



**Examining health care from the drug user  
perspective: what works, what doesn't and  
what needs to change**

*Mary Ellen Harrod*

# ACKNOWLEDGEMENTS



- I would like to acknowledge the traditional custodians on the lands on which this work was conducted, the Gadigal People of the Eora Nation and pay my respects to Elders past, present and emerging and recognise the impacts of colonization and dispossession that continue today
- NUAA is a peer-based, community-controlled drug user organisation and we represent the voices and needs of drug using communities in NSW. NUAA and the community of people who use drugs were instrumental in averting the HIV epidemic and we remain central to improving the health and human rights of people who use drugs in NSW. We acknowledge the legacy of the peers who came before us and affirm our commitment to fighting the effects stigma and criminalisation in all their manifestations.
- I would also like to acknowledge the honesty and courage of the peers who contributed to this work

## BACKGROUND TO THIS PROJECT

- NSW Health recognises that stigma and discrimination are significant issues that reduce access to services for people who use drugs
  - 2022 – 2025 Hepatitis C and HIV Strategies call for a 75% reduction in stigma by people accessing health care
- This work was performed by NUAA as part of a larger stigma project that is being conducted by the Centre for Alcohol and Other Drugs



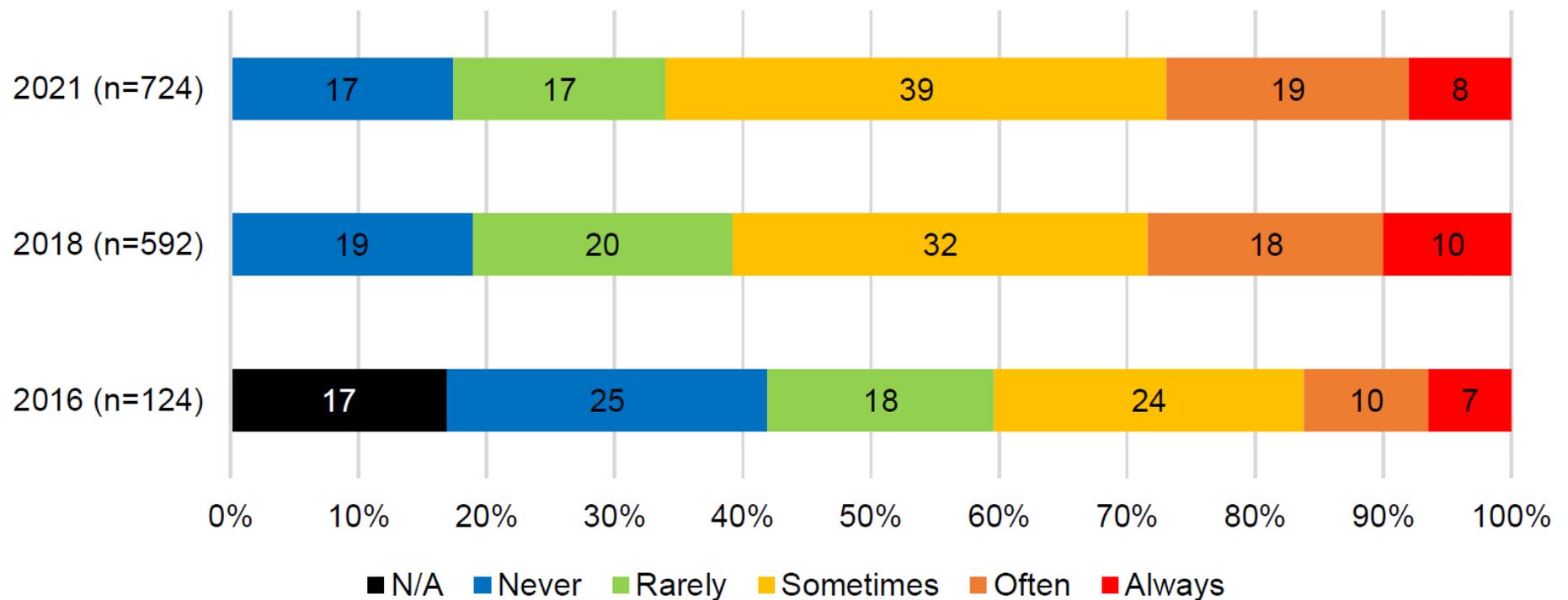
## STIGMA AND DISCRIMINATION - DEFINITIONS

- A strong feeling of disapproval that most people in society have about something, especially when this is unfair – e.g. HIV, smoking, drug use, obesity, mental health issues
- Discrimination are actions based on these beliefs

# STIGMA IN AUSTRALIA



In the last 12 months, have you experienced any stigma or discrimination in relation to your injecting drug use?

