by the group work style of the workshop.

Participants also pre-empted barriers relating to stereotypes of consumers, and suggested that trainers need to have sufficient experience working with AOD treatment consumers so that trainees have a positive experience. Lola (pre-training interview) said:

If you don't have experience with people that are users and stuff like that, it could thwart the process, because you really need to be open minded when you are talking to people [...] Like if you didn't have a lot of experience with AOD, me saying that I'm a sex worker might make you ... put you back a bit and make you feel bias towards me or ... like a lot of people in the group came through emergency and some of them had positive experiences and some of them were sent away and talked down to.

As has been widely reported in published research, people who use alcohol and other drugs experience discrimination and are likely to have had negative experiences with mainstream

health services and institutions. As such, promotion of the workshop (and any associated programs) would be advised to include information that reassures consumers that they will be treated with respect. Indeed, the word of mouth recommendations made by participants within this study would vouch for the trainers or be reassured by the presence of fellow consumers.

In addition to potential barriers described in pre-training interviews, participants who provided input post training raised some specific and location-based barriers that affected the model in their service. Post-training, Jade was frustrated by delays in implementation of consumer participation due to significant changes experienced at her site. She felt that consumer participation forums are affected by such scenarios. She said:

It's an absolute shit fight. People have ... awesome people have actually resigned and gone because of that much of a shemozzle, you know...It is a shame and it's a shame also to the people that are trying to come there for help.

Unsurprisingly, Jade had concerns about the quality of service she and her fellow consumers would experience given the upheaval she had witnessed at her site. In doing so, she highlights the contextual nature of such models and the effect that service-functioning plays in its implementation. Consistent with other reports, then, the recent implementation of consumer participation training was subject to a varied range of complex challenges. Participants perceived the state-of-mind and physical capacity of consumers to also be influential on attendance and follow up activities. They also witnessed barriers relating to change-factors within one service.

Recommendations from consumer interviews

During the closing section of the interviews, participants were prompted to consider ideal world scenarios for consumer participation, as well as any information or recommendations they could make. In line with suggestions described above, participants tended to recommend that formalised tasks be implemented soon after the workshop to consolidate what was learnt at the workshop and bring the model to life. While Shane's pre-training response tended to conflate consumer participation activities with general treatment approaches, he nonetheless emphasised the need for more structure at his service and a more proactive approach to collaborative activities. He said it is important to:

Have dedicated days you know once a month or twice a month [...] We really need to have more groups and we need to have better structure and I really think they need to look at having consumer participation in the buying of the food for the house. [...] They need to make it more of a communal event you know so that everybody feels like their needs are being met.

As with other responses described in the "barriers" section, Shane expressed concerns about the feasibility of consumer participation related to the culture of the service. Given

gaps he perceived in the operationalising of the service, he held low levels of confidence that it would be effective. While these contextual barriers fall outside of the influence of a consumer participation model in the short term, it is advisable that ongoing implementation facilitate highly structured and consistent actions to maintain consumer participation procedures. At the same time, it is important to emphasize that some services are not currently equipped to effectively implement consumer participation and the risk is not in not acknowledging this fact, but rather that consumer participation will be seen as the failure.

Other participants recommended providing more information about the model when promoting the training (Todd, pre-training interview). Lola (pre-training interview) recommended hiring “open minded” people to undertake the workshops. As highlighted previously, participants also recommended continuing to incentivise the training and associated activities. While the incentive might initially motivate attendance-only, the workshop would like inspire ongoing participation. Nigel said in his post-training interview that incentives also communicate to consumers that their opinions and perspectives are valuable:

Well, I would offer the people some money, some incentives to come along, some people will go, “well I’m going to get paid for this” so they think I’m worth it and then they will work better, so ... That’s the main one, offering them something. Then you will find they will come and who’s got the staying power and who’s going to be there over and over... so then once you have the people there, then they’ll look at what it is [...] The main thing you will get a core body to start if you offer them some sort of financial incentive.

In this round of training, and in other experiences with consumer participation, Nigel perceived the cash incentives to be useful for motivating participation but also to convey respect for the potential contributions consumers will make. As with other findings from interviews with consumers, both pre- and post-training, the workshops and resulting initiatives seem to be highly affected by the perceived and experienced relationships between consumers and staff, and between fellow consumers, and ongoing implementation needs to overtly communicate highly respectful and relational approaches to be feasible. In the next section, we build upon consumer accounts by exploring the perceptions and experiences described by the professionals involved in this project.

