Victorian AOD Service Users'

Needs and Experiences during the

COVID-19 Crisis

Consultation Report

Association of Participating Service Users

July 2020

APSU
ASSOCIATION OF
PARTICIPATING SERVICE USERS

sharc
Self Help Addiction Resource Centre

Acknowledgments

We wish to thank all the alcohol and other drug (AOD) service users who have participated in this consultation. Without them this project would not have been possible. We work with them and for them.

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Conducted and written by Edita Kennedy

Copy-edit by Sam Schlicht

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Enquiries and comments about this report should be directed to:
Edita Kennedy, Association of Participating Service Users
140 Grange Road, Carnegie, VIC, 3163
Ph: 03 9573 1776
Email: apsu@sharc.org.au
Website: www.apsuonline.org.au

Self Help Addiction Resource Centre (SHARC)

SHARC is a Victorian community-based not-for-profit organisation.

SHARC provides housing, education, advocacy and support to members of our community who have been impacted by the effects of AOD addiction or dependency.

SHARC works with families and individuals through a peer support model. Our team consists of people with the combination of lived experience and professional expertise.

Association of Participating Service Users (APSU)

APSU is the Victorian consumer representative body for people impacted by AOD related service delivery, policy and research.

APSU believes that people who use (or are eligible to use) AOD services have a wealth of knowledge and experience, and that their needs, strengths and expertise should drive the system.

APSU recognises the diversity and complexity of the community impacted by AOD issues.

APSU is membership based and its membership is free of charge.

APSU is a service of SHARC.

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Introduction

Implementation of COVID-19 restrictions began in Victoria in the first half of March 2020. Within a few days everything changed across the whole of society. With social distancing rules an essential measure in curbing the pandemic, AOD service providers had to reinvent the way they worked with their clients. The changes needed to be implemented swiftly, with little or no time to assess how they would impact AOD service users.

Communication between the government and AOD service providers was strikingly fluent and vibrant. Exceptional flexibility was needed to ensure everyone's safety, and it appeared that everyone was on board to be as creative and adaptable as necessary. However, an important voice was missing from these conversations. The nature of this emergency had pushed service users out of all decision making.

As the Victorian consumer body for people who use AOD treatment services, APSU's primary concern is to provide a platform for consumer voices. Hence, we decided to find a way to hear from consumers themselves about their needs and experiences during COVID-19 restrictions. That is where this consultation originated.

This report is an account of experiences of 32 people who have participated in our consultation. As such, it does not aspire to be an accurate representation of all the changes that took place in each Victorian AOD organisation. However, the 32 participants accessed various treatment programs in 17 different AOD organisations, so their experiences represent a good overview of how various changes in service delivery affected service users. Nevertheless, we recommend that each individual organisation should seek direct feedback directly from their clients to have an accurate sense of the effects of their specific service modifications.

We needed to conduct this consultation rapidly, because the situation required a rapid response. This placed a time limit on our recruitment. All interviews were conducted over thirteen working days, and recruitment was open for the entire duration. Workers from AOD treatment services were of great help in this process.

It is also important to note that interviews were conducted between 21 May and 9 June 2020. At this time there was a sense that Victoria was coming out of lockdown and regaining normality. This possibly added a positive note to participants' feelings at time of interviews, and some might have answered differently if interviewed a few weeks later. The rapidly changing environment caused by the pandemic is yet another reason for each organisation to have processes in place for direct client feedback.

Method

This report is the result of consultation with 32 individuals who have used Victorian AOD services between March and May 2020, when COVID-19 restrictions were put in place. The APSU Advisory Committee provided consumer input in the development of this project. The members of the Committee reviewed the information for participants, helped in the development of the interview questions, and provided their insights and ideas for the project overall.

There were two main eligibility criteria for the recruitment of participants. Firstly, participants needed to be clients of AOD treatment services. Secondly, they needed to have accessed AOD services between March and May 2020, during the COVID-19 restrictions.

We recruited the consultation participants from three sources:

- An email was sent to the APSU membership on 18 May 2020 – see Attachment 1.
- A call to AOD workers was posted on VAADA Enews on 18 May 2020 – see Attachment 2; an additional call was posted on 2 June 2020 – see Attachment 3.
- Through professional contacts.

A total of 42 participants were recruited: 17 were self-referred, and the remaining 25 were referred by their AOD workers. Ten people who expressed an interest in participating could not be contacted in time.

Several other applicants were not eligible because they had only accessed needle and syringe programs. Consultation focused on treatment services, so people who accessed only harm reduction services could not be included.

The final 32 participants accessed a variety of programs from 17 different AOD organisations. Nine participants also used pharmacotherapy services with various prescribing doctors and dispensing pharmacies.

The consultation was conducted via phone interviews in the period between 21 May and 9 June 2020. The average length of the interviews was 26 minutes, ranging in duration between 12 and 54 minutes.

Before the start of each interview, participants were informed about project details and asked to provide their consent for the recording of the interview. This information can be found in the Attachment 4.

Participants were then asked for some general personal information:

- Gender
- Age
- Location
- Housing situation
- Employment status
- Internet access*

*The question about internet access was introduced after the first three interviews, as its significance became evident.

The interviews were conducted in a conversational form, allowing participants to steer the conversation and bring up topics they wanted to talk about. The interviewer followed a list of the main questions, asking additional questions where appropriate.

The main questions were:

Which AOD treatment services have you been accessing?

What are your treatment goals?

How have the services you access changed since COVID-19 restrictions?

What has been your experience with the changes? What works well and what doesn't?

Do you have any support in managing your substance use other than the services?

How have you personally been impacted by COVID-19 restrictions?

What has been the most difficult aspect of managing your substance use issues during COVID-19? How is this different to before?

Do you keep connected (with friends, family, services…)?

Has your financial situation changed during COVID-19?

How would you describe your overall experience in this period?

What would you find helpful to better manage your substance use?

What would be helpful during COVID-19?

What would be helpful in general?

All interviews were recorded. The recordings were then analysed in the preparation of this report.

Each participant was paid with a $35 prepaid Mastercard. The cards were sent by registered post to each participant's preferred address on the first Friday after their interview.

