

APSU is a service of sharc

‘Your Feedback Matters’:
A snapshot of consumer
experiences with
Victorian AOD services in 2018

Survey Report

**Association of Participating Service Users
(APSU)**

APSU is a service of SHARC (Self Help Addiction Resource Centre)

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APSU would like to acknowledge and thank all the services users and family members who kindly took the time to complete the survey and provide this valuable feedback, to those who helped with promotion and to Tania Evers who volunteered her time to assist with completing this report.

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Introduction

Around 40,000 Victorians currently access treatment services each year, which is delivered through a number of streams including: intake, counselling, withdrawal, rehabilitation and pharmacotherapy¹. The Victorian Alcohol and Other Drug (AOD) system continues to struggle to cope with the immense demands for treatment. This results in issues with access to services, especially in regional areas, and issues with the quality of service provision. This is exacerbated by the fact that consumers of AOD services are often experiencing co-occurring issues such as mental health, trauma, homelessness and criminal justice issues. They are among the most disempowered, vulnerable groups in society and due to the fact that substance use issues are often treated as criminal justice issues rather than as health issues, consumers often experience stigma and discrimination and have very little avenues for their opinions to be heard. Therefore it is important to create platforms for consumers to give feedback on services and policies that impact upon them and for their voices to be heard.

This report documents the results of the 'Your Feedback Matters' survey that the Association of Participating Service Users (APSU) ran over a 6 month period from March to August in 2018. The survey gained feedback from 57 consumers, including family members and service users, in regard to AOD treatment services they have accessed, or attempted to access, within Victoria.

APSU originally designed a survey of the same name to gain feedback on consumer experiences after the significant reforms within the AOD sector in 2015- 2016. This current survey was re-designed in the aim of gaining more generalised feedback from consumers on their experiences with AOD treatment services and supports in Victoria. More specifically, the survey attempted to gauge how easy or difficult it was to navigate, access & engage in AOD treatment services, the length of time taken to do so, any concerns regarding quality of services received and what consumers think would improve the overall process & experience. The survey also explored consumers' opinions on the biggest AOD issue(s) facing their communities as a whole.

Method

The survey was designed using 'Survey Monkey' and contained a total of 12 questions which took consumers an average of 6 minutes to complete. The questions contained a mix of open ended responses and prioritising selections from set options. The survey was promoted through the APSU membership base, social media and throughout the AOD sector. Primarily this promotion was undertaken online however promotional postcards (see Appendix.1) were also distributed and a phone number provided for consumers who have limited access to technology or have low literacy levels. The majority of responses were received towards the end of the time period, in August which was due to a competition that APSU ran as an incentive, awarding two Gold Class Movie tickets to a random participant.

Limitations

The survey results do not necessarily reflect all consumer experiences as consumers have hugely varying experiences with treatment services depending on their personal capacity to find and navigate services, the complexity of their issues and the type of services they are engaging with, among many other things. Other limitations of include the fact that

¹ Victorian State Government, 'Alcohol and other drug treatment services' *Health. Vic*, <https://www2.health.vic.gov.au/alcohol-and-drugs/aod-treatment-services> (accessed 01.10.2019).

there is no way of knowing if participants were providing feedback solely on their experience with government funded services. There are several examples in the responses where participants mentioned private counsellors etc. The survey was primarily promoted and completed online which creates barriers for those with low literacy levels and no access to computers. Finally, it should be noted that the data in the survey is dated from 2018. These limitations should be taken into consideration when interpreting this consumer feedback.

Demographics of participants

A total of 47 people responded to the survey which consisted of 74% service users and 26% family members, and of these, 82% accessed services in metropolitan Melbourne with the remaining 18% accessing regional/rural services. Of those who responded 37% were seeking access to AOD services for the first time. This statistic was similar for both metropolitan and regional/rural areas, with only 4% more metropolitan respondents having accessed AOD services previously (64% metropolitan vs. 60% regional/rural).

Summary of the key findings

This survey reflects that the most prevalent concerns that service users and family members have in regards to accessing AOD treatment and services are:

- **Wait times** to access most services (public) are too long and the services that consumers need are not often available directly when consumers need them;
- The process/systems are often **complex** and difficult to navigate;
- **Repeating** one's story and/or doing the same process over and over again in order to access a service can be frustrating, painful & challenging; and
- Consumers experience significant **stigma** and this is a barrier to accessing treatment.