Professional interviews

In this section, we shift our attention to the data provided by the staff and other professional stakeholders, including case workers, peer workers and trainers. First by describing the participants through broad demographic categories relating to their role on

the project and their professional trajectory, and then by presenting interview excerpts relating to the key research questions.

Professional participant profile

Seven professionals took part in an interview for this evaluation, at the post training stage of the project. The majority were female (n=5) and most had been involved in the training (n=4), with two being case workers and one a peer worker. Professional participants ranged in age from 30-55 and most were in their mid-30s (n=4). All but two participants had previously been a consumer of AOD treatment and drew from these experiences in their interviews. These professionals were relatively new to paid employment, and 6 had worked for less than five years in this sector. Only one had a post-graduate qualification, as the majority had diploma level training, and some had only received the training to undertake the workshop and similar informal training-without-assessments. Having said this, professional participants, particularly the trainers, had had extensive experience in volunteering within AOD services, including peer support, advocacy and activism and were able to express their perceptions and experiences eloquently.

Findings from professional interviews

Similar to findings from the consumer interviews, professional-participants tended to view the culture within the host site as highly influential to the effectiveness of the model and its training workshop. Consistent with findings from the CHANGE Evaluation (Wilson et al., 2013), staff attitudes can impact on the uptake and operationalising of the model. In this study, a lack of communication between host sites and the training team, and changes at short notice, led to challenges for the training sessions. There was also thought to be disparity between in house staff as to their level of investment, and in some cases managers may be elected to take part in the project upon NADA's invitation, but it is the frontline workers who might be responsible for operationalising the workshop itself. In addition to busy workloads, this was considered burdensome by some staff members. It is noteworthy that these findings are drawn from the speculation by those who took part, as staff members who were not invested in the model were, unsurprisingly, not interested in the associated evaluation. It is also noteworthy that this initiative seemed to invite such varying levels of investment and cooperation, despite being an opt-in process.

Despite these challenges, staff provided rich and enthusiastic input about consumer participation and its outcomes, and some key recommendations for future implementation. While these reflect the themes emanating from the consumer interviews, such as the empowering and capacity building opportunities for consumers taking part, they also tend to be more ambivalent or disappointed about how this project played out. Professional participants requested more detail about how the principles of consumer participation could be applied in practice and suggested that the training should be clearer in this respect.

They also suggested greater clarity be provided about the roles that consumers might play in these initiatives and that adequate support be provided to these key players. Finally, while participants reported witnessing changes among consumers who had attended the workshops, they also described the apparent lack of 'action' post training, and the frustration and disillusionment they felt as a result.

As with the consumer interview data, findings drawn from professional interview data have been collated via the following themes: prior knowledge and experience of consumer participation, including perceptions of the level of interest in consumer participation both individually and in the participant's workplace; the participant's role in the project; the perceived strengths and weaknesses of the model; witnessed changes as a result of the training, and descriptions about consumer participation activities at their location; the impact the training had on those involved, including their descriptions of the capacity building effect of consumer participation on the participant's professional skills; perceptions about barriers, including any opinions about what resources are need for optimal functioning of the model; and, finally, any recommendations participants made for future initiatives. While professional interviews were undertaken at a single time-point, that is, post training implementation, participants were nonetheless invited to reflect on changes in perception and knowledge levels retrospectively.

Professional participants' role in the Consumer Participation project

Participants connected to NADA were directly involved in the project, and could provide insider knowledge and recommendations for future development. In addition to the work undertaken for this initiative, the NADA professionals had experienced AOD services as consumers and had had lengthy involvement with consumer participation in other contexts, both in paid employment and in voluntary roles. In contrast, the non-NADA affiliated staff members were new to the sector, and tended to be less familiar with consumer participation. Apart from one professional, the caseworkers interviewed for this study had not experienced AOD treatment as a consumer and had no prior role in consumer participation. Moreover, they had not volunteered to take part in the project, and its tasks had been delegated to them. These tasks were undertaken alongside their usual work. Despite being somewhat burdened by the project, they were supportive of consumer participation as a principle. They demonstrated concerns about the extra work involved and felt that they could only show support long-term where it did not create an onerous workload. For example, one professional said that a dedicated role was required at their facility and until they had a dedicated staff member, it would be difficult to get it off the ground:

