

# ATODA Policy Position Statement

## Involving People Who Use Drugs in Decision-Making Processes

### Key Messages

- Decision-making regarding drug policy and programs requires input from the individuals impacted by those decisions.
- People who use drugs can provide valuable input due to their proximity to real world harms of drugs and the criminalisation of drugs. These views are an important contribution to evidence-based decision-making.
- The people whose views should specifically be sought include, people who currently use drugs, people with a lived experience of using drugs, and people who access alcohol, tobacco and other drug (ATOD) services. For the sake of brevity, this position statement refers to all three groups as “people who use drugs”.
- It is important to empower the community that disproportionately suffers the consequences of the criminalisation of drugs.
- Engaging with people who use drugs requires expertise, resourcing and an appropriate process that values this input.
- Involving people who use drugs in relevant decision-making processes aligns with a human rights approach, specifically the right to participate in public life. Additionally, it works towards the human right of equity to access healthcare.

### ATODA Policy Position (Summary)

- It is critical to prioritise the participation of people who use drugs in decision-making processes that impact them.
- Relevant stakeholders, including government and non-government organisations, should provide meaningful and accessible pathways to involve people who use drugs in all relevant decision-making processes.

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### Note

While the term AOD (alcohol and other drug) is commonly used to refer to the alcohol, tobacco and other drug sector, ATODA’s preference is to use the term ATOD. This acknowledges the role that specialist service providers in this sector play in providing tobacco cessation support, and because tobacco use is the leading preventable cause of the burden of disease in Australia, contributing far more than alcohol or all illicit drugs combined.

### Disclaimer

The views expressed in this Policy Position Statement are ATODA’s alone. However the Statement was reviewed by the Specialist ACT Alcohol, Tobacco and Other Drug Executives Group, and the views of people who use drugs were incorporated via one-on-one conversations with nominated clients from ACT ATOD treatment services and via input from the ACT consumer peak, Canberra Alliance for Harm Minimisation and Advocacy (CAHMA).





## Background

In recent decades there has been increased attention on the need to include consumers in relevant decision-making processes, and this has been particularly prevalent in relation to health policies and programs.<sup>1</sup> The importance of involving people who use drugs is recognised and valued in other areas of policy.<sup>3</sup> Likewise in relation to drug policy, it is recognised “policy should be informed by the people it directly affects”.<sup>3</sup> However stigma and discrimination have been significant barriers to the engagement of people who use drugs in decision-making processes to date.<sup>1</sup> Use and in particular dependence on any drug, including alcohol, is stigmatised in Australia. The criminalisation of many drugs adds another layer of stigma, meaning that people who use illicit drugs are often more highly stigmatised and discriminated against than people who use legal drugs. The stigmatisation of people who use drugs adds barriers to the affected community participating in decision-making processes, and it is for this reason that the active prioritisation of people who use drugs in all levels of relevant decision-making is necessary.

## Evidence

Involving people who use drugs in relevant decision-making processes is associated with positive health outcomes for many population groups.<sup>1</sup> Involving people who use drugs in relevant decision-making processes also recognises their innate human rights. **As noted in the International Guidelines on Human Rights and Drug Policy “Everyone has the right to participate in public life. This includes the right to meaningful participation in the design, implementation, and assessment of drug laws, policies, and practices, particularly by those directly affected”.**<sup>6</sup>

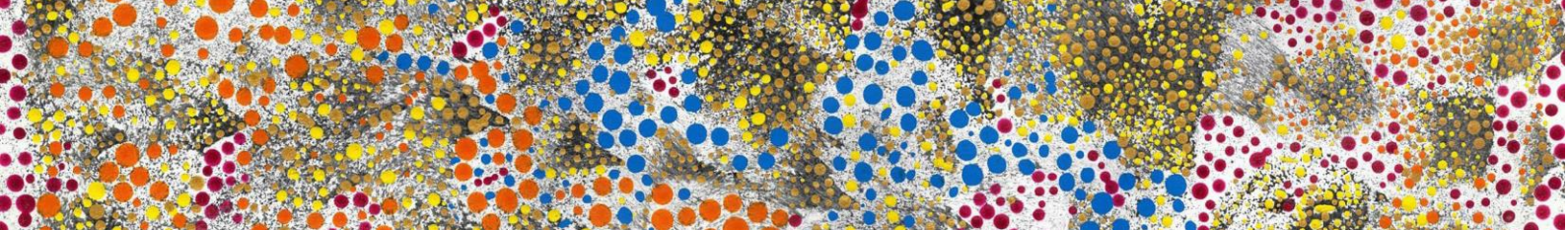
People who use drugs can provide relevant feedback in relation to the efficacy of different treatment options and harm reduction measures.<sup>3</sup> They may also play a role in identifying potentially discriminatory views, language and measures.<sup>3</sup> **Involving people who use drugs ensures that policies and programs more effectively meet the needs of the individual and broader target community.**<sup>1</sup> Increased participation of people who use drugs also empowers a highly marginalised group, builds trust, and strengthens the broader sector and service system.<sup>7</sup>