Overall, it is evident from the survey that many consumers of Victorian AOD services are appealing for:

- More government **funding** for current AOD service providers and for the creation of additional public services that are effective and meet public demand. This would consequently decrease **wait times** in accessing AOD services when initially required (in particular detox/withdrawal/long-term rehabilitation services and step-down/aftercare services);
- Treatment options that are more effective in meeting **complex needs** such as trauma informed and dual diagnosis treatment, more professionally trained peer workers and more long term and flexible treatment options;
- Treatment options that are more **accessible** such as outreach and after hours support as well as simplifying the steps in accessing various services;
- Better access to **information** about treatment options in the early stages of accessing treatment;
- Better **continuity** of services, not only between services but from one phase of recovery to the next, i.e. easy & timely movement from detox/withdrawal to long-term rehabilitation to follow-up/aftercare/outreach programs;
- Better access to inter-related health and **social services** such as housing options post-treatment;

- More respectful treatment and **less stigma** attached to substance use issues so that consumers can seek help without concern for negative consequences (i.e. livelihood/professional reputation, custody of children, criminal matters); and
- Harm reduction to be prioritised and a **health perspective** to replace the current criminalisation of substance use.

The Data- details of consumer feedback on each question

*See Appendix. 2 for a copy of the questionnaire.

Questions 1-5 gathered demographic information about the respondents.

Question 6 and 8 – Accessibility of services

Survey respondents were asked how easy or difficult is to access/receive treatment from a service/s. We defined services as including all of the treatment streams (intake, counselling, withdrawal, rehabilitation and pharmacotherapy)

Overall:

- 39% of people said it very difficult (32%) or difficult (7%)
- 31% said it was okay (neither difficult or easy); and
- 30% said it was easy (19%) or very easy (11%)

Metropolitan figures for this question were:

- 43% said it was very difficult (6%) or difficult (36%)
- 25% said it was okay (neither difficult or easy); and
- 32% said it was easy (19%) or very easy (13%)

Regional/ Rural figures were:

- 20% said it was very difficult (10%) or difficult (10%)
- 60% said it was okay (neither difficult or easy); and
- 20% said it was easy (20%) or very easy (0%)

We also asked the participants how long it took them to access treatment services with 43% of respondents saying that it took them a month or more and one consumer responding that it took them 6 months.

Two quotes in particular aptly sum up how simplified, faster access to services is desired by many service users and family members: **“When you need help, you need it then”** and **“you can’t get help when you need so you give up”**.

From our regional data regarding how easy or difficult respondents found it to access AOD treatment/services, in specific catchment areas:

- 100% of Barwon respondents* found it easy or okay (neither difficult nor easy), with 75% accessing services under 2 weeks and 25% taking over a month.

**representing 40% of regional/rural data*

- 66% of Gippsland respondents* found it okay (neither difficult nor easy) and 34% found it difficult, with 33.33% accessing services under a month and 33.33% taking over a month (33.33% did not answer this question).

**representing 30% of regional/rural data*

“Country providers weren’t linked in with rehab beds and had little knowledge.”

- 50% of Loddon Mallee respondents* found it okay (neither difficult nor easy) and 50% found it very difficult, with 50% accessing services under 2 weeks and 50% taking over a month.

*representing 20% of regional/rural data

“There was nothing except AA & NA.”

- 100% of Great South Coast respondents* found it okay (neither difficult nor easy) [no data given for how long it took to access service/s].