So yeah, we have got very limited sort of you know ideas and we are not that familiar with what it actually looks like for our facility, because we haven't had to date anybody that has actually been in that role yet. (3)

The other caseworker (professional 4), who had been delegated this responsibility also felt that the model requires a dedicated role. In contrast, she valued imagining this as a

consumer-driven activity that could change the shape of the facility she was working in at that time:

We feel that [consumer] participants involved in the processes here is fundamental. It would help to make it more of a therapeutic community, which means we can get them more involved at all times.(4)

That these professionals did not directly volunteer to be involved in this project, or volunteer to adopt the responsibility for model implementation within their workplace, but demonstrate in principle support for the model, is encouraging. While they indicated understandable concerns regarding their workload, and preferred it to be a dedicated role, they demonstrated a supportive attitude towards the principles of consumer participation, and the opportunities it fosters for consumers. This is consistent with previous studies where consumer participation initiatives were 'added on' to existing staff workloads rather than being accorded 'core business' status. This data is missing key insights from professionals who did not seem to support the project, or its evaluation, but these professional insights provide encouraging evidence for the uptake of the model, even in situations where professionals have challenging workloads. In the next section, we explore the professionals' perceptions and experiences of consumer participation more fully.

Prior knowledge of Consumer Participation and the level of interest at their workplace

Prior knowledge and experience of consumer participation was very rich among professional participants, some of whom had been involved as both consumers and professionals in the model. Given this experience, their accounts tended to be both more detailed and more critical than consumer accounts. Although participants believed in the principles of consumer participation, they tended to reflect on the effort and energy required to get such action off the ground. For example, Professional 1 wondered if the commitment required was realistic among most consumers. She said:

I find it's like, you got to be constantly switched on and you constantly got to be like "alright, I am going and fighting for my rights" and I am more chilled, like I know the system needs change but you really have to do a lot like study the laws and like yeah, it's just a lot to be involved as a casual consumer.(1)

This reticent attitude is possibly influenced by their long-term work in the area, and their disappointment regarding the low level of change witnessed as a result of this work. Another professional (2) said: "I've been involved in consumer participation for a long time [...] It kind of feels like to me we haven't moved much forward." In contrast, professionals who were newer to the concept of consumer participation had more factual and less jaded responses. One of the case worker participants (3) said:

It's my understanding that the role is predominantly a liaison between the consumers, both current and past consumers, and staff and management. Just to be able to be that go-to for you know to get on-the-ground information from the

residents and see what sits best in some of our practices and some of our routines and the program. Somebody that they can sort of be on a level with, that they can share a little bit more sometimes than you know about their experience in our facility, rather than sort of putting a complaint into staff [...] someone with insider-knowledge, if you will, of what's actually working and what doesn't actually work, you know because we can do it from our side but we are not people that are receiving the treatment. (3)

This participant had not undertaken AOD treatment, and valued the opportunity to gain authentic feedback from consumers to improve their practices. This excerpt also reflects the recurring themes throughout the consumer interviews, that to lay people, inexperienced in consumer participation models, it is to be defined as a feedback loop between consumers and staff for quality management purposes. It is possible that greater opportunities could be fostered where staff and consumers have more expansive understandings of what consumer participation can do, such as system change through legal channels and other strategies. As to be expected, prior knowledge of consumer participation among our professional participants was high. Given the long relationship that some participants had had with the model, professional participants also tended to convey a sense of disappointment with the results of previous work they had undertaken. It is possible, given the onerous workload described by the more experienced professionals, that these participants fatigued and this had led to their disillusionment, and increasing supervision and support would improve their outlook. In the next section, we turn our attention to more direct comments about the perceived strengths and weaknesses of the model.

Strengths and weaknesses of the model

Those directly involved in providing the training felt that the model and its implementation could be improved by boosting the training for the trainers. This would be in relation to the model itself with greater emphasis given to formalising the training and the practicalities of implementing consumer participation in practice.

