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

vaada CONFERENCE FEBRUARY 9-10 2023
Shifting Landscapes
Building the Holistic Treatment Mosaic

Tackling Stigma through Co-design

Tina Lam, MARC
Kirsty Morgan, Peninsula Health
Jessica Reece, Peninsula Health

Kirsty Morgan, AOD Educator
Jessica Reece, AOD Lived Experience Educator

Amelia Berg, Lived Experience Researcher

Dr Tina Lam,
Senior Research Fellow

Tackling Stigma through Co-Design

Acknowledgment of Country

Peninsula Health

Recognition of Lived Experience

We acknowledge people with lived experience of substance dependence and the experiences of those who support them.

We recognise the vital contribution of lived experience at all levels & that the voices of people with lived experience inform our work.

What is our working definition of Co-design?

A process where people in lived experience, clinical, education or academic roles, **partner as equals** to improve health services by listening, learning and making decisions together

Image source: https://metronorth.health.qld.gov.au/get-involved/co-design/what-is-co-design

Linking Co-designed Research & AOD Education

AOD Patient Journey Study

(Academics & LE Researcher)

- What are the barriers/enablers to treatment access through hospital & community services?

AOD Education program for Hospital-based clinicians

(AOD Educator & LE Educator)

- Aims to improve capability of nurses & junior medical staff to provide care for inpatients with co-occurring AOD needs

What is Lived Experience?

What is a Lived Experience Peer Researcher?

- People with lived or living experience have either a history, or current experience, of a particular issue, or have been impacted by another person's experiences.
- Lived Experience Peer Researchers have a declared experience of the issue the research is focused on and are recognized as a peer by the community.
- Co-design and co-production- involve us at all stages of the research process- this is meaningful involvement and will make your research more relevant and responsive to the needs of the community.
- When choosing things you would like to research, consult with the affected community FIRST to see what the community's needs and priorities are

Why work with a lived experience peer researcher?

- Ensuring adequate training and support in place for peer researchers
- Dual-interviewing has the potential to create power imbalances

- We have close connections with community
- Participants can feel more comfortable when a peer is involved
- Peers act as a “bridge” between academic researchers and the community to mitigate power imbalances
- Unique insights come from lived experience
- Shared learning and support
- Data will be richer

“Mapping the Alcohol and Other Drug Patient Journey” Study

Research Aims: To improve care in the Frankston and Mornington Peninsula region by understanding alcohol and other drug treatment journeys through:

- mapping people’s experiences;
- identifying barriers and facilitators from a patient/consumer perspective;
- identifying barriers and facilitators from a service organisation perspective; and
- identifying how treatment journeys can be improved.

Findings – High Level Themes

From Lived Experience:

- difficulty in locating services;
- poor or no responses from services;
- stigma from staff;
- alcohol and other drug use (current/historical) exclusionary to service access;
- unstable housing for women; and
- inexperienced alcohol and other drug specialist staff.

From Service Providers:

- structured service delivery processes and procedures (including frequency of intakes and assessments without bridging support);
- stigma from staff;
- long times on wait lists; and
- lack of collaborative cross-sector relationships.

Findings: What people told us

"I get so hurt, like people and their bloody judgment" (C52F).

We "… meet them, greet them, treat them, and street them" (HS119M)

***"I know we're all drug addicts and that, but don't speak to us like we're drug addicts. It's fucking rude. We get it, we get what we are, but we're trying to get help, that's why we're here, so treat us like humans, don't treat us like we are drug addicts … people aren't going to respond well to being treated like shit"* (C35M)**

"I couldn't tell you that there were definite remarks that I heard, but I felt like it was just 'alright get him better, flush out his system, and kick him out' that was my feeling … that was definitely my feeling on every occasion I'd have to say" (C37M)

"And it is embarrassing and it makes you not want to reach out to get help" (C39M).

"You're doing this to yourself. You're not sick. This person with the heart attack that is our sick patient, this person is just wasting our time" (HS104M)

Why involve an illustrator in research?