## ATODA Policy Position

People who use drugs should be involved in the making of decisions that impact them. This is broadly accepted in theory, but more progress can be made in practice, including by both government and non-government organisations. **A fundamental shift is required to seeing people who use drugs as part of the solution, rather than part of the problem.**<sup>4</sup> Increasing the involvement of people who use drugs in decision-making processes has a wide scope, extending to government, researchers, treatment and harm reduction providers, education providers, the broader healthcare sector and allied sectors such as youth, justice and homelessness.

It is important to keep in mind that people who use drugs are not a homogeneous group, and genuine efforts should be made to ensure a diversity of experiences, views and backgrounds when engaging with people who use drugs. The experience of marginalisation also varies amongst people who use drugs, and every effort should be made to engage people who may be the most difficult to engage.

It must be recognised that engaging with people who use drugs around decision making processes requires significant expertise. Decision-makers seeking to involve people who use drugs in decision-making processes need to be mindful of the persistent stigma, discrimination and disempowerment faced by this group. Engagement needs to take this into account to ensure the free flow of information in a non-judgmental environment.



Engagement must also include, where appropriate, support to ensure the safety of the people who use drugs engaging in the process especially where issues may bring up vicarious trauma. In many cases increased empowerment of people who use drugs may be an additional goal or outcome of their involvement in decision-making processes in a manner that validates their experience and contribution.

Relevant decisions may include government policy, including for healthcare, education, employment, housing, justice issues; government investment decisions; treatment design and policy; and program evaluation. This is not an exhaustive list. People who use drugs may be impacted by decisions in different ways, for example as consumers of a particular service, a priority population for a particular policy, or more generally as citizens impacted by a course of government action.

**At the outset it is important to consider the institutional capacity to engage with people who use drugs.** Effective engagement with people who use drugs requires specific expertise and dedicated resourcing. There is evidence that many organisations do not have capacity to appropriately engage at the outset of such a process;<sup>2</sup> however organisations can increase their capacity in a number of ways. Decision-makers, whether in government, advocacy and research organisations or in treatment services, should take the time to thoughtfully consider whether they have sufficient expertise and resources to engage with people who use drugs. If they do not, they should take steps to ensure that they have appropriate capacity before commencing engagement. This could include setting aside funds, hiring people with appropriate expertise, and entering into partnerships with other organisations, such as those which represent people who use drugs.

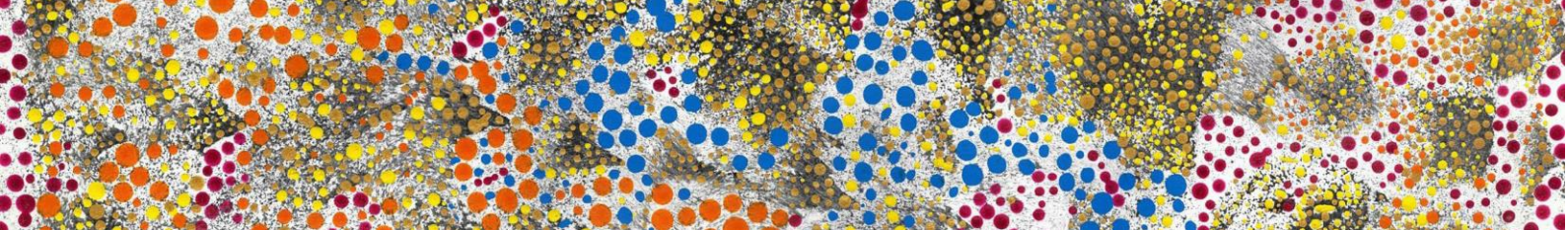
**Before engaging with people who use drugs, decision-makers must commit to genuinely considering and actioning as appropriate all feedback and insights gained through the planned engagement.** Engagement with people who use drugs needs to be clear about what the engagement is seeking to achieve (beyond engagement for its own sake), what information or input is sought and why, and what is within and outside the scope of the decision being discussed.

It is important to recognise that **decision-making processes include the identification of the problem and of potential solutions, and people who use drugs should be part of the process from the start.** Similarly from the outset there should be a plan for how the outcomes from the engagement and the relevant decision will be shared with people who contributed. Planning for decision-making processes needs to take into account the time required to genuinely engage with people who use drugs in a meaningful way.

