



LIVED AND LIVING EXPERIENCE

CHAIR: JANE MORETON, VAADA

1. Tackling Stigma
through Co-design

1. Integrating complex
client needs into the
treatment of
benzodiazepine
dependence: evolving
service design

1. Elevating consumer
voices - consumer
participation in
practice

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Elevating consumer voices - consumer participation in practice

John Quiroga, NWMAODS

Roland van Olphen, Uniting

Candice Folkard, NAHMSU

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Elevating consumer voices – consumer participation in practice

February 2023

Candice Folkard (Research Assistant & Peer Researcher), Roland van Olphen (Consumer Consultant) & John Quiroga (AOD Health Services Planner)

Introduction

- ❑ **Feb 2021** – *Consumer Participation & Lived Experience Project* commences operation
- ❑ Project supporting catchment planning across North & West metro Melbourne
- ❑ Involving practitioners from various partner agencies working alongside consumer representatives & peer researchers

Consumer Participation & Lived Experience Project – overview

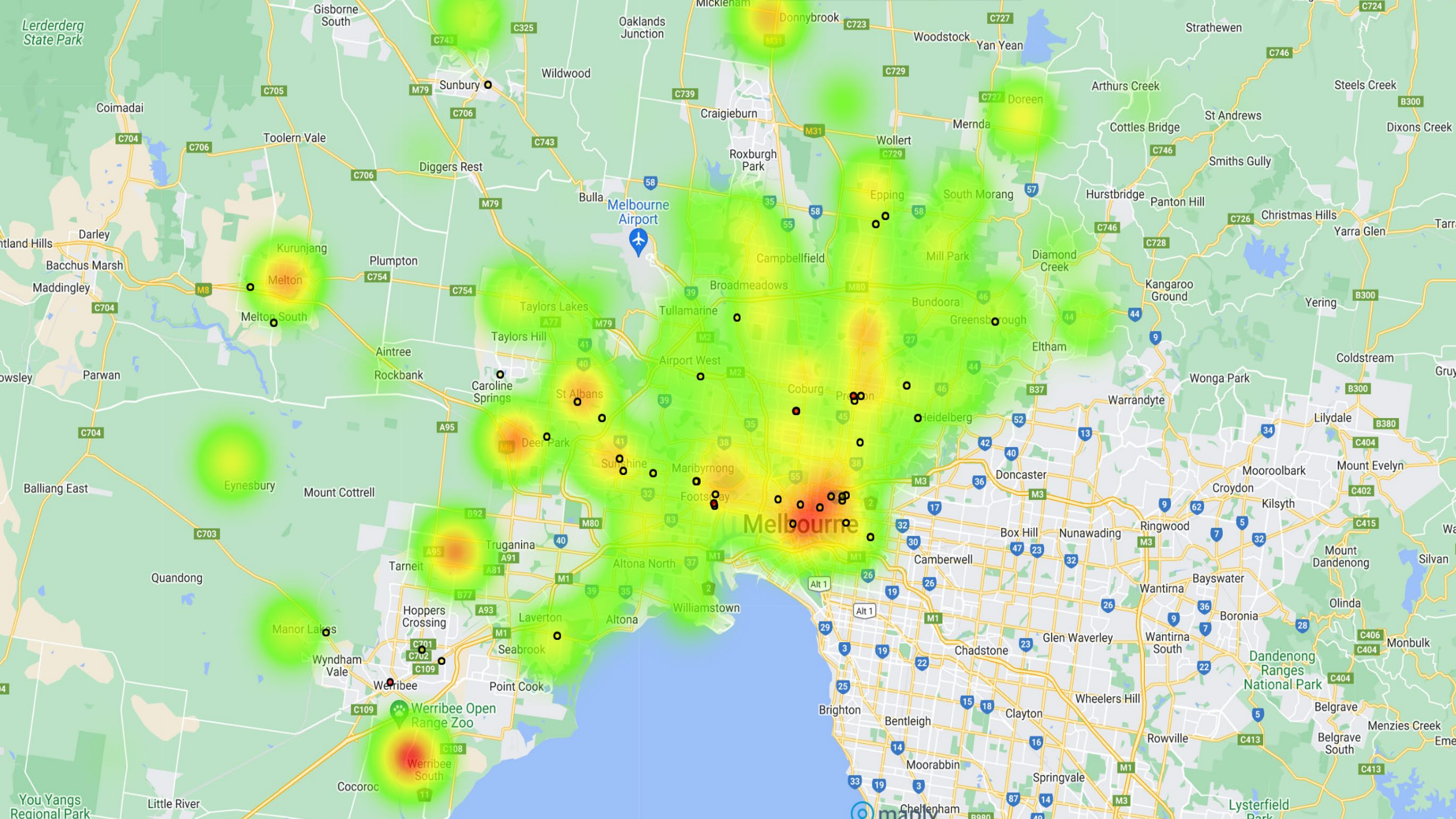
Project aims to **elevate service user & family member/carers voices & prioritise their feedback in the planning process**