Traditional outputs

- Too much text, complex statistics
- Narrow audience

Poisson regression to generate incident rate ratios (IRRs) to estimate the supply-adjusted rate of ED presentation of each opioid (the outcome variable) and how the rate changed over time (the predictor). The primary analysis considered each of the opioid categories as mutually exclusive–that is, a presentation was included in the rate calculation where the specific opioid was the only opioid involved in the presentation (Table 1). A sensitivity analysis explored the effect of selecting single-opioid poisonings versus multiple opioid poisonings. To this effect, rates were calculated using presentations where the specific opioid was the only opioid involved or was one of multiple opioids involved in the presentation (Supporting information, Table S3). Supply-adjusted rates were not calculated for the 'multiple opioids' category due to the heterogeneity of the OME denominator for each presentation. Rates were aggregated over 6-month periods for analyses to enable minimum cell sizes of five, and were presented by year for ease of interpretation.

Aim 2: characteristics of presentations

We used multinomial logistic regression to analyze opioid-poisoning characteristics to explore how opioid type varies by presentation characteristic. Opioid type was the outcome variable in all regressions, with morphine serving as the reference category (the standard reference opioid for calculating opioid doses [24]). Separate regressions were run, with each of the eight characteristics serving as the primary independent variable. Year was included in all models as a secondary independent variable to assess whether the opioid type variation by presentation characteristic varied over time. The regressions also controlled for age and sex (see Supporting information, Figs S3–S10).

Categories were aggregated where necessary to ensure that all analyses reported cell sizes of at least five. All quantitative analyses were conducted in SAS or Stata, with *P*-values less than 0.05 considered significant with no correction for multiple testing [25].

Missing data

There were minimal missing data (< 5%), with fewer than five presentations missing data for sex, 75 with a missing birth country and 59 with unknown geographical region (which was grouped with overseas and interstate presentations for the purpose of analysis). Presentations with unknown geographical region were a subset of the 118 presentations with missing data for SEIFA, which is calculated based on postcode. With the exception of country of geographical region, all missing data were handled via list-wise deletion in the multinomial regression.

We could not locate codeine content information on "Chemists Own Cough Suppression Linctus 200 ml" from the previous or current brand owners (Aspen and Arrow). Available data states 6858 units were sold January–August 2009 to August 2010 (of more than 63 million total codeine units supplied in the study period, or approximately 0.1% of all codeine sales). These units did not contribute to the total volume of codeine used to calculate supply-adjusted rates.

1–3 (most advantaged)	Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		
4–5	1.02	0.61	1.69	0.73	0.35	1.52	0.38	0.07	1.97	0.89	0.51	1.54	0.70	0.38	1.31	
6–7	0.77	0.49	1.23	0.81	0.43	1.54	0.86	0.27	2.71	0.90	0.55	1.49	0.79	0.46	1.37	
8	1.35	0.79	2.31	1.06	0.52	2.16	1.27	0.39	4.12	0.92	0.51	1.66	1.03	0.55	1.95	
9–10 (most advantaged)	0.76	0.47	1.24	0.45	0.21	0.94	1.67	0.58	4.86	0.72	0.42	1.22	0.71	0.39	1.27	
Year	1.19	1.13	1.26	1.55	1.42	1.69	2.19	1.76	2.73	1.18	1.11	1.25	1.19	1.11	1.27	
Intent																
Intentional self-harm	Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		
Other	0.57	0.45	0.78	0.49	0.32	0.77	0.43	0.21	0.91	0.55	0.39	0.78	0.40	0.27	0.59	
Year	1.19	1.13	1.24	1.55	1.42	1.69	2.23	1.80	2.76	1.18	1.11	1.25	1.18	1.11	1.26	
Admission outcome[b]																
Admission	Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		
Presentation only	1.53	1.13	2.08	1.74	1.12	2.70	1.22	0.58	2.54	1.07	0.77	1.50	1.11	0.77	1.61	
Year	1.21	1.14	1.28	1.57	1.44	1.71	2.24	1.81	2.78	1.18	1.11	1.26	1.19	1.11	1.27	
Triage category																
Requires immediate assessment	Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		Ref.	Ref.		
Does not require immediate assessment	1.52	1.11	2.10	1.51	0.94	2.42	2.34	0.97	5.68	1.45	1.16	2.36	0.96	0.65	1.40	
Year	1.20	1.14	1.27	1.55	1.42	1.70	2.24	1.81	2.78	1.18	1.11	1.26	1.19	1.11	1.27	

Abbreviations: IRR = relative risk ratio; CI = confidence interval; OS = overseas