Participants' Profile

Treatment Goals

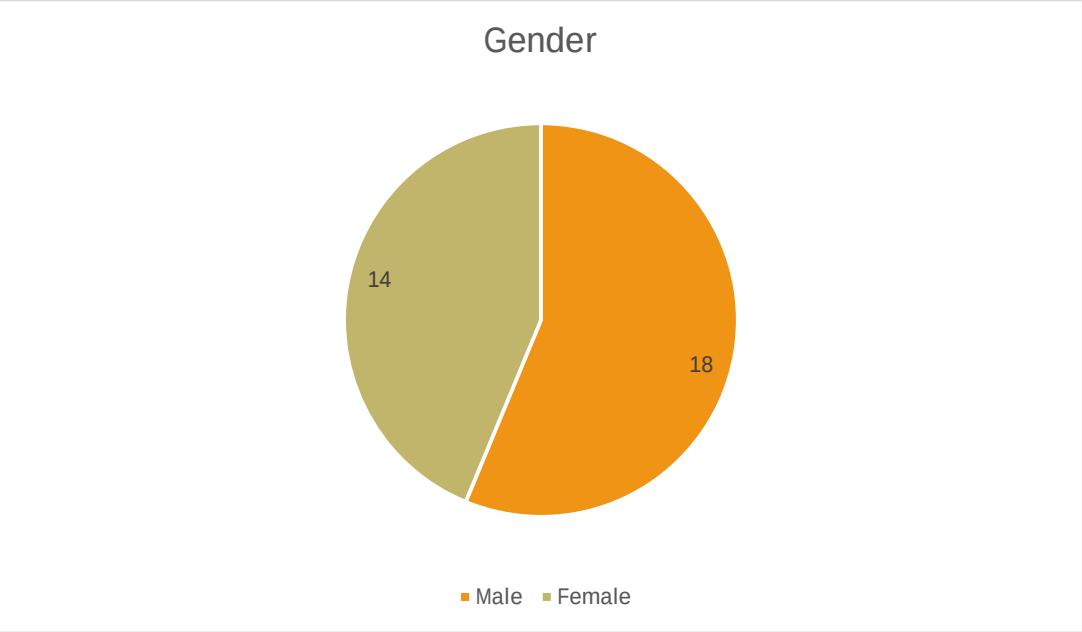
"I want to improve my behaviours."

25 participants (80%) said that their ultimate treatment goal was complete abstinence from all drugs. Some had already been abstinent at the time of the interview, and were using AOD support to solidify their recovery. Others were still trying to achieve abstinence.

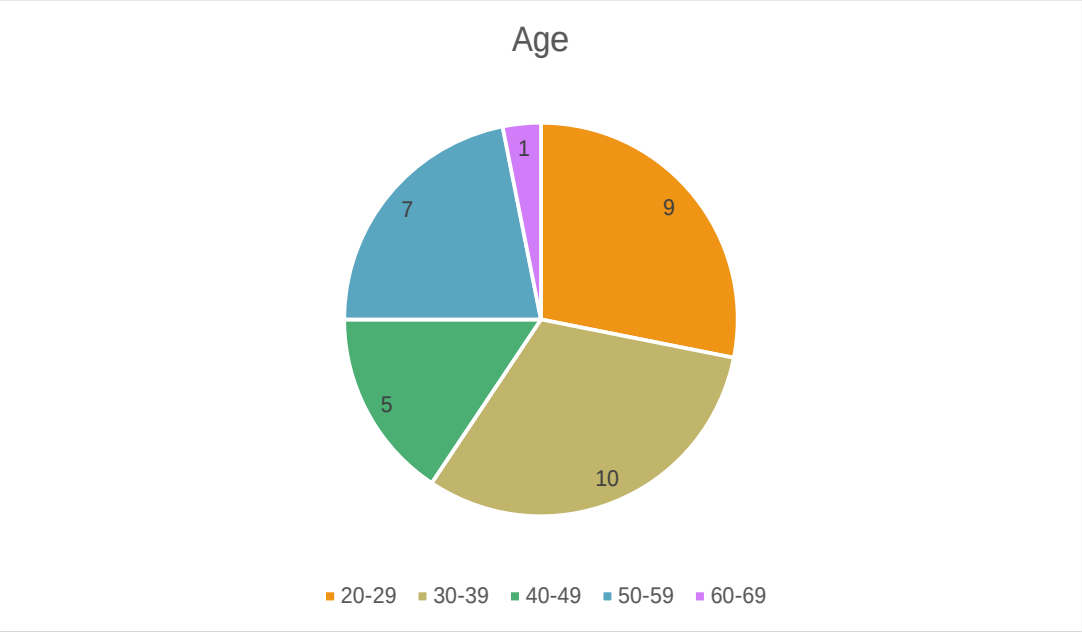
"Not sure, but I can't keep doing what I'm doing."

The remaining seven participants had different treatment goals. Most hoped to maintain stability, even if in the long term some aspired to abstinence. One was trying to achieve abstinence from only one drug (crystal methamphetamine), and another to drink less alcohol.

One participant felt trapped by the system, and didn't feel that his desires and goals were relevant in his treatment: "*I just comply with whatever the doctor says. It doesn't matter what I want, it's what the worker wants. Whatever services want, whatever is applicable. I don't have no choices or options*."



Eighteen participants were male, and fourteen female.



Participants were aged between 21 and 65, with an average age of 39.

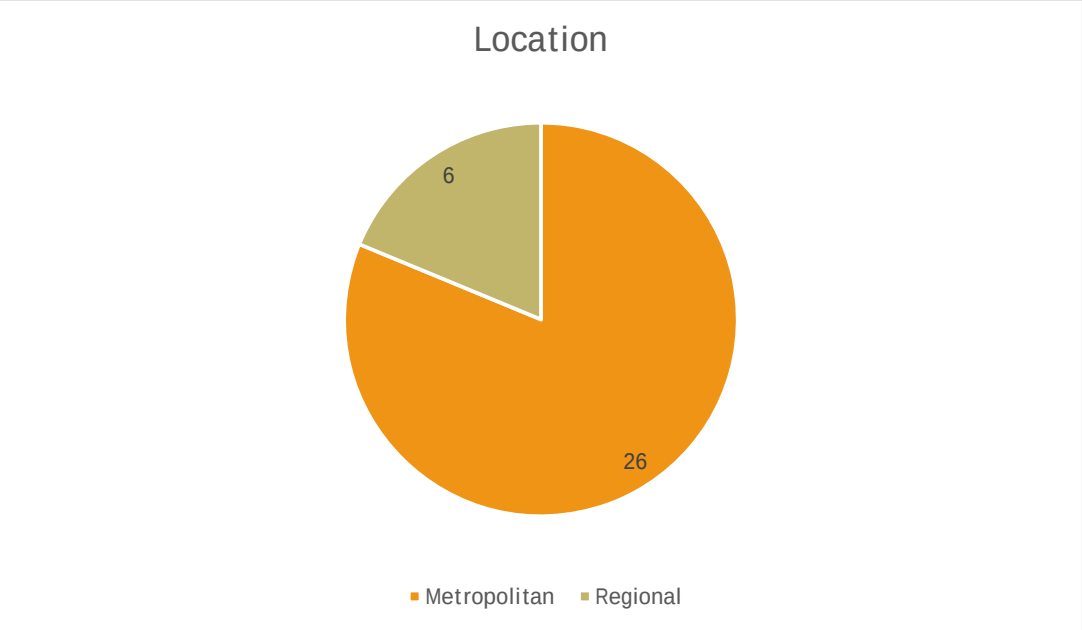
Nine participants were in their 20s.

Ten participants were in their 30s.