I don't think it was really training, like we just went in there and got shown something and then we would talk about it, it wasn't so much training. We would practice it a lot, so yeah [...] it was unorganized [...] it wasn't formal enough and like 'well, you should know what you're doing' (1)

For another professional who attended the consumer participation workshop at her site, it was thought that greater clarity would improve the model's key messaging: "the training was a bit muddy I guess, the information wasn't that clear" (3). In other examples, professionals described consumer participation as principle-oriented, but that more work is required to define the components of consumer participation in practice, or how to put it into action:

We are still working out what that actually means on a day-to-day basis, what activities are we going to do, are we going to have a consumer group? We don't know, you know...? We are still working out what can work and what can't work, which ... there is a lot of theory about it, but there is not much knowledge to how to actually do it...(2)

For professionals less experienced with consumer participation activities, this lack of implementation wisdom was thought to lead to challenges in integrating consumer participation into their systems. This is again consistent with findings from the CHANGE Report (Wilson et al., 2013) where there were lots of ideas for consumer participation but a struggle to translate them into practice. In turn, this seems to increase employees' fears about the model:

We are not sure where it is going to fit within our program; we are not sure what we, as staff, are responsible for; we are not sure how it is going to work. So I think if it was going to move forward in our facility, we just need some really clear information about what that role is about, what that person or those people are going to be doing on a daily basis and what their scope of their role is, because once we know that, I think everyone's a little bit more comfortable with that [...] I am only sort of speaking on behalf of the staff that I have spoken to about it, but it seems to be the general consensus, that it's just sort of something that we are a little bit afraid of I guess on what's going to unfold, yeah (3)

In addition to a lack of shape or information about role and praxis, professional participants reported that the lack of motivation by key staff at the host sites weakened the model. This, they suggested, lead to a lack of communication to set up the training:

It was hard. The services kept on saying, "okay, come on Friday" and then they were like, "no, no, we can't do Friday, come on Wednesday" and then it just kept on changing

The lack of attendance by senior staff at the workshops was also thought to negatively impact the implementation of the project: "senior management, you know? Didn't attend...it was really disappointing, you know?" (1). For this participant, the lack of attendance communicated a lack of support for consumer participation, to the workforce and consumer cohort. They felt that the model could be strengthened by the overt participation by senior management.

For others, the high turnover of consumers led to weaknesses within the sustainability of knowledge transfer through the workshops. In order to sustain the knowledge and awareness level among consumers, periodic and repeated training was recommended. For example, when asked about the perceived weaknesses of the model, professional 4 said, "the change in the population... I don't think a lot of people that participated in that training

are still on the program.” As suggested during the consumer findings, ongoing and repeated training could prevent this loss of knowledge and expertise.

Nonetheless, reflecting the positive outcomes reported by consumers, this professional participant noted the positive impact of the model on consumers’ self-esteem as a particular strength:

In terms of raising people’s self-esteem: incredible... I think people are so sort of beaten down and stigmatized, they are so used to that, to be in a group or room of people saying “you know, you have rights” and “you have a right to argue for your rights and stand up for them” and you know “not everyone thinks you ought to be getting treated the way you do and we really want to work on that and change that and we want your help with doing that”. I think that’s just really good for people with beaten down egos, you know self-worth as a person (2)

Another participant was excited by the opportunities to reverse the dehumanising impact of ongoing stigma and discrimination among the AOC consumer community. He said:

Just starting a conversation and treating people that use drugs like treat them with some humanity you know? And not put them in a box and point fingers... I have had feedback on a couple of the workshops that we delivered at one site, so I did get feedback on that and the participants said that the workshop went very well and they were excited about things. Me personally, what it’s done for me, it has empowered me to sort of follow the course you know? Follow and keep going with what I believe is challenging stigma. So it’s empowered me to talk, it’s empowered me to speak to people that are in the sector. (7)

Echoing previous interview excerpts, the professionals’ in this study perceived consumer participation as worthwhile due to the positive effect it can have both on consumers who are potentially empowered and more confident, and on their work through gaining authentic feedback and insider perspectives. Nonetheless, professional participants also reported concerns regarding the additional workload and the varying levels of investment among colleagues, who may choose to either delegate or absent themselves from key activities. Ultimately, these accounts suggest that there is room to improve consumer participation initiatives by defining it as ‘core business’ and formalising staff roles and tasks.

Outcomes and impact, including witnessed changes at their service

In line with previous sections, participants tended to express frustration at the lack of outcomes and changes related to the initiative. One of the trainers (1) was particularly disheartened:

Well, me personally, I was a bit let down, because I went to one site, and they said, “no, we haven’t had enough time to do all like the training, we are going to have to

let someone else do it” and yeah, I just felt like that I didn’t ... that I wasn’t good enough basically. Very disappointed.

Similarly, professional 7 stated that “a lot of work had gone into the preparation and facilitation of the workshop” but due to the lack of change they witnessed, they had been disappointed about the initiative, and their role in it.