*representing 10% of regional/rural data

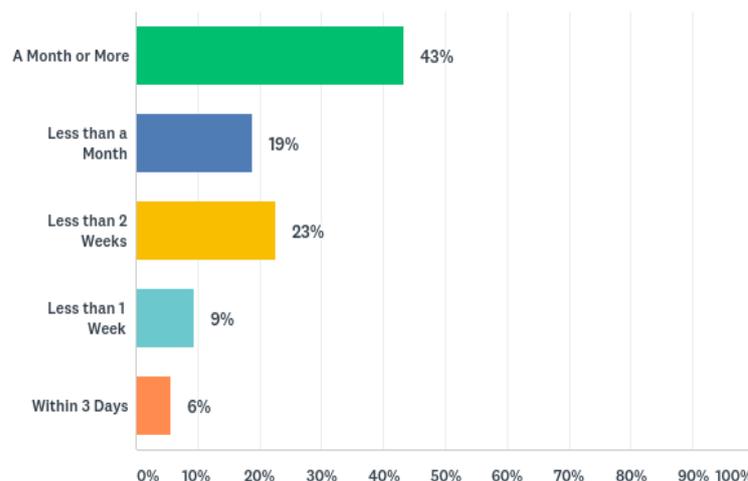
“Distance made it difficult to access treatment”

* See Appendix. 3 for breakdown of catchment areas of services accessed in metropolitan Melbourne and regional/rural areas.

From our Melbourne metropolitan data regarding how long it took respondents to receive the treatment service they referred to:

- 43% said it took a month or more
- 19% said it took less than a month
- 23% said it took less than 2 weeks
- 9% said it took less than 1 week
- 6% said they received treatment service within 3 days

Chart from Question 8: How long did it take to receive the treatment service you are referring to? (Metropolitan data)



Further comments

Most participants chose to provide further comments to these responses which offer further insight into their experiences. In relation to how long it took consumers to access services participants made comments which reflects on the variety of their experiences. One consumer stated that they felt the fact they called every day helped their case. Another participant commented that they attempted to receive public treatment but was going to have to wait more than four months so used the private system instead. Many participants did comment on the **wait times** throughout every stage from intake phone lines to rehabilitation beds. One participant responded that the wait times were particularly **“scary”** for them and too long to provide any help as they were experiencing homelessness and crisis at the time. This participant stated that once accepted into a

service it was great and **“helped save his life”** Another participant commented that they had waited for over 6 months.

Question 7- Reasons for difficulty accessing services

We asked participants who responded that they found it difficult to access services, to choose what they felt the main reason was. Overall, the main reasons our survey participants found it difficult to access service/s were:

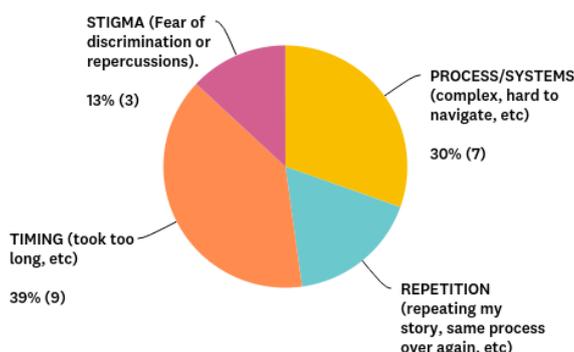
- 39% said 'timing' (it took too long, etc.)
- 30% said 'process/systems' (complex, difficult to navigate)
- 18% said 'repetition' (repeating my story, same process over again, etc.)
- 13% said 'stigma' (fear of discrimination or repercussions).

The other options included:

- Support (lack of support for child care, etc.)
- Information (lack of info or info not timely, etc.)
- Finances (lack of financial or other resources)

Chart for question 7: What are the main reason that you found it difficult to access services?

Q7 And what was the main reason you found it difficult? (Please choose only one of the following:)



Further comments

The consumer comments for this question reflect that it really depended on the type of service they were utilising as to how fast and easily they accessed services. One participant in Bayside commented that they received pharmacotherapy treatment through their general practitioner (G.P) and this was done relatively quickly, whereas a participant in a regional area commented that pharmacotherapy was difficult to access. Several consumers commented on the **difficulty of navigating** a complex, clunky system. Participants were concerned about having to **repeat their story** throughout intake and referral, having to chase up referrals and how difficult it was to **find the initial contacts** and information. One participant commented that their family member was too unwell to fill out forms, follow up on phone calls and navigate the system but no one **“seemed to realise just how bad she was”**. Similarly another consumer commented that the hoops they had to jump through to try and get into withdrawal and rehabilitation services were **“stressful and felt like a nightmare”**. They reported having to call at particular times and if they couldn't get through the beds would be taken and they would have to wait to try

again days later. This consumer commented that **“when you are desperate this adds enormous pressure”**.