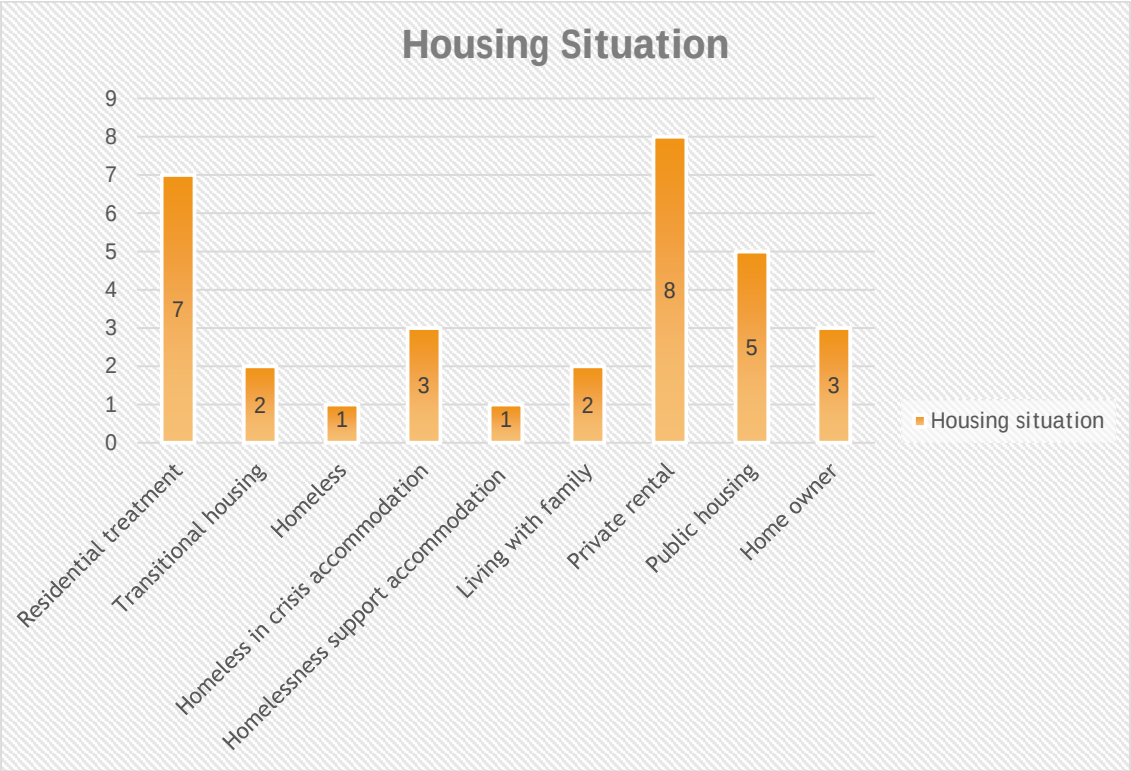
Five participants were in their 40s.

Seven participants were in their 50s.

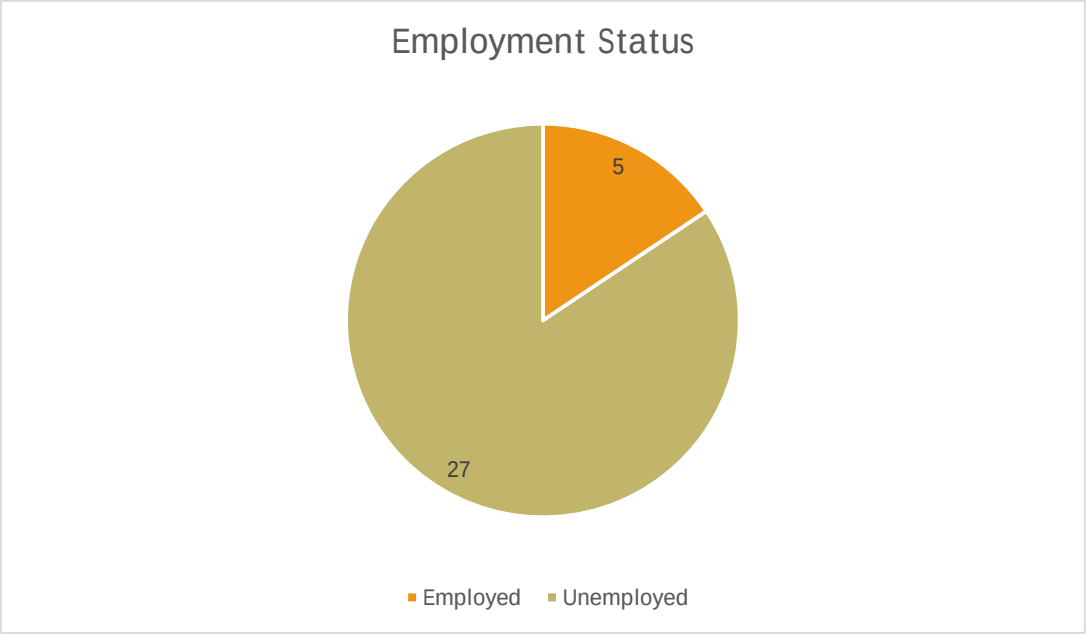
One participant was in their 60s.



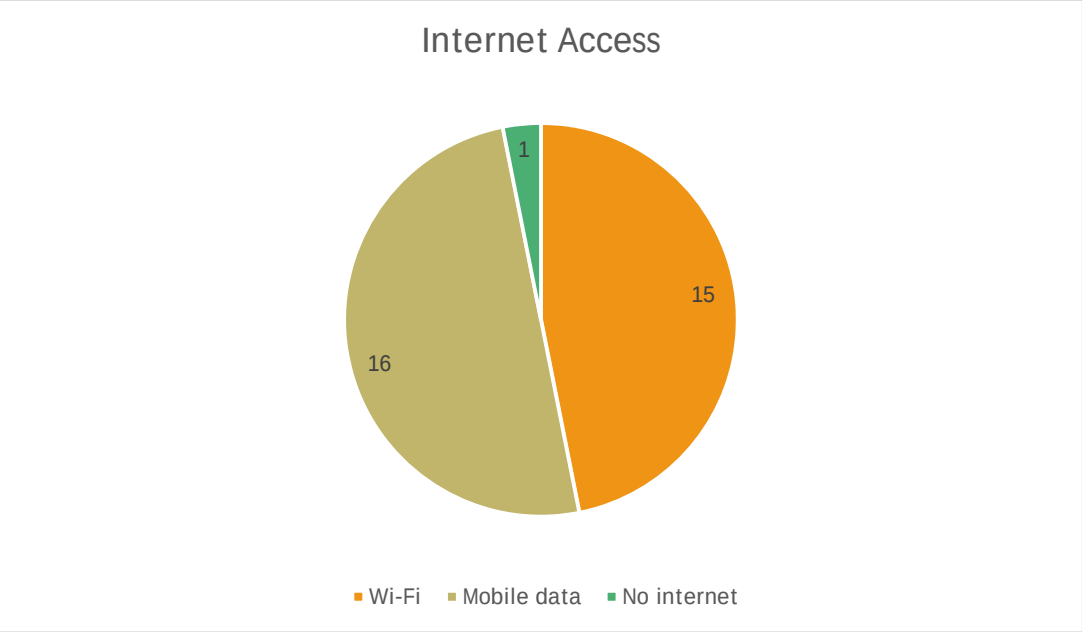
Twenty-six participants resided in metropolitan Melbourne, six in regional Victoria.