There are a number of ways of involving people who use drugs in decision-making processes, and stakeholders should give careful consideration to which method/s are most appropriate and which will ensure the greatest extent of participation commensurate to the scope and scale of the decision. It is also important to ensure that the rationale for how people who use drugs are invited to participate in an engagement process is transparent and openly communicated to the community. The appropriate level of involvement should be informed by the scope of the decision (including its longevity, intended outcomes, risk profile and unintended consequences) and the scope of other stakeholders' involvement.

The following is a non-exhaustive list of examples of how people who use drugs can be involved in decision-making processes:

- Through the involvement of peer-based organisations at the local and national level (e.g. the Canberra Alliance for Harm Minimisation and Advocacy (CAHMA), the Australian Injecting & Illicit Drug Users League (AIVL));



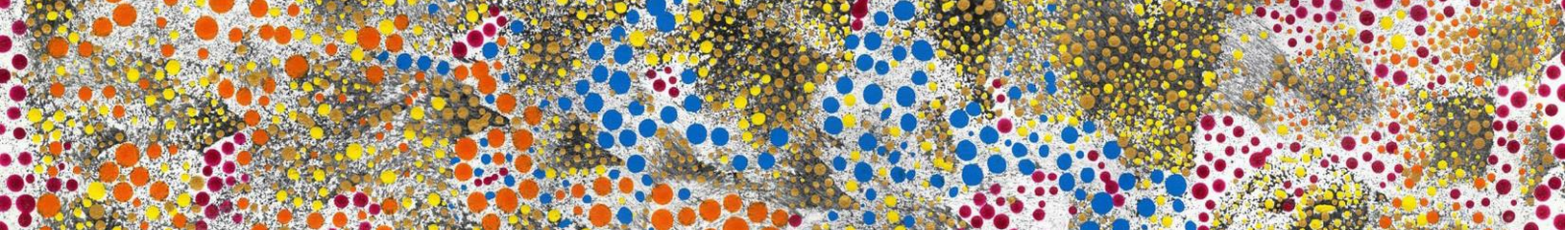
- Through establishing advisory groups consisting of people who use drugs to provide advice for specific initiatives or organisations;
- Through including people who use drugs as part of relevant forums, committees, evaluation groups, reference groups, etc.;
- Through seeking input from service users and/or consumer advisory groups, noting that these services are likely to have established trust with people who use drugs;
- Through consideration of ATOD service user feedback; and/or
- Through consideration of local or national surveys (e.g. the ACT ATOD Service Users Satisfaction and Outcomes Survey, the national Illicit Drug Reporting System (IDRS), the national Ecstasy and Related Drugs Reporting System (EDRS)).

In making a determination between the above and other options for engagement, consideration should also be given to the precedent being set for future decision-making processes, and what scope there is to establish a regular pattern of engagement and feedback to build up trust, rather than engaging on an *ad hoc* basis.

Where possible, people who use drugs should be appropriately reimbursed for their time and expertise and for any costs incurred in the engagement (e.g. travel costs). Appropriate reimbursement recognises the valuable contribution of people who use drugs, and can also be a motivating factor in facilitating engagement. In addition stakeholders should ensure that opportunities to engage with decision-making processes are accessible and that people who use drugs will not face any negative repercussions as a result of their input. Practical options regarding accessibility may include allowing individuals to opt in to in person, virtual or over the phone conversations; arranging the engagement at a known location such as a service setting where individuals may be familiar and more comfortable; assuring anonymity; and being mindful of the time chosen and the amount of time scheduled.

Flexibility is a critical trait of good engagement, and it applies to both the logistics and to how the engagement is facilitated and structured. For more long-term engagement (such as consumer governance groups), adaptation of organisational processes and policies, as well as adaptation of organisational culture, may be required to facilitate meaningful ongoing engagement. It is also important to recognise the trauma that some individuals may have experienced or re-experience in discussing their lived experience. Adequate support is required and may include pathways to counselling, peer support or other relevant services. Participating as a person who uses drugs can be isolating and difficult and therefore appropriate training (for example healthcare consumer representative training) should be provided to the extent required, and where possible it is more appropriate to invite a number of representatives rather than just one.<sup>4</sup> It is also important to recognise that there will be differing views amongst people who use drugs,<sup>3</sup> however **acknowledging and adjudicating different viewpoints is a feature of any robust decision-making process.**

Specific Australian resources exist to inform the participation of people who use drugs in drug treatment settings<sup>2</sup> and in research.<sup>5</sup> Given that research findings and treatment provider insights may be privileged in the development of policy, getting participation right in these contexts is critical.



## References and Further Resources

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**Artwork:** Unspoken History, Map of Pain by Sharon (2020). To learn more, go to: <https://www.atoda.org.au/featured-artwork/>