



GRASSROOTS CONSUMER GATHERING

SEXUAL HEALTH AND BLOOD
BORNE VIRUS
FRIDAY 1ST MAY

Summary of Meeting held 1st May 2020

Background

This virtual meeting was convened as an action point from the 31st March inaugural Sexual Health and Blood Borne Viruses Consumer Alliance meeting. The SHABBV Consumer Alliance was formed by the Health Consumers Council and consumer members of the SHABBV Advisory Committee as a strategy ensure a strong, diverse, representative, effective consumer voice in this sector. The 31st March meeting highlighted the need to have a consumer-only meeting. The purpose of the 1st May Grassroots Consumer Gathering was:

- To bring together a group of consumers (as opposed to staff members)
- To provide background about the Sexual Health and Blood Borne Viruses Advisory Group and the current focus on ensuring consumer feedback about the implementation of the WA Sexual Health and Blood-borne Virus Strategies.
- To seek feedback on:
 - How do we reach people who aren't here today?
 - What would an ideal sexual health and blood-borne virus service look like to you?
 - Anything else

Attendees

Members of the SHABBV Consumer Alliance advertised the meeting through their networks. Consumer payment of \$50 was offered for the 1.5 hour session. There were 29 registrants and 19 attendees on the day.

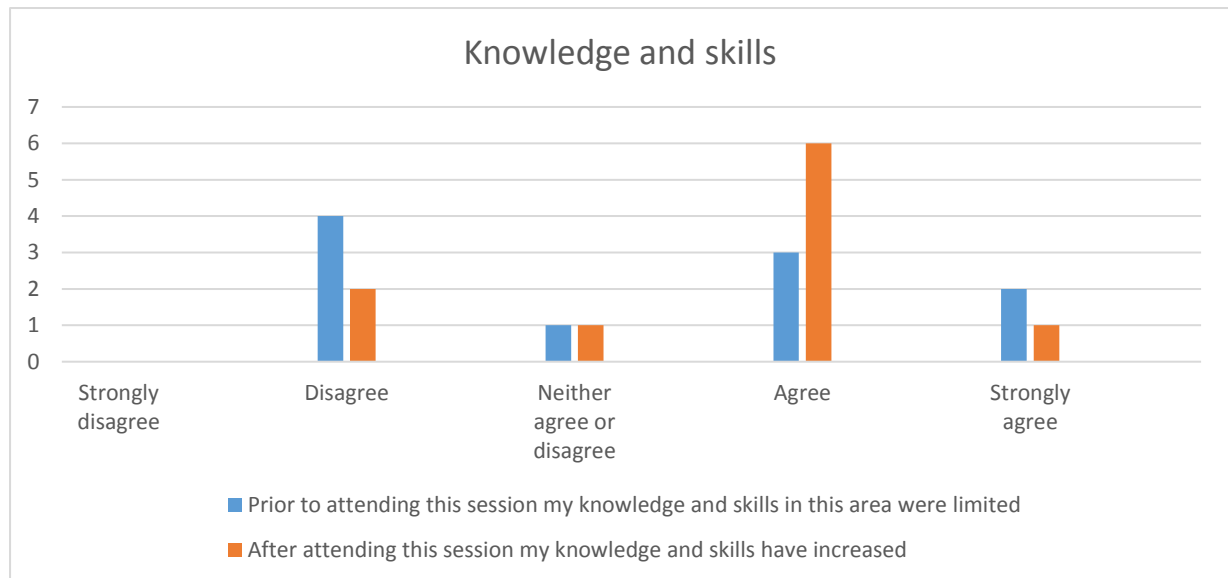
Summary of discussion

Key points to emerge from the discussion included:

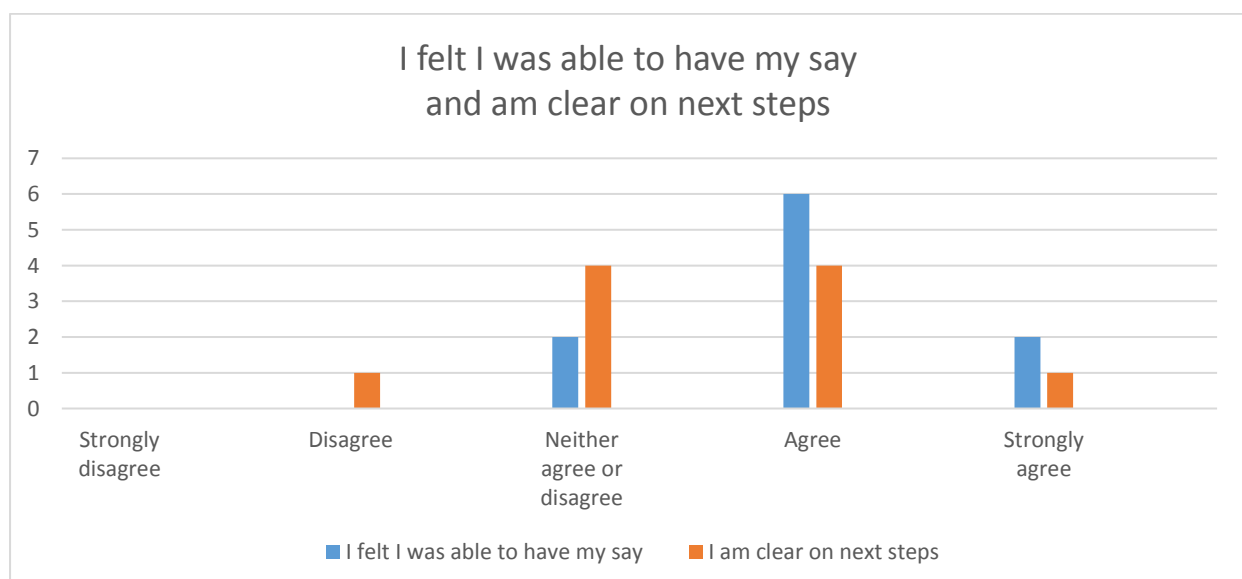
- The current division of services – mental health, AOD, blood-borne virus – don't serve the consumer. This approach doesn't address the question for people "what is the service I need to live my best life?" People are complex and multi-layered, and divided services reflect funding imperatives rather than people's actual needs.
- A consumer group driving an independent evaluation of services emerged as one of the recommendations of the group.
- There was some concern about feeling included very late in the picture – the WA Sexual Health and Blood-borne virus strategies are now in place.

Feedback about participating in the event

- An online survey was forwarded to all registrants whether or not they attended. Ten of the 19 attendees responded to the survey. They responded to questions about their skills and knowledge before and after the workshop and the results are shown below.
- Seven of the ten survey respondents agreed or strongly agreed that their knowledge and skills in the area had increased after attending the session



- Attendees were also asked whether they were able to have their say, and whether they were clear on next steps.
- Eight of the ten attendees agreed or strongly agreed that they felt they were able to have their say.
- Only five of the ten agreed or strongly agreed that they were clear on next steps. This suggests further sessions are required to continue to develop and articulate next steps.



Detailed discussion

After the introductory session, there was a discussion session on two questions:

1. How do we reach people who aren't here today?
2. What would an ideal sexual health and blood-borne virus service look like?

While there was an attempt to break into two discussion groups, the technology got in the way so there was a plenary discussion instead. The plenary discussion was both a verbal conversation, and the Zoom chat. The chat informed the live discussion and has been recorded for future reference. People were also provided the survey afterwards to provide their feedback, and the raw feedback appears from page 4. A summary of feedback follows here:

1. How do we reach people who aren't here today?

- There were many references to the importance of Social media, but also people's social, informal and peer networks. The importance of creating a safe, inclusive space was reiterated, with stigma frequently named as something that prevented people from participating
- Incentives such as consumer payments were also discussed.
- Conversely, people discussed the value of connecting with health professionals as the first port of call for people requiring support.

2. What would an ideal sexual health and blood-borne virus service look like to you?

- A key element was non-judgemental, safe space for people to come and access services.
- A holistic service that addressed the whole complexity of human need was also highlighted.
- It was acknowledged that people are different, and finding one solution is not going to help everyone. Peer-based support was mentioned many times as very important.
- The vital importance of true trauma-informed care was mentioned many times in the chat and in the survey.

3. Other issues

- Conversations emerged about the importance of undertaking meaningful, effective engagement. Concern about convening this discussion when all the Strategies were already in place (and all siloed by diseases) highlighted people's issues about engagement processes which are not meaningful or inclusive.
- Supporting people to be consumer representatives was mentioned several times. Peer support and education were key strategies highlighted in discussions.
- The importance of community awareness initiatives about sexual health in general and as a mechanism to reduce stigma also came through the discussion.
- A powerful demonstration of effective consumer involvement crystallised in a discussion about a consumer-led evaluation of services. This is the key takeaway action from the meeting.