Professional participants struggled to describe any concrete changes in service delivery or consumer involvement since the training, and this was highly disappointing for some of those involved in the training. Professional 1 sums up the various challenges and weaknesses of consumer participation in AOD services:

Working on this project, it’s really cemented for me what the barriers and challenges are. It’s not only like the staff challenges you know, their concerns and fears, and organizational change and acceptance, and consumers getting an understanding of it and the benefits for them [...] We felt, as facilitators, an ongoing responsibility to the consumers who attended the training. [...] And to the co-facilitators who put a lot of work in. Really intensive, got to know them and established relationships, and I think they thought that there’d be more and it’s just it. It just stops and it’s gone, it’s over, you know? (1)

It seems that while there was in principle support for consumer participation, the fixed term nature of this project, combined with differing levels of investment among staff, led to these professionals having concerns about the sustainability of the model in the host sites. Given the time and energy they put into this initiative, professional 1 seems to have concerns that the initiative fizzled out and ongoing action has been thwarted.

In contrast to the trainers’ perspectives, caseworkers indicated satisfaction with the workshops, and felt that they had led to positive change within attending consumers:

Interviewer: Did you witness any changes in your consumers who did the training?

Interviewee: Oh definitely... The participants who did that training were more engaged in the program, when they came back, I think, and more engaged in welcoming the newcomers to our service (4)

Another professional also expressed a positive attitude to consumer participation, given what they had witnessed during treatment episodes at AOD services and while conducting the training for these workshops:

The philosophy behind it is brilliant, you know what I mean? it really is and not only consumer participation and getting better results for their health issues or whatever industry they’re in or sector they’re in, rehab or whatever, to get better outcomes. But it also teaches us to help each other as a community, so it empowers us to help each other and lift each other up, which is a great thing you know? And then if it

spreads from there, it's a really good thing, because you've got a resource of people that will be in a position to sort of help

In another example, a more experienced caseworker (2) enjoyed witnessing the passionate discussion among consumers during the session at her facility:

Security came down to check we were all okay, due to the volume of the discussion. People really contribute and really, really care you know? When you get them in a room together talking about what matters to them! (2)

Professional 3 was less enthusiastic about the high levels of passion expressed during the training at her site: "we had to work closely with all our consumers all afternoon to get them to calm down again!" Given the impassioned, potentially disturbing effect of the discussions, facilitator training would be advised to include skills necessary for group work, so that respectful management of strong emotions can enable positive expression of opinions and avoid causing distress and conflict between fellow consumers.

Echoing previous statements within the consumer interviews, professional participants also felt that there was a risk that some consumers could be adversely affected if they undertake the training too early in their therapeutic journey. More specifically, one professional expressed concern for the consumer participant who may be exposed to challenges they are not qualified to deal with. This has implications for the trainers, participants and consumers involved. Professional 3 said:

Some people would be fine with it, you know, but it would just be, we would need to monitor that role quite closely I think, if we had somebody here to get the information that the consumers are telling them, because they are not trained the same way as staff are trained and you know you get that transverse trauma and all that sort of stuff if they decide to open up because they have you know got this bond with this person, which is great. But that person is actually not trained to deal with the stuff they hear. So, there are lots of things I guess you know and it would come down to just you know management monitoring that role and what it is looking like for them and you know? (3).

Similarly, professional 2 felt that any ongoing role needs to include adequate supervision to avoid adverse effects on their wellbeing. She said:

We really need to support them like you would any staff member and there's a difference between peer education and peer support too. I've only been thinking about this recently. In my mind, support might be a bit more like you know borderline counselling role, whereas education in a way is a lot more cut and dry. (2)

This need to provide clinical supervision for consumers that take on an accidental counselling role was also found in TSU2 (AIVL, 2011) and CHANGE (Wilson et al., 2013).

Barriers to Consumer Participation: what's needed?

Those directly involved in the training would like more hours to prepare and facilitate the workshops, or where they had undertaken additional development to improve their facilitation, that this should be acknowledged and remunerated. The trainers involved in study interviews tended to say that their biggest barrier was “funding.” They also felt that workshops were affected by the poor resources evident at the host sites. Professional 1 felt that “small rooms” and the lack of training hardware, such as “screens” or other presentation technology, hampered workshop delivery and put additional pressure on the trainers.