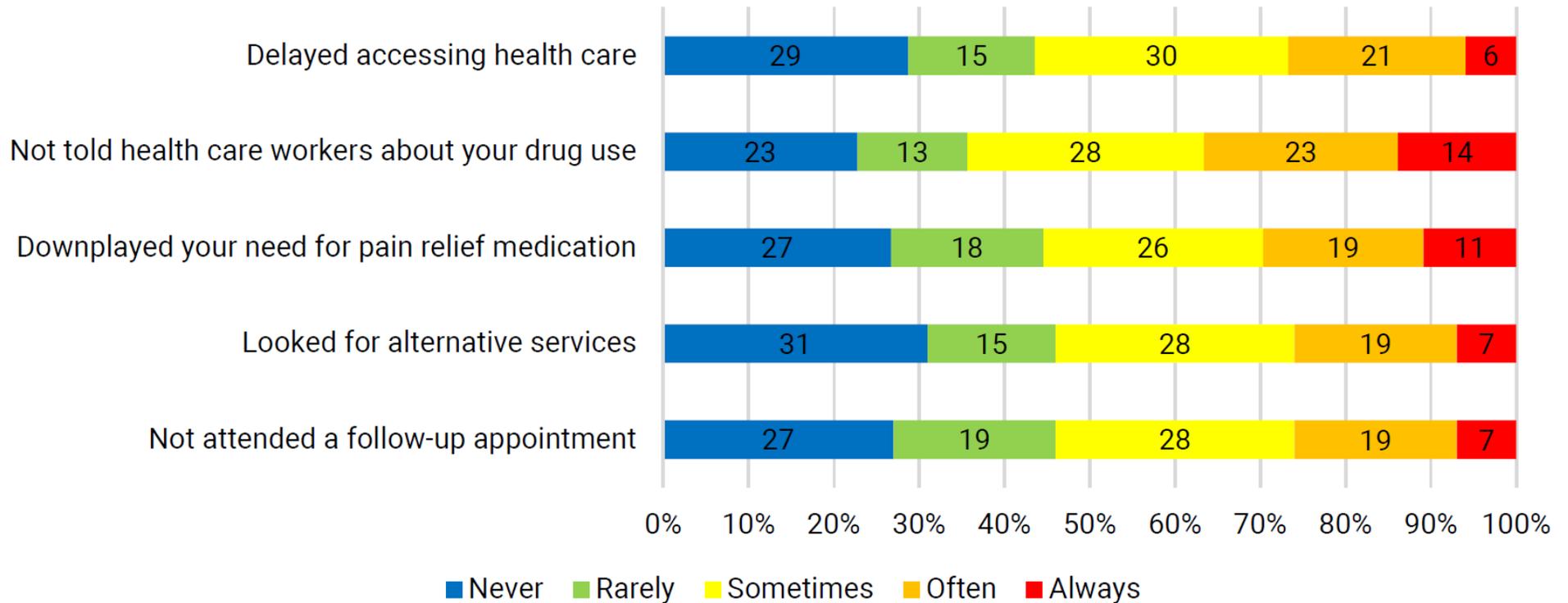


Data from the CSRH Stigma Indicators Monitoring Project, n=731 age 18-69 people who are current injectors (94.4% within the last month)

# THE IMPACT OF STIGMA ON HEALTH CARE ACCESS



How often have you done the following to avoid being treated negatively by health care workers?



Data from the CSRH Stigma Indicators Monitoring Project, n=731 age 18-69 people who are current injectors (94.4% within the last month)

## METHOD

- 38 participants interviewed, drawn from community networks with priority populations groups targeted for inclusion – Aboriginal People, people in contact with the criminal justice system, young people, older people, pregnant women, people living with a disability, people living in rural/remote areas, people who experience mental health issues, culturally and linguistically diverse people
- Open ended questions about positive and negative health care experiences
- Peers with interviewing experience
- Thematic analysis with two independent coders

Table 1: Priority populations represented by participants with category representation. Aboriginal = Aboriginal and/or Torres Strait Islander; Alcohol = people who have identified issues with alcohol use; CJ System = people with experience of the criminal justice system; CALD = people from culturally and linguistically diverse backgrounds; Disability = people with a disability; LGBTQI+ = people who identify with the queer community; MH = people who have identified mental health challenges; Older = people aged over 55; Parents = people who have children or who have recently given birth; Rural = people living in rural or remote areas of NSW; Young = people who identify as young; Comorbid = people with a significant co-morbid health condition.