Raw Data

1. How do we reach people who aren't here today? (Survey)

- I feel these [online] options may be helpful, although as I attended and was able to speak perhaps I'm not positioned to answer for others: perhaps offer a range of different engagement options i.e. online, in person, at events etc; Also meeting people where they feel safe and accepted such as at services or in peer groups; payment is definitely helpful; and assisting people prior to participation to be heard i.e. engagement/ consumer training, added education on the topic; and peer-led focus groups may also help demographics difficult to reach
- Advertising, social media
- Social media, instagram/facebook. Personal letter.
- Reduce stigma... each person to know their own prejudice - culture change... Sex is barely spoken about, drugs are looked down upon... Let's get these basic human experiences in common everyday conversation
- As discussed on the day shame & stigma can be getting in the way. So I ask myself "who is the first person we usually have contact with to receive diagnosis?" DOCTOR....so I tend to think running workshops for medical professionals where they can hear what your aims are and how they can be involved and help. E.g. they keep information packages and try to personally advise on next stages and support services available. AdvertisingWhy Not?
- Via phone calls perhaps
- Continue to use various means to access diverse groups, including peer networks. Incentives always assist as well as confidentiality Independent consumer/peer service evaluation with regard to service quality would provide reliable service evaluation
- By creating spaces where the consumer is comfortable to seek help and discuss sexual health.
- Liaise with medical centres
- paid engagement opportunities promoted through existing networks (just like what you did, I loved it congrats)
- paying consumer reps to work with orgs providing welfare services, will need basic partnerships for this to happen but that is where the people are, in the park for soup trucks and at services providing food relief... all the faith based welfare orgs that get left out of the in-house AOD sector convos
- SW PBHRWA offer \$15 for doing blood tests and \$15 for bringing in a friend that hasn't been before and then \$15 for getting bloods out of that person, nice

1. How do we reach people who aren't here today? (Zoom Chat)

- Ok are we talking about people who may or may not be engaging in at risk behaviours who have yet to be diagnosed and access services?? I think it's more than just at risk ppl
- Getting that consumer chat portal will be a start, I am sure they are going to be hugely nervous about this though...
- Networks, networks, networks
- Drag all your buddies along wherever possible...
- Social media yes, and personal networks...
- I think social media advertising could be effective

- I agree social media advertising will work
- A meme in 15 mins if they're encouraged but the problem is that there's nowhere to share. larger groups are more concerned about controlling consumers content than in empowering consumers
- paid sponsor ads
- social media is where a lot of people get their news and grassroots people can make

2. What would an ideal sexual health and blood-borne virus service look like to you? (Survey)

- Welcoming, non-judgemental, include providers who are peers/lived experience persons and have pleasant and grounding surroundings/waiting area/rooms etc. (help people feel safe, calm as possible and welcome)
- Phone support through phone line, an office or offices at locations all around the Perth metro area north and south, where people can drop in to these offices for help and questions.
- Having a one stop shop would be ideal. Multidisciplinary, mental health/sexual health/GP/Drugs and alcohol.
- One that I would go to, not ashamed to ask for a check... etc.
- My ideal for any of these community services is for them to be ALL inclusive or holistic. Looking at the whole person not just the presenting issues. For teams to work together under 1 Co-ordinator/ Counsellor/Main person. For example someone presents with an STD who is a victim of domestic violence with alcohol & addiction issues who is an immigrant and has children. They need help support and advocacy to address these issues and improve their lifestyle.
- Not sure, it was my first time
- There is no ideal as such a diverse group of consumers, what may be ideal for one is not suitable for another. Continue to provide peer-led (not pretend peer e.g. I used 'E' at a dance party & thus am a peer - not) services that have the ability to offer flexible, tailored services where consumers are (some can't or won't travel, postal is too hard & doesn't allow peer education) via outreach, community & other networks. Ongoing independence peer service evaluation is essential to capture current trends etc.
- Medical/ educational combined in a non-judgement atmosphere.
- Friendly, open, engaging, trauma-informed psychologically safe. Available
- only some feel comfortable going into SQH, WAAC, PBHRWA etc so specific service not the best
- needs peer workers and nurses at existing AOD/MH services and welfare services, dedicated arms of an existing service etc... for some people rehab doctor appts are the first contact with general health, that is if the GP even covers off on sexual health, that they've had!
- components of sexual health ed/treatment need to be integrated into general health and MH service provision/care
- AOD services have a stronger link/understanding but still not dedicated enough