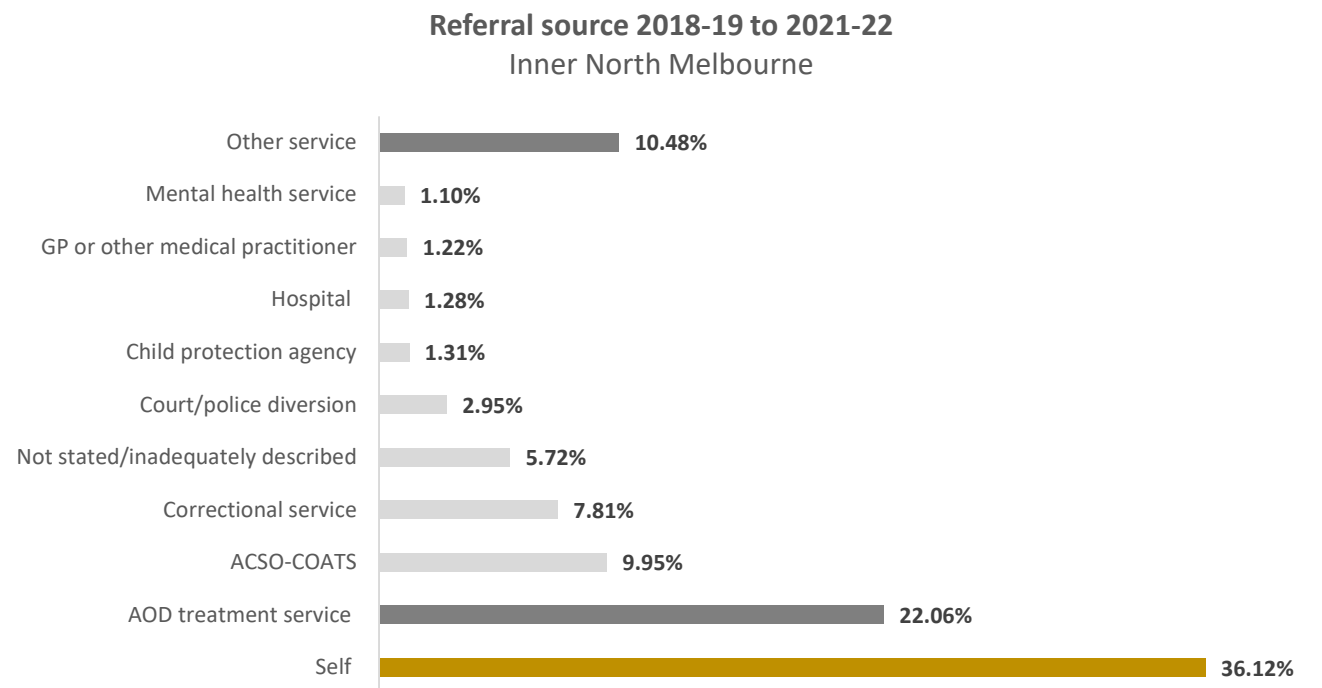