Participants had a variety of housing situations. Five participants were generally homeless, although in different accommodation arrangements at time of interview. Another nine were in residential treatment, with no stable housing options available once they leave the treatment. Only half of the participants had a stable housing situation, being in public housing, private rental, or owning a house.



Twenty-seven participants were unemployed. Of the five who were employed, three were full-time and two were part-time.



Most participants had internet access, although 50% only had access through their phone with limited mobile data. Fifteen had Wi-Fi access, which includes the majority of those in residential treatment. One participant had no internet access.

AOD Services Accessed by Participants

Consultation participants accessed a variety of AOD treatment programs in seventeen different organisations between March and May 2020. The programs include (in alphabetical order):

- Art therapy
- Care and recovery coordination
- Counselling
- Day program
- Detox
- Overdose response unit
- Peer support
- Pharmacotherapy
- Supported accommodation for adults
- Supported accommodation for youth
- Therapeutic community

Role of AOD Services

"I've had an amazing worker, and now another one who is also amazing. Just knowing that they are there and that I can always seek their support means so much. It's such a relief."

Our consultation confirmed that AOD treatment services play an essential role in the lives of people who access them. Nine participants (28.8%) reported not having any other support. Others had friends and family they could rely on for some help, but for many this did not extend to help with management of their drug use issues. Some participants had caring duties for their family members, so they were providing rather than receiving support. Many participants expressed a sense of comfort knowing they could call upon their AOD workers if needed.

"I went into rehab pretty broken. I couldn't even have this conversation back then. And it's been life changing."

AOD services were often a point of access to other support services, as well as being the primary source of social interaction. A sense of community and group activities were particularly cherished among participants, and several stated that they would like to be involved in more social gatherings at their AOD service. Many also intended to remain connected to their services after treatment, or wanted to try other programs within the same service.

Although there have been a variety of experiences with AOD services during the COVID-19 crisis, the majority of participants expressed a strong sense of gratitude for the support they received, and the flexibility demonstrated by AOD workers and their organisations.

Changes in AOD Services

Consultation participants reported experiencing the following changes in AOD service delivery because of COVID-19 restrictions:

- Counselling and support moved from in-person to telephone appointments.
- Group programs, including peer support groups, moved to online delivery.
- Residential and detox facilities introduced social distancing measures. This was ensured by admitting less clients into a program, reducing the number of people involved in group activities, and shortening the duration of group activities.
- Clients in supported accommodation programs stopped attending community gatherings and interacting in person with clients in other houses.
- Community outings with workers were suspended and replaced with text messages or telephone calls.
- The number of pharmacotherapy takeaway doses increased, requiring less frequent pharmacy visits.
- Consultation with pharmacotherapy-prescribing doctors moved from in-person to telephone appointments.
- Many extra activities were put on hold. These included art therapy programs or consumer participation activities.

Consultation Participants' Experiences of Changes in AOD Services

Telephone Service Delivery

"It's a lot better than not having anything. It's good to know that they're there for you, rather than being completely on your own. But by the same token, it's nowhere as good as a face-to-face meeting."

The vast majority of consultation participants reported that receiving support and counselling over the phone was a poor substitute for being in the same room as a worker. However, many accepted it as a necessity during the pandemic, and were appreciative for receiving any support. "Better than nothing" was a phrase frequently used to describe the experience.

Some participants disengaged and relapsed due to a lack of connection in telephone interactions. These participants were all in the earlier stages of recovery or seeking recovery. One participant observed that he didn't feel any accountability towards his worker without seeing them face-to-face. Another participant suggested that the transition to telephone support would have been easier if there had already been an established relationship with the worker, whereas establishing a relationship over the phone is difficult.

Many services compensated for this transition by increasing the number of phone calls, so if a client would normally have weekly appointments, they would have telephone sessions twice per week. This compensation was generally very well received by service users. One participant stressed that having this additional support prevented her from a certain relapse, due to her particularly harsh circumstances.

Some workers were getting in touch with their clients more frequently via text message. While this was appreciated, a phone call was preferable to a text message.

Although 90% of the consultation participants found telephone support a poor substitute for "the real thing", three participants reported their appreciation for the telephone appointments. They said that having the option of replacing some in-person appointments with telephone calls would be beneficial once the COVID-19 restrictions are lifted. These three participants were all in established recovery, and have parenting responsibilities for young children. Not having to attend the appointments in person allowed them to attend to their many other everyday duties with less stress.

Online Service Delivery

"The [AOD service] did a really good job of transitioning to online delivery. They did a brilliant job of adapting and facilitating the program as if we were all in the room. They even managed to get new people engaged in the group and participating. They adapted and made modifications to the rules. They also sent emails after each session and they included anyone who had been through the program before so they'd know that there is help available if they struggle. Definitely hats off to them."

All participants involved in group programs reported that the programs transitioned to online delivery. The quality of transition was rather patchy. Some organisations succeeded in delivering a seamless transition, while others took two or three weeks to get organised.

The slower transition was strongly felt by clients. Those who experienced it reported struggling and feeling particularly isolated, and a few reported a lapse to drug use during that time.

Participants found the online gatherings very useful, even if not ideal. Many appreciated being able to interact with their peers. Some participants were also very complimentary of how their group facilitators handled the transition and maintained a healthy and supportive group environment. Online group catch-ups were a highlight of the week and the principal source of support for most.

"If they're gonna put all services online, then they gotta make sure people can access them."

The main issue with online service delivery was a lack of access to IT equipment and/or inadequate internet connection. While some participants owned a computer and had a good internet connection, many could access the online programs only through their mobile phones with limited data. A few reported having very basic phones, which made the access additionally difficult. Lack of other IT equipment has also been noted.

Insufficient IT skills were another issue when accessing the online programs, both through mobile phones and computers. Several participants said that they would benefit from having some technical assistance with IT.

While the online group programs were very beneficial, participants did not view them as a potential long-term replacement for meetings in person. Some participants

reported feeling uncomfortable with solely verbal communication, noting that it precludes most non-verbal forms of communication and inhibits feelings of togetherness. However, several participants did say that having the option of accessing the online group programs from time to time would be helpful, although none said that the online access alone would be sufficient.

One participant from a regional area reported having received the necessary equipment, as well as internet data, from her AOD program. She said that she would not have been able to attend the program without this aid. This also enabled her to access other forms of online recovery support, which boosted her personal growth during the lockdown.

Pharmacotherapy

"Going to the pharmacy only once a week has been good. Sometimes you have to wait in the pharmacy up to one hour and it can mess up your whole day."

A quarter of consultation participants were on the opioid replacement therapy (ORT) program at time of interview. They were impacted by two changes in this program: an increase in the number of takeaway doses and the consultations with the prescribing doctor being held by phone.

The increase in the number of takeaway doses was very well received. All participants on ORT appreciated the opportunity to limit their exposure to COVID-19 and save time in general. There was a unanimous expression of hope that the number of takeaway doses will remain the same after COVID-19 restrictions are lifted.

Telephone consultations with prescribing doctors were also well received and deemed sufficient. One participant reported receiving their doctor's phone call several hours late, but that was the only negative experience with telephone consultation.