One participant stated they felt it was getting progressively harder to access services and had to use the emergency ward to deal with urgent situations. Another participant stated that what made their experience difficult was **stigma**. They felt that their G.P had no meaningful engagement with them due to stigma. Of the consumers who found it easy to access services, there was one participant who stated it was easy for them because they were on a drug treatment order.

Question 9- The main concerns with treatment

Participants who felt they had received poor quality treatment service were asked, through an open ended question what their main concerns were. Again, the most common answers were in relation to **access**. Numerous consumers stated that they could not get the services they needed when they needed them and that the system in general did not meet their needs. There were multiple mentions of the **waiting lists** for treatment services and some consumers mentioned the wait lists for related services such as **housing** after leaving rehab.

Several **family members** commented about their difficulty in supporting their loved ones to navigate treatment services. One family member felt their sibling was significantly over medicated, another participant commented that the treatment services her sibling engaged in were not followed up with **assertive outreach**, which she felt contributed to her sibling relapsing each time she left a rehab facility and becoming increasingly unwell.

On a similar note, a participant with direct experience of treatment services commented that while the day treatment service they attended was of a good quality, there was no staff or **support available after** they had finished the day program and they found this difficult while in such early recovery. Multiple participants stated that there was **not enough staff** to engage with all of the clients in a meaningful way and to meet the complex needs of different clients.

One participant provided details about her experience at a particular rehab where she felt they relied primarily on consumers gaining support from their **peers** in the program and failed to provide her professional, medical support when she was in a vulnerable, high-risk state. She stated that this led to her feeling so overwhelmed she had a psychotic episode and had to be hospitalised. After years of recovery and utilising different treatment she reflects on this experience as something that **“scarred her”**. From a different perspective, a participant commented that in their experience of treatment there was not enough access to peer support and they felt **“they could not connect to workers who had never experienced what they were going through”**. They commented that access to **professional peer workers** is important.

Other comments focused specifically on the **intake process**. Several consumers commented that the intake number was not answered and that the intake process was **“slow and not inclusive”**. Another key area that was mentioned was the **stigma** that individuals faced when navigating treatment services. Consumers commented that stigma made the treatment system difficult to navigate, one participant commented that they felt **“they were not treated as individual or in an empowering way”** and another commented that **“the underlying cause of their addiction was not addressed”**.

It should also be noted that there were a number of **positive responses** to the treatment that consumers received once engaged. For example, one participant commented, **“my treatment was brilliant”**. Another commented that once she was in treatment she had no complaints and that she felt safe and supported rather it was getting there that was problematic.

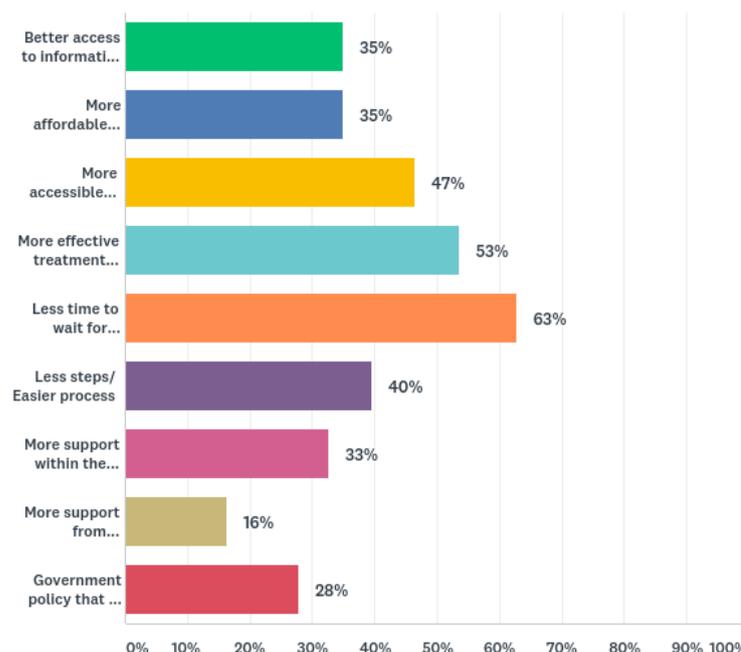
Question 10- Potential improvements

To provide insight into potential solutions, we asked participants what were the main things they felt would have improved their experience of navigating treatment services as well as the quality of service(s) received?