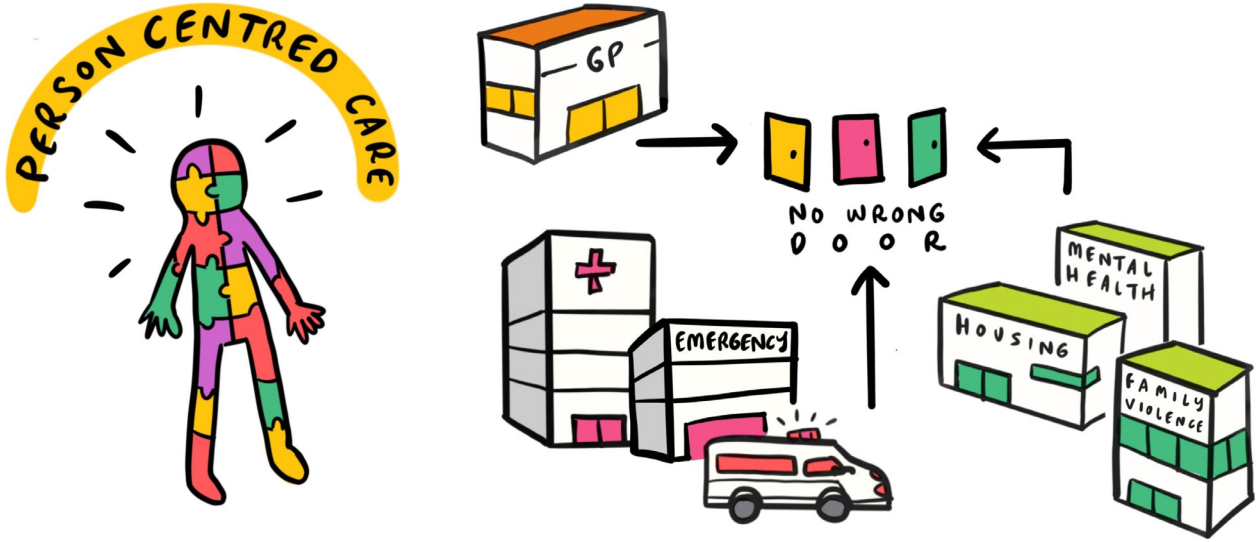
Proportion of cells which contained fewer than five observations for the regression: age (5.6%), sex (50%), admission (68%), country of birth (7.4%), intent (67%), region (71%), SEIFA quintile (82%) and triage (68%). All models controlled for age and sex.

[a]SEIFA is a proxy for socio-economic status; categories were split to reflect approximately evenly sized quintiles for the analysis.

[b]Presentation only includes discharge to home or left without treatment completed; admission can be at the same hospital or another hospital campus.

Illustrated summaries

- Intuitively understood
- common understanding between stakeholders



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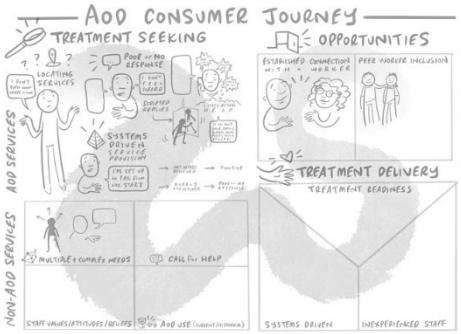
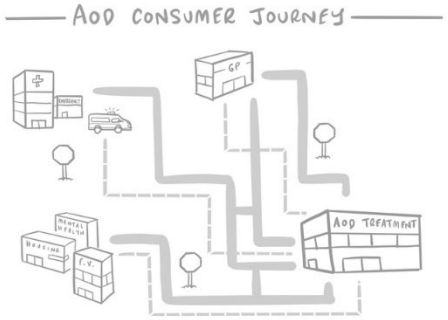
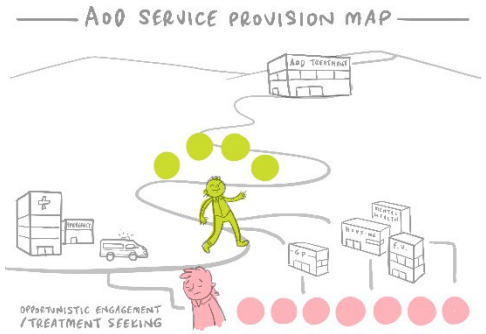
Process for developing posters

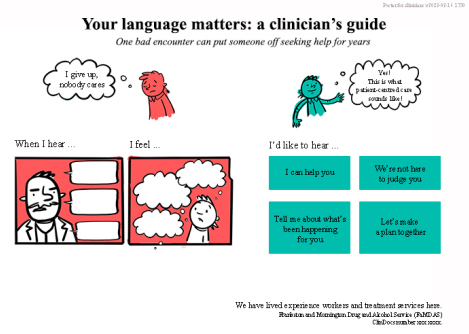
1. **Iterative** process refining the **content & poster structure**

Content from n=40 participants (AOD CAG, clinicians). Then, weekly collaborations between the illustrator & the academic & LE research team.