"I was worried about methadone supply getting cut. Pharmacist couldn't guarantee that it wouldn't happen. And if that happened I know I would get seriously ill."

With many sudden changes across the whole of society, several participants felt anxious that their pharmacotherapy drug might become unavailable. Some sought reassurance from their pharmacist who told them that it was unlikely, but could not provide any guarantees. One participant suggested that receiving a message of reassurance from the authorities would have been helpful.

With the exception of some uncertainty around continued supply, pharmacotherapy was the only form of treatment where participants reported an overall improvement in their experience.

Residential Services

"Community is an important part of the service, and with restrictions we couldn't be in person together, so we're a bit disconnected. At times I felt disconnected from the community. Workers organise weekly check-ins together and we do group meetings. We have started checking in with each other and supporting newer residents. That's something we should keep after these restrictions."

For the purpose of this consultation, the definition of a residential service is any service where a client is provided with accommodation as well as AOD support, including:

- Detox
- Homelessness crisis accommodation
- Supported accommodation
- Therapeutic community

Twelve consultation participants were in a residential service during the COVID-19 lockdown between March and May 2020.

Participants reported that residential services introduced a range of measures in response to COVID-19, including reducing or pausing admissions, and reducing the duration and size of group activities. Some services also suspended any external visits and excursions. Supported accommodation programs stopped any physical community gatherings among clients from different houses, and contact with the workers and the rest of the community transitioned to online or over the phone.

Most participants reported a strong impact on the sense of community in their residential programs. For some, this was due to the community getting smaller with no new admissions, and for others because of the inability to share the same space or do activities together.

However, while the community as a whole was somewhat weakened by the restrictions, several participants found that interpersonal bonds between individuals grew stronger,

as those still sharing the same spaces increasingly relied on each other for support. In some programs, this peer support model among residents was formalised, which they considered helpful. Many also found online gatherings useful, although only as a temporary solution in the extraordinary circumstances.

All residential clients commended the staff in various programs for their ability to implement changes and find new ways to meet clients' needs. Safety restrictions had an impact on the intensity of some programs, and a couple of participants expressed their concern that they were not doing enough "recovery work", but also said that workers' flexibility compensated for this.

Participants in crisis accommodation programs reported little impact from the COVID-19 restrictions. With the assistance of the crisis accommodation staff, they were able to access a range of other medical and legal services during the restrictions.

Peer Support

"Zoom peer support is pretty good. For couple of weeks I had nothing, but when Zoom meetings started I realised that's what I needed. I prefer face-to-face, but it's good."

Fourteen participants were using peer support groups during the COVID-19 restrictions. This included twelve-step programs, such as Narcotics Anonymous (NA) and Alcoholics Anonymous (AA), which ten participants accessed. Another four participants joined peer support groups hosted by AOD organisations. A few others stated that they wanted to access either NA, AA or SMART Recovery, but had not done it yet. Some were reluctant because these meetings had also moved to online.

Peer support was greatly appreciated by all who took part in it. They found comfort in seeing how their peers were coping in the new circumstances, and for some it was a source of information. Some participants from regional areas noted that online meetings enabled people from regional areas to attend, and they expressed hope that some online meetings would remain available after the restrictions for that reason.

Twelve-step meetings were an important source of support for those who attended them. For some, this was the only support they had other than the AOD services. A few participants reported that twelve-step meetings online became available quickly and were of a very good quality: "*They understand the importance of connection, and so the online stuff is really quite good"*. A couple had also "travelled" to meetings overseas.

Service Access

"Lapse or relapse goes a bit longer when you can't access support."

Only one participant reported trying to access AOD services during the restrictions. This person had a relapse at the beginning of the COVID-19 crisis and immediately tried to access support by calling the AOD service she had used previously. The service never responded to her messages, which delayed her treatment. At time of interview she had scheduled to commence treatment with a different organisation, but said that her relapse lasted longer and became more serious because of the difficulty in getting timely help.

Experiences with Other AOD Service Changes

"I needed a food voucher and they don't mail them out, so that was pretty tough."

A range of other programs were impacted by the COVID-19 restrictions. A few participants were involved in art therapy programs, which were put on hold. A couple of participants received art materials to work on their own until the program resumed. One participant collaborated on a consumer project, which was also suspended.

A few participants were no longer able to receive in-kind support, like food parcels and vouchers. This added further pressure to their already strained financial resources. As this coincided with the food shortages caused by widespread panic buying, the first few weeks were quite difficult for these participants.

Experiences with Other Public Services

"I didn't get to see my daughter for two months because of Child Protection not allowing any contact. She is only ten months old. That was really difficult for me to cope with. Child Protection handled this situation very poorly. Having to interact with her on video calls was really hard because she is so young."

Twelve participants reported some experiences with other non-AOD public services during the restrictions. Two participants were waiting to continue with family violence support programs, which were put on hold during COVID-19 restrictions, and another three participants stopped seeing their psychologists. Several accessed medical, legal and job service support, and one was still receiving food vouchers from a church.

One participant was not receiving Centrelink benefits and had to apply during restrictions. This was a difficult process, additionally complicated by lack of internet connection. Most other participants were already receiving welfare payments.

Two participants were involved with the Child Protection Services. Both reported that the Child Protection Services introduced a blanket policy suspending any physical encounters during COVID-19 restrictions, instead shifting to online video meetings.

This caused a great amount of stress and frustration, and one participant said she would have relapsed if not for the intensive support provided by her AOD workers. Her baby had been temporarily placed in the care of a relative, their meetings facilitated by a worker from the Child Protection Services. When these were put on hold, she could only communicate with her daughter via online video applications. The baby was still very young, and communicating online was very difficult. The mother had been abstinent from any drugs for eight months at time of interview. She was required to undergo weekly urine drug tests, which had not stopped with the onset of restrictions. At time of interview she was expecting to be reunited with her baby within weeks.

The second participant was living with her child, but physical reintroduction of the other parent was postponed. In this case the child was of a speaking age, and the video encounters were somewhat more useful. She said that in a hindsight it may have been better for the child that the other parent was introduced gradually, starting with video meetings, but at the time it was very frustrating.

Finances

"It's nice to get more money from Centrelink. It will be tough going back to the usual pay. I struggle so much to pay my bills on the usual pay, not to mention having to buy things for my child."

Most participants were in a precarious financial situation – even some of the few who had a job. For some, having a job was more about having something to do and "staying out of trouble" than the prospect of achieving a healthy financial situation. Two participants lost their jobs when the restrictions were introduced and were unsure if they would find new ones anytime soon.

Many participants benefited from the increase in the welfare payments. Some reported being able to cover some outstanding bills, and others were excited about having savings for the first time. One purchased a sewing machine, hoping to be able to do something creative and potentially useful. Several expressed anxiety about losing the additional payment, particularly those with young children.

"I've been thinking about getting a better internet access, but I simply can't afford it."

During the COVID-19 crisis, the internet has become necessary to access some essential supports and services, but most participants could not afford to improve their access to IT equipment or a better connection. In a world of social distancing and remote service delivery, the internet has become a utility, but for many AOD service users it is still a luxury.