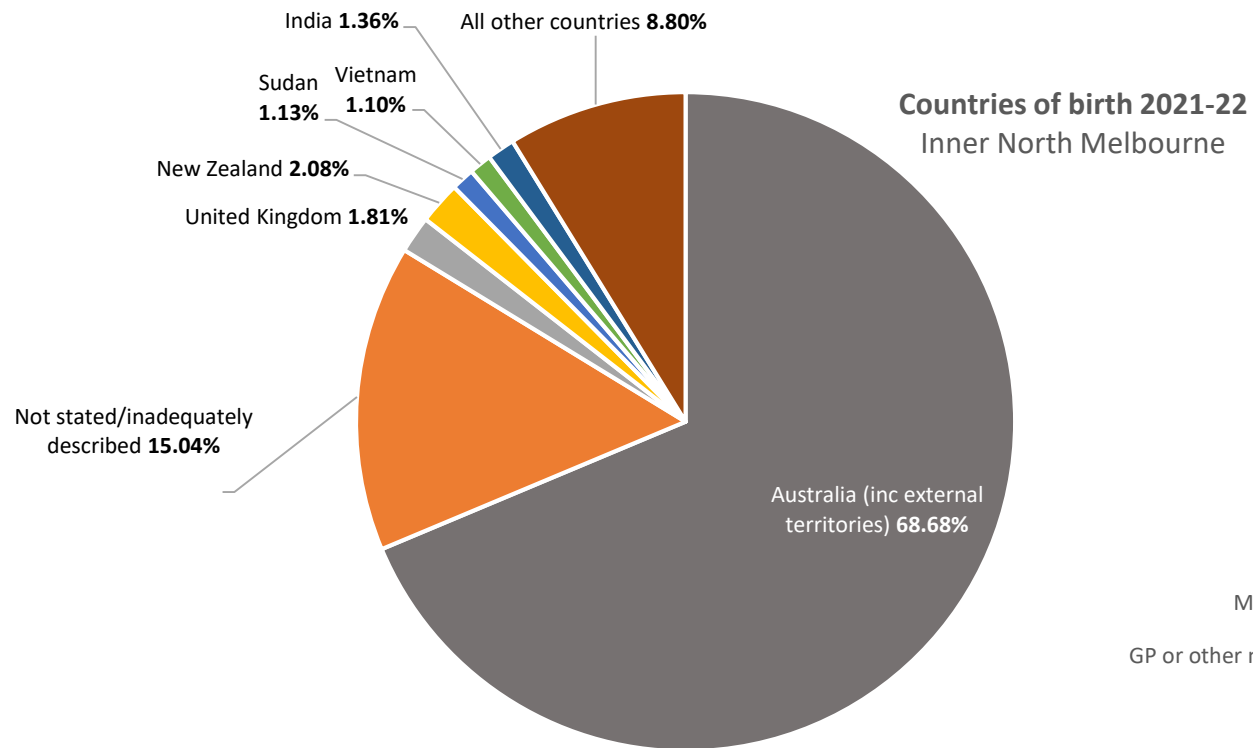
Key activities:

- Undertaking research (e.g. focus groups) – **inviting service users & family members/carers to reflect on their experiences of the service system**
- Meaningfully engaging consumers in the co-design of interview schedules & other consumer feedback tools
- Collating & analysing the data
- Drafting recommendations based on the findings & advocating for change



Why is it
important to
gather **consumer**
feedback?





Project rationale

- ❑ AOD providers too heavily reliant on service statistics – fixated on **throughput & other KPIs**
- ❑ Limited opportunities for consumers to participate in service design, development, review & implementation
- ❑ Agencies restricted in their capacity to obtain detailed qualitative information on consumers' experiences seeking & obtaining treatment
- ❑ Especially the case for hard-to-reach populations (e.g. CALD & people with disabilities)

Prioritising consumer feedback using a shared model

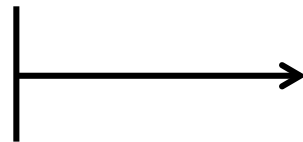
Researcher led

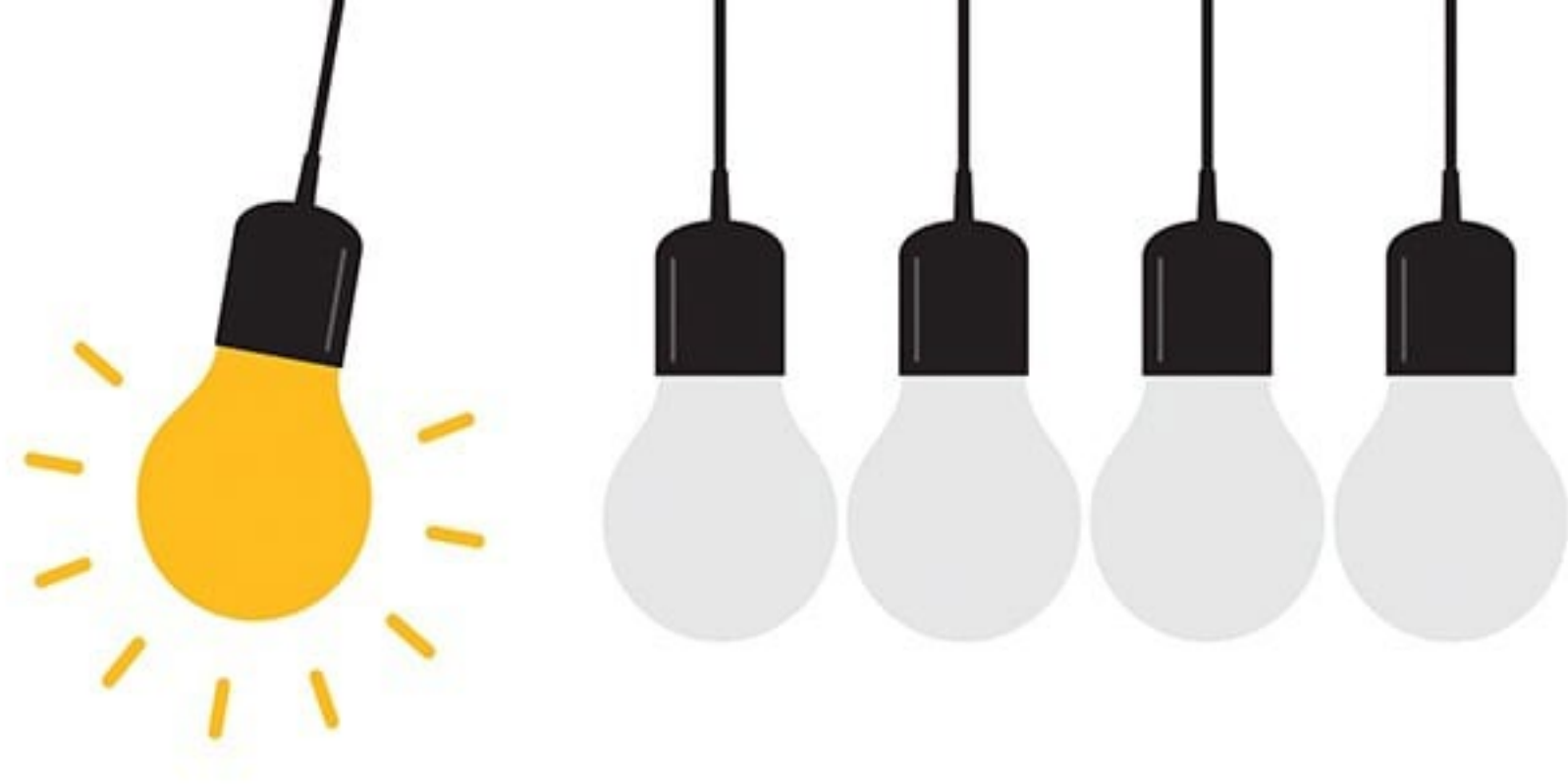
- Activities led & carried out by trained researchers/practitioners
- Little involvement of people with lived experience
- Minimal compensation set aside for consumers undertaking peer research

Shared model

- Activities led by trained researchers/practitioners, who work alongside people with lived experience to build their capability
- Resources set aside for coaching/peer research training
- Consumers undertaking peer research paid for their time
- Co-design of survey instruments & other consumer feedback tools
- Consumer influence into research topics covered