Other barriers and resourcing needs were related to the fixed term nature of the trainers’ contracts. One professional perceived the trainers to be “great speakers! Reliable, articulate and experienced people” (1) and without an ongoing role, this talent was lost. By providing ongoing funding and longer contracts, the project would be able to better capitalise on the experience of the trainers, whose talent and learning on the job would be retained. In the next section, we build on these insights by exploring direct recommendations provided by the professionals at the closing section of their interviews.

Recommendations from professional interviews

Perhaps unsurprisingly, given the perception that host sites were reticent to take part in key activities for this project, professional participants felt that training staff within host sites would be advantageous. In reflecting upon conversations, she had witnessed at her workplace, professional 2 said:

And also to just sort of educating staff, so even staff who are on board, who I think are really supportive, still ask me out of the blue questions like, “so, why do we have to pay them, don't they care enough to come to meetings?” And this is someone who I thought was on board... So staff attitudes... (2)

This participant perceived there to be training needs for staff and that given the pivotal role they play in project implementation, their training should occur at the outset. These sentiments were echoed by another participant who felt that staff members at host sites were not supportive of consumer participation “because they don’t understand the benefits of consumer participation, both for their consumers and for themselves” (1). Reflecting earlier comments, professional 3 recommended developing clearer definitions and boundaries for future implementation of the workshops, and associated actions post training. In doing so, she provides further support for recommendations about training staff at host sites, pre-implementation:

I think first and foremost we definitely need to have some really strong defined boundaries into what that role is in regards to responsibilities and information sharing [...] I think one of the issues with us as staff, we are not really familiar with why that role is there. Not why the role is there, how that role is going to work, we

all know why it's there, we all understand why it's there and we all agree that it's a great idea in theory, but we have just got reservations about how it is actually going to work in the real world because you know of all these issues. (3)

Professional 1 felt that this activity would bolster motivation among staff, and to further prevent senior management hindering project implementation at host sites, she suggested making their attendance at meetings and training “mandatory”. While she made this suggestion with an element of humour, she perceived this a reasonable request given the funding NADA provided each site to support implementation.

Other suggestions were related to gathering feedback from consumers about the workshop training. They felt that consumer feedback is more achievable via their phone technology and suggested sending survey invitations through this mechanism. Professional 2 suggested a similar process to an exit survey:

One facility has just introduced an exit survey for all patients leaving the site. You get sent a text message “how was your stay, what was good, what was bad?” and I think lot of our guys in drug and alcohol might really respond to that kind of input “ooh, I like texting” and everything in between. (2)

It is possible that similar mechanisms could be used to provide a communication pathway for consumer participant activities where input is required from the broader consumer community. And for the caseworker who had witnessed positive changes in consumers who attended the workshops at her site, she recommended that the project continue, but that NADA provide “more of them” to enable access to the AOD consumer population.

DISCUSSION

Findings from both the qualitative and quantitative arms suggest that while it appears that some consumer participation is not uncommon in these AOD services, it is often low-level involvement concerned with providing and receiving of information. Encouragingly, some services however did seem to show a willingness to involve consumers in high level consumer activities such as soliciting consumer input in planning and offering consumer representation on the governing body or board of the service.

Findings suggest that there is a strong relationship between staff attitudes and beliefs around consumer participation, current levels of consumer participation and beliefs around positive changes as a result of this project. Staff who believe more in the value of consumer participation and see more benefits associated with consumer participation tend to have more positive attitudes towards consumers being involved in the service planning and delivery of their service, and also have greater levels of current consumer participation in the service. In addition, the more positive staff members’ attitudes are towards consumers

participation generally, the more these staff members felt that their service would benefit as a result of participating in this consumer participation project.

Consistent with findings from TSU 1 (AIVL, 2008), where data showed that almost all consumers (89.9%, n=161) and providers (84.4%, n=54) believed in the principle of consumer participation, it was evident from both the surveys and the interviews that consumers and staff members were in favour of and supported the notion of consumer engagement. However, consumers seemed to have low levels of knowledge around consumer participation and tended to assume that consumer participation was a feedback loop between consumers and program providers. Consumers appeared not to know about consumer engagement activities nor how to participate and were concerned how it would impact on their treatment goals. Staff were aware that consumers were reluctant to be involved, and this finding in both the qualitative and quantitative data suggests that this is an area in which improvements can be made through an emphasis on the need for strong pastoral care to support consumers in their engagement in consumer participation and to explain/define to participants what is involved in consumer participation. The benefits of pastoral support in consumer training could already be seen with word of mouth recommendations by some in this study, where fellow consumers vouched for the trainers, or that consumers were reassured by the presence of fellow consumers. This reinforces recommendations from TSU 1 (AIVL, 2008) to improve consumer knowledge and support their skill development in this area.