Of the following responses, each respondent was asked to select up to three choices. The results, in order, were:

- Less time to wait for initial support & treatment 63%
- More effective treatment options 53%
(more long term, trauma or step down support etc.)
- More accessible treatment options 47%
- Less steps/easier process 40%
- Better access to information about treatment options 35%
- More affordable treatment options 35%
- More support within the system (treated with more respect) 33%
- Government policy that was more supportive of harm reduction 28%
- More support from family/friends/partner etc. 16%

Chart from question 10: Overall what was the main things you feel would have improved your experience of navigating treatment services as well as the quality of the service you received?



Further comments

Comments by participants reflected the desire for **services which are flexible** and meet the **complex needs** of clients. For example, one participant stated that while he would like to see more **long term rehabs**, his family member was unable to utilise these because as a public housing resident there are restrictions on how long she can be away from her housing. This participant suggested finding ways for the **housing sector** to be more supportive and/ or provide daily outreach workers for those who can't access long term rehabilitation. Other participants requested more **trauma informed, long-term** after care and more **population specific** services such as Aboriginal mental health and AOD workers.

Participants commented on the desire for frontline services to provide better **consumer education** on services available to them. One stated *“I was only aware of counselling and it took me a long time to get on top of my AOD issues.”* Another participant suggested that the **funding** to services should be more consistent so that successful services were not suddenly cut when consumers were relying on them. The inherent conflict caused by the **criminalization** of substance use was identified and its impact on reducing the harm associated with substance use and on providing effective treatment. Finally, participants that had good experiences with staff or services being respectful, non-judgmental and inclusive or going above and beyond expectations, wanted to voice their appreciation and to see more of this.

Question 11- The biggest AOD related issues in consumer’s communities

To close the survey we asked participants, in another open ended question, to think about their community as a whole and what they think the biggest alcohol and other drug issue(s) facing the people who live and work around them is?

Their responses with direct quotes are broadly grouped below, however it should be noted that not all responses have been included:

- **Not enough AOD services to meet demands resulting in service gaps and excessive wait times**
 - *“Not enough services and waiting lists that are too long”*
 - *“More public services”*
 - *“Having access to quality, affordable treatment, without long waiting lists”*
 - *“Being able to access detox and rehab quickly”*
 - *“No smooth flow from detox to rehab”*
 - *“There needs to be more long term rehabs”*
 - *“Rural areas often suffer when it comes to availability of services”*
 - *“Services should be available no matter what your postcode”*
 - *“More preventative services, treat the problems not the symptoms”*
 - *“Lack of choices for treatments”*

- **A more simple & less complex process/system to navigate when seeking help**
 - *“(Not) knowing where to get help”*
 - *“Care co-ordination for those who don’t know how to navigate system”*
 - *“It’s hard to find one directory that has details for every service”*
 - *“Difficulty in locating the intake and assessment number for a local catchment”*
 - *“More accessible information”*
 - *“It is the difficulty in obtaining assistance that leaves me & my friends fending for themselves. This is a huge risk if you self-detox and it generally goes nowhere.”*

- **Lack of funding for AOD services**
 - *“Not enough funding and resources. I waited six months to get into a public rehab that when I got there the rehab was only half full because they didn’t have the finances to hire more staff to attend to more clients.”*
 - *“Insufficient funding for a range of services with adequate staff numbers”*

