

## Principles for collaborative partnerships with people with lived experience in research projects

<u>Anke van der Sterren</u>, Elisabeth Yar, Chris Gough, Natasha Nikolic, Dean Wang, Karen Gorst, Taylor Munday, Amanda Bell, Elzbieta Kuc, <u>James Poole</u>, Jordan D'Silva, Nathan Guymer, Simone Politch, Ella Dilkes-Frayne, Sarah Robinson, Anita Mills, Patrick Rawstorne, Sally Nathan

APSAD Conference Canberra, Wednesday 30 October 2024







Supported by

We acknowledge the Ngunnawal people as traditional custodians of the land we are meeting on and recognise any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and region.

We recognise and continue to learn from the contributions of Aboriginal and Torres Strait Islander people to the alcohol, tobacco and other drug sector.





# The authors have no conflicts of interest to declare



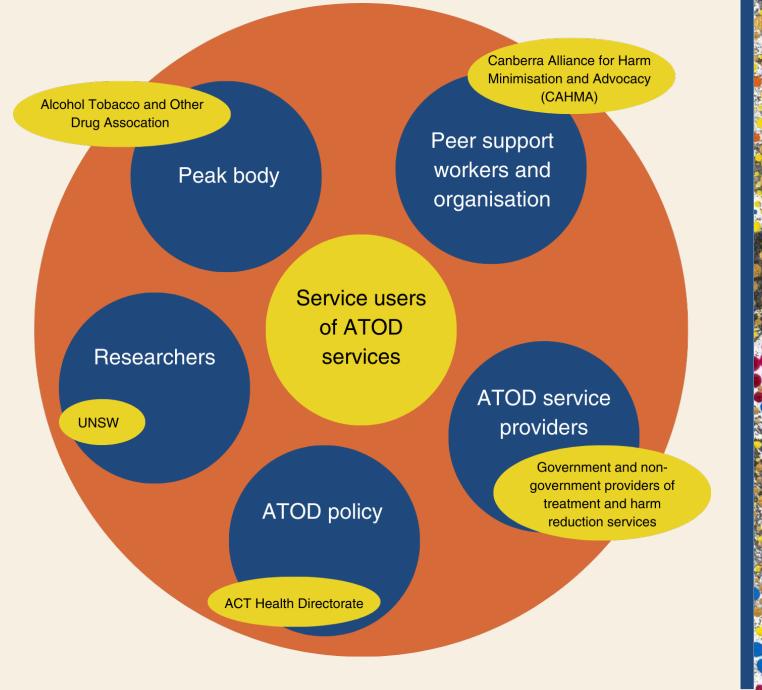






Codesign **Collaborative Consultative** Collective **Design of the Service Users Survey of Outcomes**, **Satisfaction and Experience** 

Alcohol Tobacco & Other Drug Association ACT





#### Meaningful involvement

 Give service users a voice and opportunity to contribute

When you're using

substances you're made to

feel unappreciated and like

nobody; but then you come

in here [and you feel

appreciated]

- Really want people to participate and provide genuine input
- Remove barriers and provide facilitators to participation
- Take input seriously and put mechanisms in place to act on contributions
- Setting clear expectations of involvement and outcomes





#### **Creating a safe environment**

- Shared power
- Valued expertise and opinions
- Empowering
- Opportunities to learn and grow
- Respectful engagement heard and listened to with patience
- Destigmatised language
- Facilitating participation by creating welcoming and inclusive spaces and ways of communicating







#### Adequate time and resources

Early engagement

You need to have people who are flexible and available. That's not always the way of organisations

- Takes time to build relationships, confidence, and to get across the project and research process
- Flexibility and adaptability of researchers and process
- Adequate resources to match process needs





### **Diversity of perspectives valued**

 Diverse perspectives are respected and seen as positives It's a platform for different people with different perspectives being able to listen, share and come together

- Abstinence/recovery to harm reduction
- Lived experience to 'book learning' expertise
- Different lived experiences of ATOD use
- Accommodating variations in literacy, numeracy, research skills
- Put in place processes to support this diversity



#### Acknowledgements

- 63 service users of ACT AOD treatment and support services who participated in the FGDs
- 302 service users who participated in the SUSOSE survey
- Project Advisory Group:
  - Amanda Bell, Devin Bowles (to March 2023), Ella Dilkes-Frayne, Jordan D'Silva, Amy Faden (to November 2023), Karen Gorst, Chris Gough, Nathan Guymer, Elzbieta Kuc, Anita Mills, Taylor Munday, Natasha Nikolic, Simone Politch, James Poole, Sarah Robinson, Dean Wang, Anke van der Sterren, Elisabeth Yar
- ACT AOD services (Contact people who facilitated survey implementation)
- ACT Specialist AOD services Executive Directors
- ACT ATOD Workers' Group
- School of Population Health, UNSW Sydney: Sally Nathan, Patrick Rawstorne
- Funding from the ACT Health Directorate; support from an Australian Government Research Training Program Scholarship





Alcohol Tobacco & Other Drug Association ACT Title: Unspoken History, Map of Pain Artist: Sharon

Date: 2020

To learn more, scan the QR code or click <u>here</u>.



For more information about the SUSOSE: anke@atoda.org.au