Consumer & carer feedback prioritised using a **participatory research & stakeholder engagement approach**, via a shared model





**Key learnings, challenges &
opportunities**

Consumer participation in the AOD sector

- ❑ Broad consensus that enhancing consumer participation within the AOD sector is important
- ❑ Some meaningful work undertaken by APSU/SHARC, VMIAC & others
- ❑ However, much more needs to be done, including:
 - *Dedicated ongoing funding*
 - *Establishing a consumer participation infrastructure*
 - *Agreement on standards & accepted interagency processes*

Meaningful consumer participation vs tokenism

- ❑ Project set up with the intention that practitioners work in partnership with consumer representatives & peer researchers
- ❑ **Practitioner & lived experience knowledge** viewed as carrying equal weight (as much as possible)
- ❑ Attempts made to minimise power imbalances & open up opportunities for project members with lived experience to step up

Level of engagement	Level of consumer control	Explanation	Purpose
Inform	Nil	Information is given to consumers	Used to convey information to consumers (e.g. media release & fact sheets)
Consult	Very low	Information is gathered from consumers	Two-way exchange to find out what consumers think about an issue (e.g. surveys & focus groups)
Involve	Some influence	Consumers are involved in the process	Shared decision making. Processes & outcomes are jointly owned (e.g. panels & workshops)
Collaborate	High influence	Organisations & consumers work together in partnership	Consumers & other key stakeholders work together to develop solutions (e.g. advisory committees etc)
Empower	Consumer control	Consumers make decisions about	Consumers make the decisions which are implemented (e.g. steering committees, boards etc)

Source: Adapted from the *International Association for Public Participation (IAP2) Spectrum* (2007)

Requirements for meaningful consumer participation

- ❑ Co-design processes implemented where decision making is shared
- ❑ Lived experience knowledge viewed as complementary & adding value to practitioner knowledge
- ❑ Consumers adequately paid & recognised for their time & contributions
- ❑ Support for consumers to provide input & develop skills & experience



Consultations focused on:

- Consumer health literacy
- Referral pathways & entry points
- Help seeking behaviours
- Views on treatment barriers, service gaps & opportunities for improvement

Round 1 consultations



Feedback received ...

- Concern from family members about being dismissed/excluded
- Mixed messaging about available AOD supports diminishing service access
- Widespread difficulties navigating AOD treatment system
- Consumer advice & support viewed as really important

Recommendation 1 –

Enhancing family inclusive practice & collaboration

Recommendation 2 –

Co-design of resources for consumers

Recommendation 3 –

Provision of more timely & accessible treatment information (updates)

Recommendation 4 –

AOD education & health promotion targeting priority populations

Recommendation 6 –

Expanding the role of consumer participants & peer workers

Recommendation 5 –

Upskilling & growing the pool of consumer participants

Establishing a Community of Practice (CoP) Network featuring:

- *Customised training*
- *Online noticeboard & exchange*
- *Paid work placements*

Consultation fatigue & bridging the credibility gap

- ❑ AOD service system has a poor record when it comes to engaging hard-to-reach (priority) populations
- ❑ Largely due to short term funding
- ❑ Resulting in CALD communities & other populations experiencing consultation fatigue & feelings of abandonment
- ❑ Now a credibility gap exists which needs to be overcome



**Advocacy
Works!**

**Mixed results when it comes to
advocating for change**

**Broad-based in principle support for
recommendations, but severely limited by:**

- **Lack of dedicated funding**
- **Ongoing & escalating reform resulting
in agency & worker fatigue**
- **Lingering effects of COVID-19**



Where to
from here?

Contact details

John Quiroga – Health Services Planner AOD (Catchment Based Planner)
North & West Metro AOD Service (NWMAODS)

Email: jquiroga@odyssey.org.au

Mob: 0466 838 380

Candice Folkard – Research Assistant & Peer Researcher

Email: candicefolkard@gmail.com

Roland van Olphen – Consumer Consultant

Email: rolandvanolphen@icloud.com