- *"Competitive tendering with DHHS causes funding issues for services so they are unable to focus on the services they deliver"*
 - *"The treatment options that are being funded don't reflect dependency as a long term, relapsing and complex condition".*
- **Alcohol and ice, in particular, were mentioned as the most problematic substances for communities to face**
- *"Alcohol is easily accessible and a cultural norm"*
 - *"Too many alcohol outlets in our area, which brings more crime and violence"*
 - *"Alcohol without a doubt. It's not that illicit drugs aren't an issue, but in regard to the majority of people in my community, it's definitely alcohol."*
 - *"The acceptance of alcohol and other problems it causes such as domestic violence, relationship breakdowns, anti-social behaviour, and mental health. It's an issue that gets a golden ticket because it's 'legal' and more acceptable to abuse."*
 - *"Young people and how pervasive Ice is. Ice has pervaded sporting clubs and young people can't seem to find too many places where it's not in their faces."*
 - *"Dealing with the ice issue, ice is everywhere"*
- **Criminalisation of substance use rather than prioritising a health perspective and harm reduction**
- *"Government policy which is focussed less on health and harm reduction and rather on criminalising substance use"*
 - *"Government policy being too afraid to try radical approaches"*
 - *"There will never be anything like sufficient treatment of users of currently illegal drugs while these drugs retain criminal status. The contradictory nature of a drug policy that seeks to implement harm reduction measures while retaining the criminal status that creates the greatest harm of all will continue to compromise well-intentioned efforts."*
 - *"The criminality attached to the use of certain stigmatised substances"*
 - *"If people were referred to treatment rather than prison we would have a much better outcome"*
- **Stigma and discrimination**
- *"The stigma associated with being a user, fuelled by constant negative portrayals of drug users in the media"*
 - *"Lack of G.Ps willing to prescribe ORT (opioid replacement therapy) results in difficulty accessing pharmacies who treat clients with respect"*
 - *Barriers to treatment due to stigma and discrimination from within the health sector as well as the community, for example, not seeking treatment due to fear of consequences and treatment not being effective because of stigma from health professionals"*
 - *"Demonising AOD use, creating shame for families and putting users at risk"*
 - *"Community attitude towards drug dependent people"*

- *“Problems begin in childhood but go untreated because more people need to be educated to lessen stigma for those talking about their experiences”*

Conclusion

This survey provides a snapshot of consumers' experience navigating various alcohol and other drug treatment services in Victoria, it is not an exhaustive study but provides unique insight into some of the issues that consumers are facing while navigating the treatment system, areas for improvement and issues of importance. While consumers had many positive things to say about the treatment services that they had engaged in, the issues of concern that the participants raised in the survey have been persistent for some time in the Victorian AOD service sector. Without practical & realistic change, they will perpetuate and continue to have consequences for consumers and the communities we live in. APSU hopes that the feedback tabled in this report can be drawn upon to improve these services and to trigger further exploration of how to best hear consumers' voices and to meet their needs through the Victorian service system.

“Recovery is a beautiful thing, and it is possible for anyone to get well, my wish and hope for the future is the government funds more solutions for problem users and creates more opportunities for people to get well”.

– A final quote from one of the participants.

Appendix 1. Promotional Postcard



YOUR FEEDBACK MATTERS

Provide feedback by calling one of our volunteers with a lived experience to complete a short survey on

1300 442 552

Leave a message for a call back if engaged or outside 9am-4pm, Mon-Fri.

Or complete the short survey on our website at
<http://sharc.org.au/program/association-of-participating-service-users/short-feedback-survey/>

*This survey is for family members and people who use/have used Victorian AOD services. This survey is not designed for service providers.



APSU is a Victorian consumer representative body of the Self Help Addiction Resource Centre (SHARC).

APSU has been set-up to ensure that opinions, ideas and experiences of Alcohol and Other Drug (AOD) service users and their families contribute to policy, research, service provision, systemic change and professional development.

We want your feedback to better understand your experience with the Victorian AOD treatment system.

By gathering your experiences APSU can work with the AOD treatment sector to make continuous improvements to the system in the future.



Call **1300 442 552**

Or complete the short survey on our website at
<http://sharc.org.au/program/association-of-participating-service-users/short-feedback-survey/>



Appendix 2. Questionnaire

Question 1.

Are you completing this survey as a:

- Service User
- Family member
- I was not assessed as not eligible to access services

Question 2.

Have you accessed a service in the Melbourne Metropolitan or Regional/Rural Area?

*Please Note that Alcohol and other drug treatment is delivered through a number of treatment streams across Victoria. These treatment streams include intake, counselling, withdrawal, rehabilitation, pharmacotherapy or a family related service

- Metropolitan Melbourne
- Regional/Rural

Question 3.