Widespread panic buying made it difficult for some participants to access basic necessities during the first couple of weeks of restrictions, as quite a few did not have cash while the supermarket shelves were still full. Inability to access food parcels and vouchers from services contributed to making this situation even more difficult.

Service Users' Needs during COVID-19

We asked participants what would help them to better manage their substance use issues during COVID-19 restrictions. They gave us the following list of recommendations:

- **Some face-to-face support** – The option of receiving some face-to-face support was preferable to some participants who were still in very early stages of seeking recovery. They did suggest that this could happen less frequently (i.e. fortnightly instead of weekly) and with necessary precautions in place, such as masks, hand sanitiser and protective screens between client and worker.
- **Online recovery support services** – One participant noted that most currently available recovery-focused online supports are American, made for Americans. She stressed the need for authentically Australian recovery support.
- **Frequent telephone support** – Frequent check-ins via telephone have been found helpful where implemented. While they did not replace the value of face-to-face support, they did compensate for lack of it.
- **Reassuring information about pharmacotherapy** – Lack of certainty about continued supply of pharmacotherapy drugs caused a fair amount of fear and anxiety. People on the ORT program are dependent on these drugs, and dread the possibility of not having access to them. One participant suggested that receiving communication about safety of supply chain would soothe these anxieties.
- **Better IT equipment and internet access** – 50% of participants could only access internet through their phones with limited data. Even among those who had Wi-Fi, several did not have a computer or had old models with limited capabilities. This caused significant difficulties in accessing essential services.
- **IT technical support** – Most participants had very limited IT skills. Some received technical support from their more tech-savvy peers, but most had no support. Lack of IT skills substantially hindered access to services.

General Experience of COVID-19 Restrictions

"I've been going to the local shopping centre most days to use Wi-Fi there, but a few times the police came and moved people who were sitting there using Wi-Fi."

Lack of IT equipment, skills and internet access was a major issue for many participants during COVID-19 restrictions was. 50% of the participants could only access internet with limited phone data. This impacted access to support services and Centrelink, as well as to other supports, information, education and entertainment. One participant had no internet or television during the first few weeks of the lockdown and was only receiving news from her peers over the phone. Inability to access information increased her anxiety and confusion. She managed to purchase a smart phone few weeks into lockdown, but was unable to get internet connection except for limited phone data. Public spaces with available Wi-Fi were monitored by the police, so she could not spend much time there. She and a few others reported that they would normally rely on public libraries for internet access, but this option too became unavailable. One participant received a second-hand laptop, but needed help to learn how to use it. Another participant was using an old computer without a camera, which made her feel awkward when accessing peer support. One participant succeeded in repairing a discarded laptop, but had no Wi-Fi access.

"I had a lapse. I was engaged in a lot of activities before the restrictions, and I felt a bit lost when everything stopped. Loss of structure played a big role in my lapse."

Similarly to the general population, many consultation participants experienced isolation during restrictions. This was difficult for some, particularly those in early recovery, who rely on keeping busy to stay well. A few talked about relying on their online day programs and peer support groups to stay connected and lessen feelings of isolation. The risk of relapse was ever-present, because many recovery-enhancing activities had to be stopped, and the new lifestyle in isolation had many similarities with the drug-using lifestyle.

The weekends were particularly hard for those who rely on AOD services as their only source of support. This was intensified by not having reliable access to internet or opportunities for leisure and self-care. One participant from an inner-city public housing estate noted that there is "not much to do in the flats". This person was craving contact with nature and outdoor activities, which were not accessible to him during restrictions.

"It was like everyone in the world lost their independence, but my independence was already gone."

However, quite a few participants stated that life in isolation was not difficult or new to them. They were already quite isolated and felt like it was a bigger problem for those who led a "normal" lifestyle before restrictions. One participant commented how experiencing prison prepared him for life in isolation. Having to live with limitations was a familiar situation for many participants, because trying to achieve recovery involves accepting some limitations. Some participants also reported that they were used to having shortages of food and other necessities.

"My anxiety was almost gone before the restrictions, I was going out and seeing friends, but now it's all back. Like when I was using, I would stay in the house all the time."

Several participants reported feeling anxious about the general situation, but also about their specific circumstances. Those who had children or elderly parents were worried for them, and some were anxious because they felt that they did not have enough information about what was happening. The anxiety was more pronounced in the first couple of weeks, and some felt calmer as time passed. However, a few others said that their anxiety was gone with the introduction of restrictions. One participant said that, although she suffers from anxiety, she felt no anxiety about the COVID-19 crisis, because it is something out of her control. Several also said that, although they had faced a lot of discomfort, they felt grateful for the restrictions and the government's handling of the pandemic in general.

"I'm in early recovery from drugs and alcohol, and I've been told that I need to take time to focus on myself. So it's actually not so bad that I don't have the pressures and the stress of having to do certain things because there are restrictions. But there is the tendency to want to isolate, so I have to be careful to maintain the connections with people."

Somewhat surprisingly, eleven participants (35%) reported a decisively positive experience on a personal level. Many took it as an opportunity to work on their recovery without external pressures. For them it felt like the entire world was taking a break, and they enjoyed having some slow and quiet time to dedicate to self-care, building or rebuilding connections, learning new skills and making plans for the future. A few had seen their circumstances particularly deteriorate in addiction, and were taking this as an opportunity to rebuild their lives.

However, it is important to note that all of those who had a positive experience during the restrictions were receiving intense support from their services. This support provided stability and realistic opportunities to change their circumstances. Many other participants said that the lockdown experience for them was neither positive nor negative, with little change in their personal circumstances.

"Very isolating. I was relying on going out and keeping myself busy. I lost my social skills a bit. My relationships with my partner and my friends have deteriorated."

Six participants (19%) reported an overall negative experience. For two this was primarily due to the impossibility of receiving in-person support. One participant struggled to access treatment, which had a significant impact on her experience. She also could not find appropriate recovery support online. Another participant struggled having to stop her outdoor activities, which were an important part of her recovery. Her mental health declined, with consequent negative effects on her relationships.

Service Users' Needs beyond COVID-19

Participants raised a range of policy and service delivery adjustments which would help them better manage their substance use and improve their circumstances:

- **Increased ORT takeaway doses** during COVID-19 restrictions were praised by participants on pharmacotherapy. This modification meant a significant timesaving. One participant commented that he felt punished when the number of takeaway doses he could access was suddenly reduced in 2016, although he never missed a single dose. Participants expressed hope that the number of takeaway doses would remain at the same level as during COVID-19 restrictions.
- Several participants on ORT lamented that they felt **stuck on methadone**, and were not told about the severity of methadone dependence when they signed up for the program. The need for clear information about the nature of ORT drugs and options to get off them has been noted.
- A few participants suggested that different forms of **group activities** be hosted by AOD services. Suggestions included sport, exercise, nature walks, art or cooking. Reclink was brought up as an example of a program providing a service of this kind. Many participants desired to be part of a community where they could safely continue their recovery, while also engaging in social activities. A couple of participants noted that group activities are good for their mental health.
- Participants praised **educational day programs**, where they could learn important life skills, such as assertive communication or boundaries. Those who participated in such programs at their services found them very helpful.
- Three participants appreciated the **option to have telephone or online appointments**. All other participants were decisively against this option. The three in favour were all in established recovery and with parenting responsibilities. This option could be considered at a late stage of treatment, particularly for those who have parenting responsibilities or other important duties.
- A couple of participants raised the need for **better community understanding of addiction issues**. They both struggled with their closest relations' lack of understanding of addiction, and faced unreasonable expectations about detoxing and stopping drug use. Family members often did not understand that

quitting a drug suddenly could lead to death, or that detoxing requires medical supervision. Similarly, many family members did not understand the underlying causes of addiction (i.e. trauma).