2. Workshops

Same interviewees who contributed the original content

3. Final version

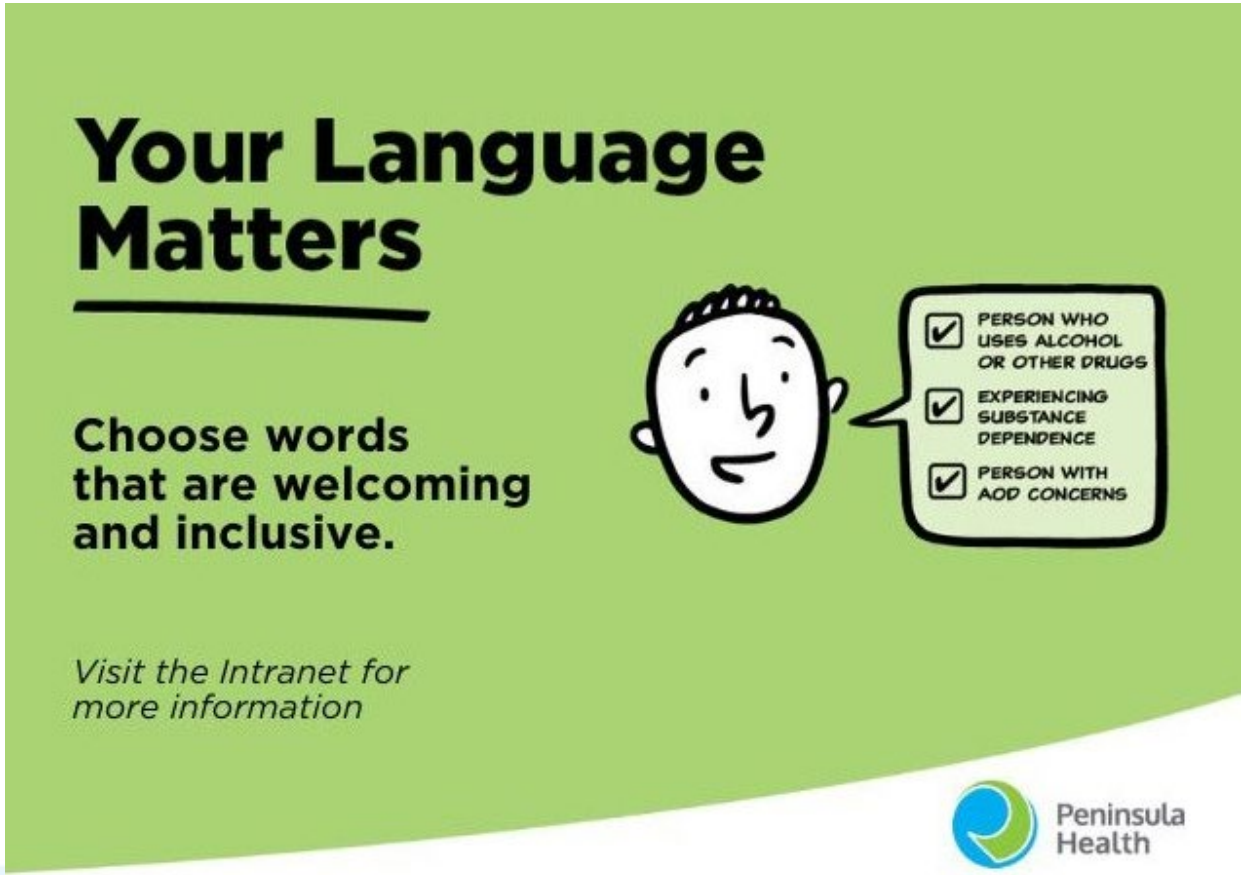
Incorporating workshop feedback & checking referral pathways

Posters developed through AOD Patient Journey Study and with AOD Consumer Advisory Group

Tackling language & stigma with a co-designed social marketing & education

Multiple & Combined interventions:

- Posters
- Virtual background for online meetings
- E-newsletter
- Staff & team meeting
- Online self-complete course
- In-services on the ward
- Revising clinical tools & templates
- Local leads to be in-situ