Consumers attendance at the training workshop, while valuing improvement in communication and relationship building, was also partly motivated by more personal interests, such as the cash incentive and opportunities for self-development. Post training, knowledge about consumer appeared to have a greater knowledge of what was involved in consumer participation. Participants who had engaged in consumer participation activities since the training had more detailed and practical knowledge about consumer participation and its benefits and aims. This indicates that ongoing workshops and the implementation of practical, task driven activities could be a robust approach to integrating consumer participation into service provision.

At the post-training stage consumers expressed greater ease in communicating with staff about the service, and with working with their fellow consumers. The workshop seemed to provide participants an invitation to use their voice, and some expressed an increase in their self-confidence. Some have even used the training to strengthen relationships with fellow consumers, with a view to transferring these skills to post-treatment scenarios. The experiences of consumer participation for consumers also has potential flow on benefits for later once they leave treatment, in terms of knowing rights, advocacy for themselves and others, navigating services, life skills and feeling valued. It is possible that future communication about the model, when inviting services, and ultimately trainees, to take part, could be enhanced by highlighting these benefits, especially those put off by the

communal nature of the training. Given that participants described some of the workshops as tense at times, with heated discussions about consumer needs taking place, these concerns may not be unfounded. Working with fellow consumers was also reported to be difficult by some consumers with consumers at times acting in stigmatising ways towards each other, based on their drug of choice or route of administration. Future workshops would be advised to consider the needs of individual trainees, particularly those in early treatment stages, and work with them to time the training at an optimal stage in their treatment plan as both consumers and staff had voiced concerns about involvement in consumer participation in early stages of treatment.

There were some significant differences among those staff members who undertook the consumer participation training, suggesting staff developed a greater understanding and knowledge around consumers and are more sensitive to the complexities and challenges of consumer participation for consumers within the context of AOD services. Staff members who had been working in their current positions for longer periods of time were statistically more likely to have taken part in the training. In addition, these staff members who had taken part in the training were significantly more likely to have had heard or read about consumer involvement and participation in the provision of AOD services and were significantly more likely to believe that consumers do not choose to engage in consumer participation because: consumers lack trust in the ability of the service to provide help; consumers believe nothing would change anyway; consumers do not want to cause trouble for staff and consumers worry that it would impact on their treatment. These staff members showed greater understanding of what prevented consumers from being involved in consumer participation suggesting staff training improved not only consumer engagement but also the ability of staff members to understand consumers reticence to be involved. Therefore, staff members who had worked at their service for longer periods of time, who have been shown to be more supportive in general of consumer engagement, might be considered staff 'champions' at individual sites or organisations and given ongoing support to mentor newer, younger and/or more junior staff members to 'bring along' the concepts involved in such a movement.

It was not uncommon for staff, particularly those who had not participated in the training, to report that clients lacked the knowledge, motivation or skill to engage in consumer participation. This sentiment was also reflected in consumer accounts where they reported needing an invitation or not knowing what consumer participation was. This was also a main finding of TSU which emphasised the need for consumers to be supported. Consumers need to gain knowledge and understanding about what consumer participation is, what their rights are, and they require pastoral care and support while engaged in consumer participation activities.

In addition, finding from both qualitative and quantitative data suggests another reason for consumers unwillingness to get involved in consumer participation is stigma. Stigma and

discriminatory behaviour such as insensitive practices, historical experiences of stigma, judgemental interactions and fear of mistreatment all acts as a barrier to engagement in consumer participation. In addition, self-stigma and shame impact the willingness of consumers to engage in consumer participation as well as consumers behaviour towards one another. The stigmatising ways consumers may act towards each other, often around drug of choice and route of administration, impacts their decision to become more involved with each other.