- Lack of **supported accommodation program in regional centres** was raised as a significant service gap. A couple of participants were planning to move to regional towns after treatment, for a more affordable cost of living. One of them was nearing exit from treatment and was concerned that he was not ready to live completely independently. In addition to being in early recovery, he was also still unemployed and could not afford a private rental. He needed a housing solution that would also provide a certain degree of AOD support.

- A couple of participants said they would benefit from having access to **prescription heroin**. These participants were long-term heroin users on the ORT program. Their personal circumstances were not conducive to complete abstinence at this time.

- One participant voiced the need for a **'one stop shop'** AOD service. He was finding that the AOD treatment system is fragmented and difficult to access. He said that the system is very good once a person succeeds in accessing it, but that information about treatment options is difficult to find. In his view, many ordinary Australians who could benefit from support for their excessive drinking would not know where to start seeking help.

- One participant found that **general practitioners need better knowledge of AOD issues**. In his experience many did not know how to manage a home detox from alcohol.

- One participant noted the need for **more detox** facilities.

- A participant in treatment for methamphetamine addiction found that there was **too much focus on the drug**, and **not enough "***old-fashioned genuine connection***"**. He stressed that clinical settings do not help addiction issues, and that "*love, compassion and empathy need to be central to every service*".

- One participant was struggling to find employment because of his **past convictions**. He wanted to work in transport or IT but was stuck on welfare because all employers wanted **criminal record checks**. In Victoria criminal records never expire, and continue to appear long after a conviction. For him it meant that any effort to change his circumstances had been futile thus far.

In addition to suggestions about policy and service delivery, participants also talked about their broader needs:

- **The sense of purpose** was brought up in various ways by many participants. An overwhelming majority (86%) were unemployed and stated that having a job would make for a more solid recovery, as well as improve their lives in general. For a few, even working one day a week would mean a significant improvement. While the financial aspect played a role in this aspiration, a broader sense of purpose, desire to contribute to society and opportunity for connection were stronger motivations. Indeed, a few participants stated that the opportunity to volunteer would equally fulfil this need.

  "When my life is not fulfilling, there is nothing to leave the drugs for."

  One of the employed participants felt lack of sense of fulfilment in his job, which made his recovery difficult. He was earning a low salary of around $500 per week working full-time hours, but was determined to continue his employment because it gave him something to do.

  One participant was highly qualified, and had lost his job because of ageism in the workplace. He was struggling to find another, settling for jobs much less demanding than his skill level. Yet when he had opportunity to work, he appreciated connection with his co-workers. The loss of employment played a major role in his addiction issues.

  Younger participants were hoping to improve their situation by completing education. A few of them said that access to training and education plays an important role in their recovery.

- **Lack of housing** was an important source of instability for a few participants who were homeless, as well as for some of the others. One participant had no accommodation whatsoever. He felt that he had no dignity and needed to beg for any scrap of kindness. A few participants were content with the crisis accommodation arrangement at time of interview, but this was a temporary arrangement and they needed a long-term housing solution. Another participant was living in private rental in a poorly serviced remote suburb with no public transport options. She was a single mother of a young child, struggling to access shops or services without a driving licence.

- **Self-care activities** such as yoga, meditation, art therapy or exercise were helpful for many participants during lockdown. Some of them expressed hope to continue having time to slow down and dedicate themselves to self-care after COVID-19 because it significantly improved their recovery.

Concluding Recommendations

Our consultation included a diverse range of people at different stages of recovery with varied support needs. While each participant had a unique set of circumstances and experiences, several commonalities are evident.

Primarily, AOD services have a vital role in service users' lives. All participants wanted to get better, and most had an awareness that they needed support to achieve that. They also wanted to be a part of a safe community, and services provided that to various degrees. With many having few to no other sources of social connection, the role of AOD services as places for informal interaction is nearly as important as any other support they offer. AOD services can improve by developing a stronger awareness of this role and implementing more social activities.

A sense of gratitude to AOD workers was deeply felt by many. Even when the treatment system was criticised, these criticisms did not extend to workers. While many found that remote service delivery did not quite meet their needs, they appreciated the effort that workers put into providing as good a service as possible in the circumstances.

Remote service delivery was generally felt to be somewhat useful, although not nearly enough. Service users' acceptance of circumstances played a major role in the extent to which they felt that remote support was useful. While many praised workers' flexibility, they too demonstrated a strong collaborative and adaptability to make do with what was available. This resilience was also manifest in attitudes towards formal and informal peer support, where many were equally eager to provide and receive support.

Although only a minority of participants reported relapses during the COVID-19 crisis, this group is the greatest cause for concern. While we can only draw conclusions based on our interviews, we fear that our recruitment may have missed a larger number of service users who disengaged from treatment and relapsed when services transitioned to remote delivery. Those who reported inability to engage in telephone and online treatment were struggling considerably. This included participants in early stages of seeking recovery, but also many who had limited internet access and IT skills. As restrictions continue, it is quite possible that others will find it more difficult to cope. We suggest that extra support to clients in early recovery, and to those with limited internet access, should be considered an essential service, and that arrangements be made for some amount of in-person treatment.

Where no treatment in person is possible, remote delivery can be improved by increasing the frequency of contact. More frequent telephone calls have been found helpful, and this is also likely to apply to online meetings. While quantity cannot entirely compensate for quality, it appears to be a useful strategy in exceptional circumstances.

Similarly, state-wide remote support options would be beneficial. These could include both online and telephone recovery support services. Although online supports appear to be the more beneficial form of remote service delivery, lack of internet access means that telephone support is still a broader-reaching option.

Peer support has also been found very useful. This applied to peer support groups in individual organisations, as well as twelve-step communities. This form of support responded to both the need for support and connection. It also appeared that trust and rapport could develop somewhat faster with peer workers, because of shared experiences.

Lack of internet access and IT skills cannot be ignored when considering service delivery options in a time of social distancing. Service providers should assess their clients' ability to access online treatment and tailor it accordingly. However, working around lack of skills and access does not ultimately solve the issue. Our consultation clearly proves that there is a need for broader intervention at the government level. This should be focused on getting everyone connected to the internet, as the present situation significantly deepens the social exclusion of the most vulnerable and isolated individuals. In practice, this means provision of adequate IT equipment, internet connection and technical support tailored specifically to these people. A specific community program, or even an organisation, should be established to cover this role, and it would need to collaborate closely with existing community services to reach the people most in need of such support.