Your language matters

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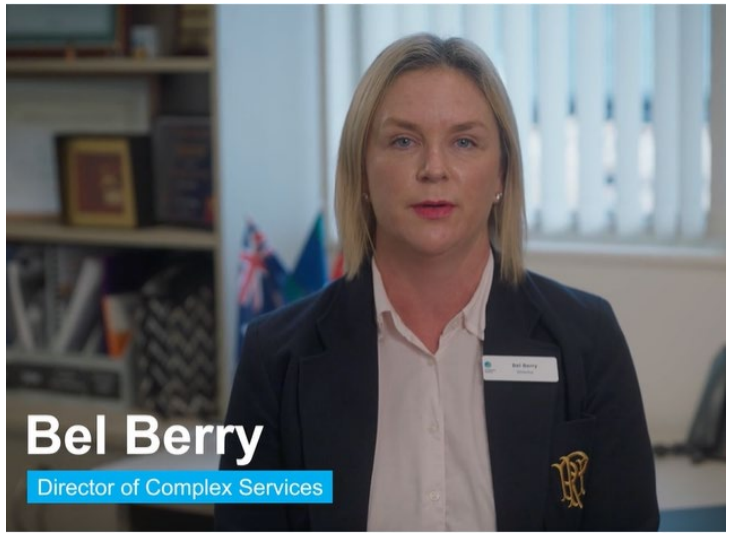

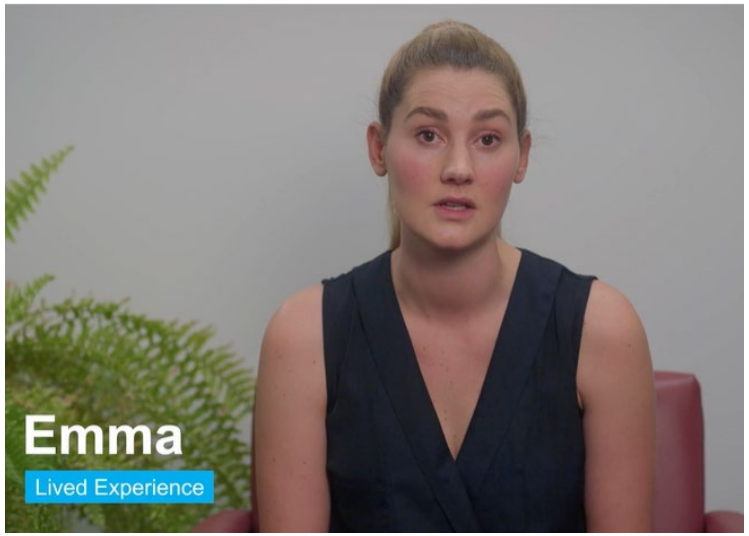

Campaign Reach

- ✓ 533 viewed newsletter article
- ✓ 374 staff participated in training sessions
- ✓ 154 views of video
- ✓ Posters on display across 6 wards, ED and some other community sites (distribution ongoing)

Feedback

“It really built my empathy and hearing from a lived experience worker about what happened after her hospitalisation and how screening & help could have made a difference made a really powerful impact” *(Nurse, ED)*

“Congrats on delivering a great course, should I work clinically again or work with consumers who have a drug dependence I will be more aware of my language” *(Improvement & Innovation Project Officer)*

Reflections from Lived Experience Educator

- Importance of co-design with people with lived experience – more than just a voice
- Impact of sharing story
- Empowering
- Co-facilitated deliver of interventions to change healthcare providers perceptions

Lessons Learnt

- Value of LE Researchers & LE Educators
- Co-design materials during study (action research) to produce outputs (posters) better enables translation of findings into practice
- Development & delivery of education with lived experience makes it more impactful
- Relationships, relationships, relationships!

Thank you!

Kirsty Morgan
AOD Educator
Mental Health Learning Hub
Mobile 0423 162 850
KMorgan@phcn.vic.gov.au

Amelia Berg
APSU and Fuse Initiatives Project Worker
Association of Participating Service Users
Self Help Addiction Resource Centre Inc.
Aberg@sharc.org.au

Jessica Reece
AOD Care and Recovery Clinician & Lived Experience Educator
Frankston and Mornington Drug and Alcohol Services
Mobile 0417 188 243
jreece@phcn.vic.gov.au

Tina Lam
Senior Research Fellow
Monash Addiction Research Centre
Tina.Lam@monash.edu

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