The culture within the service was seen as highly influential to the effectiveness of the model and in relation to the initial training workshop. Where or not consumer participation was successfully implemented in a service was thought to be highly contextual. Some interviewees felt that consumer participation was well aligned with the supportive and collaborative approach already underway in their treatment programs. Conversely, others perceived it as thwarted at sites that were not considered collaborative or equitable. Having said this, consumer participation initiatives did seem to foster cultural change where workshops took place. Some consumers and professionals were heartened by the level of collaboration and inclusion witnessed at their training session, and in the service after this. In this study, a lack of communication between host sites and the training team, and changes at short notice, led to challenges for the implementation of consumer participation at the service. There was also thought to be disparity between in house staff about their level of investment, and in some cases, managers who seemed to have elected to take initially part, however frontline workers were made responsible for operationalising the workshops. These professionals did not answer the researcher's emails about the evaluation, or declined to take part in an interview. High staff turnover further confounded these problems. In all, the professionals at the host sites expressed burdensome levels of work, which seems to have intensified during the workshop phase highlighting the need for greater resources and support. In fact, lack of resources was seen to be a main barrier to consumer participation. Staff and consumers reported being overburdened already and it was difficult to balance the expectations of consumers with limited service resources available. This can easily lead to disappointment and unwillingness to participate in the future engagement activities.

Findings drawn from interviews with professionals, reflect the themes emanating from the consumer interviews, such as the empowering and capacity building opportunities for consumers taking part in this project. In contrast to consumers, professional accounts tend to be more ambivalent or disappointed about how this project played out. Ongoing support and training for these staff is recommended to prevent disillusionment. Professional participants who were not involved directly with the project, requested more detail about how the principles of consumer participation could be applied in practice, and that the training should be clearer in this respect. They also suggested greater clarity about the role that consumers might take, and that adequate support is provided to these consumers

involved in the project. Finally, while they had witnessed changes among consumers who attended the workshops, professionals felt that there seemed to be a lack of action post training, and some participants tended to be frustrated by this. It is possible that integrating a post-training procedure would counteract these issues or perceived negativity at the project roll out, and greater support for trainers would bolster their motivation levels and help them manage their expectations.

RECOMMENDATIONS

Advocacy

1. More resources are needed to ensure longevity of consumer participation activities. Interruptions due to lack of resources reduce staff and consumer positivity and enthusiasm for the project.
2. Promotion of early engagement and commitment from all levels (Board, Management and staff) within organisations are necessary to prevent the start/stop nature of the project that can too easily lead to disillusionment and subsequently suspicion of consumer engagement initiatives in the future.
3. Increased advocacy needs to focus on consumer participation training being embedded in the delivery of treatment in order to raise awareness among consumers, whilst acknowledging and accepting that some consumers will not want to be involved.

Sector Development and Support

1. Develop a mentoring role for staff who have been employed for longer periods of time within organisations as data shows that they have a more positive attitudes towards consumer participation. Experienced staff members can be involved in ongoing staff training to share their knowledge and experience of consumer participation.
2. Consumer participation should be included in all areas of staff training with consideration to shorter training at more regular intervals. Such training could include practical/activity-based components and information about the positive benefits of consumer engagement.
3. The development of fact sheets and other resources on consumer participation targeting sector workers and consumers with consideration given to various levels of literacy.
4. Foster greater opportunities where staff and consumers can have more expansive discussions about what are important and relevant consumer participation activities.

Consumer supports

1. Improve consumers' awareness of consumer participation activities and better support opportunities for them to build advocacy skills over the long term.
2. Increase support and development for the co-facilitators role with considered thought given to selection, training, ongoing support, expectations and remuneration.
3. Give consumers capacity to navigate and successfully respond to stigmatising behaviour and work with them to feel positive about their involvement in consumer participation.
4. It is important to 'prepare the ground' in order to make sure that services can actually follow up on what is promised to consumers, otherwise consumers will be left disappointed and not trust future initiatives. Specific care should be taken when promoting and advocating for consumer engagement initiatives as it can be difficult to balance the expectations of consumers with limited service resources.
5. Timing the consumer participation training to an optimal stage in the consumer's treatment plan by exploring the opportunities with them and phasing their involvement at a time that would reduce the risk of participants being distressed or triggered by the group work style of the workshop. Consideration must be given to the type of treatment service (longer vs short stay) and the consumer's stages of treatment (early vs later) when designing consumer participation activities.
6. Increase the use of technology in future consumer participation models with particular application to questionnaires and evaluations.

Limitations

The evaluation findings were weakened by

1. Too much reliance on staff willingness and capacity to undertake practices/activities associated with the project.
2. Difficulties in obtaining staff survey responses particularly from one service.

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