Pharmacotherapy clients have reported the most positive experience during the COVID-19 crisis. The change in state policy around the number of takeaway doses has been a significant improvement for service users. We recommend that this change remain in place after restrictions are lifted, with all the necessary safeguards in place for less stable clients.

Broader issues such as housing, employment and education play a crucial role in drug addiction and chances of recovery. These factors will continue having an impact both during COVID-19 and beyond. Any stability achieved through AOD treatment requires a fulfilment of basic human needs and a general sense of purpose in order to become permanent.

Attachment 1

Email sent to APSU membership, 18 May 2020

Dear APSU member,

AOD services have had to rapidly change the way they operate since the Covid-19 restrictions have been implemented, with no time to include service users in the decision making. As the Victorian consumer body in the AOD treatment space, APSU is concerned about lack of service users' voice in these important conversations and we are starting a telephone consultation to address it.

Over the following weeks we will be conducting telephone interviews with people who have been clients of the AOD services during the Covid-19 crisis. Through these interviews we want to gain a better understanding of AOD service users' needs and experiences specifically during this crisis. The results will be presented in a report for the AOD sector, providing an opportunity to learn from this extraordinary experience.

If you or someone you know have been accessing any publicly funded AOD treatment service in Victoria, we invite you to take part in this consultation. Participants' identity and confidentiality will be protected, and they will be remunerated for their time.

The consultation details:

Project: AOD Service Users' Needs and Experiences during Covid-19 Crisis

Who can participate: Clients of any publicly funded AOD treatment service in Victoria during Covid-19 crisis (March, April and/or May 2020)

Payment: Each participant will receive a $35 prepaid debit card.

Modality: Telephone interview of up to 30 minutes.

When: Interviews will be conducted on working days from 21 May – 10 June 2020

How to participate: Respond to this email or call 0499 490 161 with an expression of interest, stating your name and telephone number, and confirming that you have been client of an AOD treatment service during the Covid-19 crisis.

If you work in a Victorian AOD treatment service, we encourage you to pass this information to your clients, or to get your clients' authorisation and submit their contact details.

For any further information, feel free to contact Edita at ekennedy@sharc.org.au or 0499 490 161.

Warm regards,

Edita Kennedy

Lead Project Worker

Association of Participating Service Users (APSU)

Self Help Addiction Resource Centre Inc.

Attachment 2

VAADA ENEWS Post, 18 May 2020

AOD Service Users' Needs and Experiences during Covid-19 Crisis

Posted to ENEWS for Edita Kennedy on behalf of SHARC

People who use AOD treatment services have been dealing with complex issues even before Covid-19. In addition to substance use issues, many AOD service users face mental health issues, isolation, financial issues, reduced job and education opportunities, poor IT skills and access, and many other complications that impact their everyday life and chances of recovery.

Covid-19 crisis has added new layers of complexity. The entire society is navigating unchartered waters, and we are all encountering challenges in our personal and professional lives that we could not be prepared for. Just like the rest of society, AOD services have also had to rapidly change the way they operate, with no time to include service users in the decision making.

As the Victorian consumer body in the AOD treatment space, APSU is concerned about lack of service users' voice in the conversations around changes triggered by Covid-19. We are working on couple of projects to address this.

In the following weeks we will release a series of episodes on our "Straight from the Source" podcast, illustrating how service users, family members and peer workers are experiencing current Covid-19 crisis. The podcast can be found on all major podcast applications.

APSU is also undertaking a telephone consultation with people who have been clients of the AOD services during the Covid-19 crisis. The consultation aims to gain a better understanding of AOD service users' needs and experiences specifically during this crisis. The results will be summarised in a report for the AOD sector, providing an opportunity to reflect on this extraordinary experience. This will enable us as a sector to learn which changes would be beneficial in the post Covid-19 world, which were particularly challenging for service users, and if there are any alternative strategies that should be considered.

We ask that you assist us in accessing a solid range of people who have been using AOD services during the Covid-19 crisis by asking your clients if they would like to participate. Participants' identity and confidentiality will be protected, and they will be remunerated for their time.

The consultation details:

Project: AOD Service Users' Needs and Experiences during Covid-19 Crisis

Eligibility: Clients of any publicly funded AOD treatment service in Victoria during Covid-19 crisis (March, April and/or May 2020)

Remuneration: Each participant will receive a $35 prepaid debit card.

Modality: Telephone interview of up to 30 minutes.

When: Interviews will be conducted on working days from 25 May – 10 June 2020

How to participate: People can express their interest to participate by calling Edita at 0499 490 161 or by emailing ekennedy@sharc.org.au with the name and the phone number of the person taking part.

We encourage AOD workers to get their clients' authorisation and submit their contact details.

For any further information, feel free to contact Edita at ekennedy@sharc.org.au or 0499 490 161.

Attachment 3

VAADA ENEWS Post, 2 June 2020

AOD Service Users' Needs and Experiences during Covid-19 Crisis

Posted to ENEWS for Edita Kennedy on behalf of APSU.

APSU is still doing the telephone interviews with people who have been clients of the AOD services during the Covid-19 crisis, as per our VAADA Enews post on 18 May. This is the final week of the interviews and we encourage you to ask your clients if they wish to participate.

Each interview is conducted over the phone, taking up to 30 minutes. Participants are remunerated with a $35 prepaid debit card. Participants' identity and confidentiality will be protected.

Anyone who has been a client of a publicly funded AOD service in Victoria during the Covid-19 crisis can express their interest to participate by calling Edita at 0499 490 161 or by emailing ekennedy@sharc.org.au with the name and the phone number of the person taking part.

AOD workers are encouraged to get their clients' authorisation and submit their contact details.

For any further information, feel free to contact Edita at ekennedy@sharc.org.au or 0499 490 161.

Attachment 4

Information and consent

Recording

This interview is recorded to allow us to do an accurate analysis of all interviews and to write the final report. The recording will be used only by APSU and only for purposes of this consultation. The recording will not be shared with any third party. What you say will be used in writing the final report. Specific quotes may also be used. Your personal information and identity will not be revealed in the report or to anyone outside of APSU.

Do you consent to this interview being recorded: Yes / No

About APSU

The Association of Participating Service Users (APSU) is the Victorian consumer representative body for people who use, have used or are eligible to use AOD treatment services, and for those directly impacted by someone's AOD use (i.e. family members).

About the project

This interview is part of a series of interviews conducted with people who were clients of publicly funded AOD services in March, April and/or May 2020, at the time that Covid-19 restrictions were put in place. The aim of these interviews is to get the sense of how people experienced AOD services, but also broader changes in the society, and to explore if there are service or policy changes that people who use AOD services would benefit from.

Payment

You will be paid $35 for participating in this interview. The payment is in form of a prepaid debit card, which will be mailed to you.

Your personal information will be used to process the payment.

Payment details:

Full name: _____

Address: _____

Change of mind

You can choose to stop the interview at any time during the interview. If you choose to stop, the interview will not be used for the final report and you will not be eligible for the payment.

Do you understand this information? Yes/No

Do you have any questions before we start the interview?