2. What would an ideal sexual health and blood borne virus service look like to you? (Zoom Chat)

- AOD consumers in health have to jump so many hoops...
- I agree with current speaker. The only sexual health testing I ever got done was in rehabs. reduce the number of services needed to be engaged and also try and streamline at risk communities who may have multiple issues
- A one-stop shop? That is non-threatening – and where orgs are not competing for funding pot.
- Like a human rights model that meets people's needs, not helps services ticking boxes
- make all services a 'whole of person one stop shop'
- if you complain you don't get services or you get black balled if you go outside the dominant factions hegemony
- The separation of different issues has been going on since the nineties, with WACOSS putting out a report called without support, the [Burdekin report](#) and many others since, yet it hasn't changed too much. We are told there is no wrong 'door', there is if you don't fit the criteria.
- yeah no wrong door, as long as you walk through the right one that is funded for what you need
- The paradigm needs to shift.....My Dr does not know anything about Trauma Informed Care and practice and he is part of a Super Clinic.....what education are we providing front line first contact clinicians/medical specialists
- How does 'stigma' affect the services you access now???Does the stigma emanate from lack of education, qualifications, cultural competence??? has the standard of care improved since you first accessed the first service???
- Haha, yeah COVID, bringing people to our world lol
- I agree - a real leveller
- It's time to drop the shame around our experiences... we can set the tone around how we are engaged if we support each other
- Because I find that self-advocating plays a huge role in getting my needs met via the medical model of service delivery. But you shouldn't have to have a law degree to assert your fundamental health consumer rights...
- Too often I have seen services select or invite compliant or particular consumers that are not going to 'rock the boat', those that have strong opinions are often not invited and/or labelled as difficult, have personal agendas etc. etc.
- However services need to be conducive to consumer reps/information gathering. Many services feel that's an intrusion on their power, authority, privacy etc.....They don't like negative criticism or the potential of...
- Cultural competence is not enforced anywhere there is NO National Standard accreditation for Services to deliver safe secure psychologically safe environments.
- I agree that trauma informed work is so very important across all services: education, health, MH, police etc. Sadly it's often a tick box exercise - it needs to be imbedded in the system and support staff to be regulated themselves too. Blueknot Foundation is a brilliant nationwide service which offers great training and also phone support etc. <https://www.blueknot.org.au/>
- trauma = confusion so systems love adding trauma to control the narrative
- most health issues emanate from ACEs

- I think the stigma/discrimination & separating issues (e.g. mental health & AOD) was also raised as well as comments regarding the lack of change even though they have been raised for years
- There's social determinants of health - the ACE aware information is so important and it needs to be delivered in a way that is trauma aware, preferably by those with lived experience that can talk from their own experience - I reckon anyway - more powerful and honouring

3. Meaningful involvement (Zoom Chat)

- So many strategies.... and we're just being included now.... mmm
- The whole implementation seems to be sketchy at best. They don't understand about external evaluation in my opinion. I always find about things after the decision making is done.
- We've got people ready to contribute here
- Consumers need to see what outcomes are implemented from survey there is an established culture that has become embedded as the norm
- I feel often like even these exercises are tick box exercises.. then with a flow down effect.. if nothing changes when a consumer fills out a survey or gives their opinion to a rep then why would they want to continue
- Lip service as opposed to walking the walk and listening to consumer voices...
- YACWA did this in the youth homeless co-design... they did a service safari that was effective and would be a good model to implement across services
- Maybe work with what we've got?
- That's a brilliant idea - qualitative research conducted by trained and supported by consumers (would perhaps take education to decision makers)

4. Supporting consumer representations (Zoom Chat)

- What are the systems and mechanisms in place to support consumer reps? (I'm guessing not many)? ... other professionals have supervision and mentoring which is something that might be good - what do you reckon?
- I think people have a lot of practical suggestions that may be a bit different if we can just get past the 'methodology/outcomes' convo...
- we need to have a workshop on health promotion evaluation

5. S100 Provider Links discussed (Zoom Chat)

Links discussed in session, forwarded by Kai

https://ww2.health.wa.gov.au/Articles/F_I/Information-for-pharmacists-HIV-s100-community-prescribers

https://ww2.health.wa.gov.au/Articles/N_R/PrEP-Prescribers

6. Any other comments?

- A few comments: there needs to be greater community and system wide awareness raising about sexual choices and AOD including the links with early developmental trauma (complex trauma), ACEs and attachment wounds. I believe that over time this

would assist in reducing stigma; lived experience speakers especially those with credibility to different target audiences; education in schools about emotions and healthy relationships within truly trauma informed environments; perinatal ACE screening and education for all parents ie circle of security; greater access to means of safe sex and injecting in destigmatised environments (harm reduction)

- The group needed to be facilitated more, a co-facilitator would have been beneficial to help the quieter ones have a say.
- Would like to see where this is going. Consumer voices can bring on some very significant changes if they are heard and respected.
- I wonder if the technical problems can be addressed
- Thanks Pip & SHBBVP. People that have a genuine interest in the needs of the consumer as well as valuing the feedback, thanks again
- thank you for holding this discussion :)