Using the map above, please select the catchment where you accessed services. (Tick all that apply)

- Eastern Melbourne
- Inner East Melbourne
- Inner North Melbourne
- North Melbourne
- North Western Melbourne
- South Western Melbourne
- Bayside
- Frankston - Mornington Peninsula
- South-Eastern Melbourne

Question 4.

Using the map above, please select the catchment where you accessed services. (Tick all that apply)

- Barwon
- Great South Coast
- Gippsland
- Grampians
- Goulburn Valley
- Hume
- Loddon Mallee

Question 5.

Is the time that you are providing feedback upon, the first time you have sought assistance with alcohol or drug services in Victoria?

- Yes
- No

Question 6.

Reflecting on your experience how easy or difficult was it to access/ receive treatment from a service?

- Very Difficult
- Difficult
- OK -or- Neither difficult or easy
- Easy
- Very Easy

Question 7.

And what was the main reason you found it difficult? (Please choose only one of the following)

- INFORMATION (lack of info or info not timely, etc.)
- SUPPORT (lack of support for child care, etc.)
- PROCESS/SYSTEMS (complex, hard to navigate, etc.)
- REPETITION (repeating my story, same process over again, etc.)
- TIMING (took too long, etc.)
- FINANCES (Lack of financial or other resources)
- STIGMA (Fear of discrimination or repercussions).

Question 8.

How long did it take to receive the treatment service you are referring to?

- A Month or More
- Less than a Month
- Less than 2 Weeks
- Less than 1 Week
- Within 3 Days

Question 9.

If you felt that you received a poor quality treatment service, what were the main concerns that you had? (Open ended)

Question. 10

Overall what was the main things you feel would have improved your experience of navigating treatment services as well as the quality of the service you received? Please select up to three choices.

- Better access to information about treatment options
- More affordable treatment options
- More accessible treatment options
- More effective treatment options (more long term, trauma or step down support etc)
- Less time to wait for initial support and treatment
- Less steps/ Easier process
- More support within the system (treated with more respect)
- More support from Family/Friends/Partner etc.
- Government policy that was more supportive of harm reduction

Question 11.

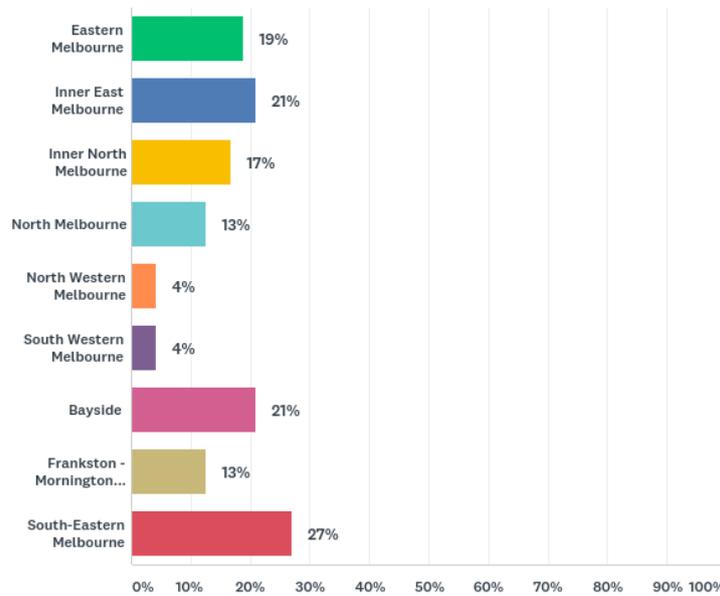
Thinking about your community as a whole, what do you think is the biggest Alcohol and Other Drug issue(s) facing the people who live and work around you?(Open ended)

Question 12.

Do you have any further comments on your experience you would like to add? (Open ended)

Appendix 3. Breakdown of catchment areas of services accessed in Metropolitan Melbourne & Regional/Rural areas:

Q3 Using the map above, please select the catchment where you accessed services. (Tick all that apply)



Q4 Using the map above, please select the catchment where you accessed services. (Tick all that apply)