Participant	ABORIGINAL	ALCOHOL	CJ SYSTEM	CALD	DISABILITY	LGBTQI+	MH	55+	PARENT	RURAL	YOUNG	PWID/OTP	COMORBID
1	■												
2	■									■		OTP	■
3	■									■			
4		■										■	
5		■						■					
6			■						■			■	
7			■			■						■	
8		■	■									■	
9		■	■	■								■	
10		■		■		■						■	
11		■		■		■						■	■
12					■	■	■					OTP	■
13			■		■		■					■	■
14		■	■		■			■				OTP	
15						■						■	
16						■		■				■	
17						■	■					■	
18					■	■	■					■	
19							■		■	■		OTP	■
20							■				■	■	
21					■		■					OTP	■
22			■					■				■	
23		■						■				■	
24								■				OTP	
25			■						■			■	
26									■			OTP	
27	■	■	■				■		■		■	■	■
28					■					■		■	
29									■	■		OTP	■
30							■			■		■	
31										■		■	
32					■		■				■	■	■
33			■	■	■	■						■	
34												■	
35								■	■	■		■	■
36										■		OTP	■
37			■								■	■	
38		■					■				■	■	
TOTALS	4	8	9	4	8	10	9	6	7	8	7		

# FINDINGS

- **Negative Health Care**

- Overt stigma and discrimination
- Medical gaslighting/refusal of care
- Power imbalances/lack of control in clinical interactions
- Inadequate pain management

- **Positive Health Care**

- Listening
- Focus on the issue rather than drug and alcohol use
- Accessibility
- Clinical competence

## POOR HEALTH CARE

- **Everyone** had at least one story
- Overwhelmingly characterized by a lack of regard for the patient – not listening, scolding, chastising, dismissing concerns, violating privacy, punitive rules based on assumptions about people who inject drugs, overtly discriminatory, incompetent, threatening, inadequate/no pain management causing severe distress

## OVERT STIGMA AND DISCRIMINATION

*The minute I sense judgement, my sense of self identity changes... I feel childlike, messy, grubby, dirty. And I'm specifically using those words – I feel physically dirty, incompetent. And as that feeling wells up in me of being a problematic child, a pain in the ass... my behaviours change to be more like that*

- Many examples including being:
  - belittled,
  - followed,
  - threatened by the police in the absence of any hostile or otherwise criminal behaviour,
  - being refused treatment,
  - violations of privacy

## MEDICAL GASLIGHTING

- *I was using methamphetamine and noticed changes in my skin. I could see (that when I disclosed my methamphetamine use) she didn't take my skin complaint seriously. And the more I tried to explain it, the more insane I felt. My heart broke.*
- *My actual issue and the way that has been impacting my life, and my experience of chronic pain and all of the ways this bleeds out into every other area: in relationships and work – none of that is actually being cared for or witnessed in a dialogue that becomes 'you are a drug seeking person'*
- Medical gaslighting is a phenomenon that includes dismissing or diminishing concerns raised by patients in the context of clinical consultations resulting in lower standards of clinical care and misdiagnosis
- Frequently happened to women, including pregnant women resulting in serious complications

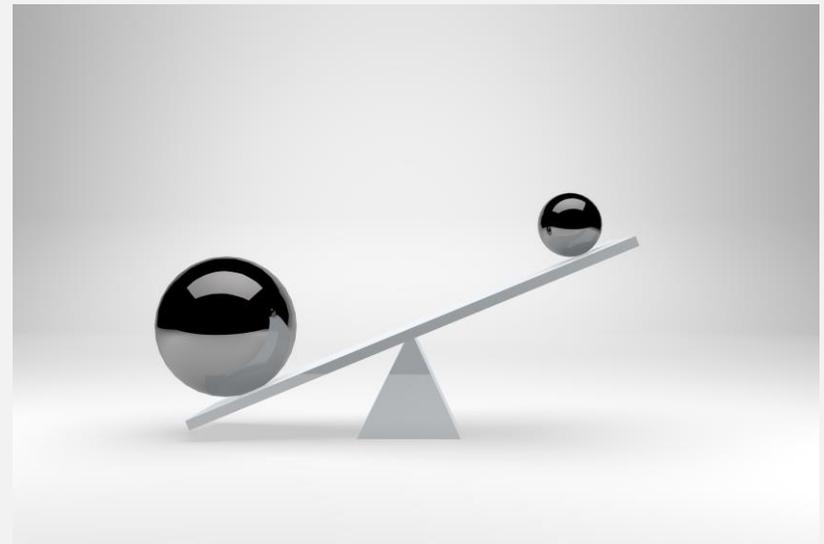
## DENIAL OF CARE

- *They treated me like I was evil... They didn't listen to me, they took blood because they needed to breathalyse me, then they basically choofed me out the door... I said 'I'm just not right, there's something wrong' and they still ignored me. And eventually, when I almost passed out and kind of collapsed, they started taking me seriously. It turned out that I'd fractured my spine... Nobody said anything. I was clearly treated differently to the others. That judgement ultimately led to nobody checking to see if I was okay properly and missing something really significant*
- Multiple examples of people just not being treated for serious medical conditions

# POWER IMBALANCES



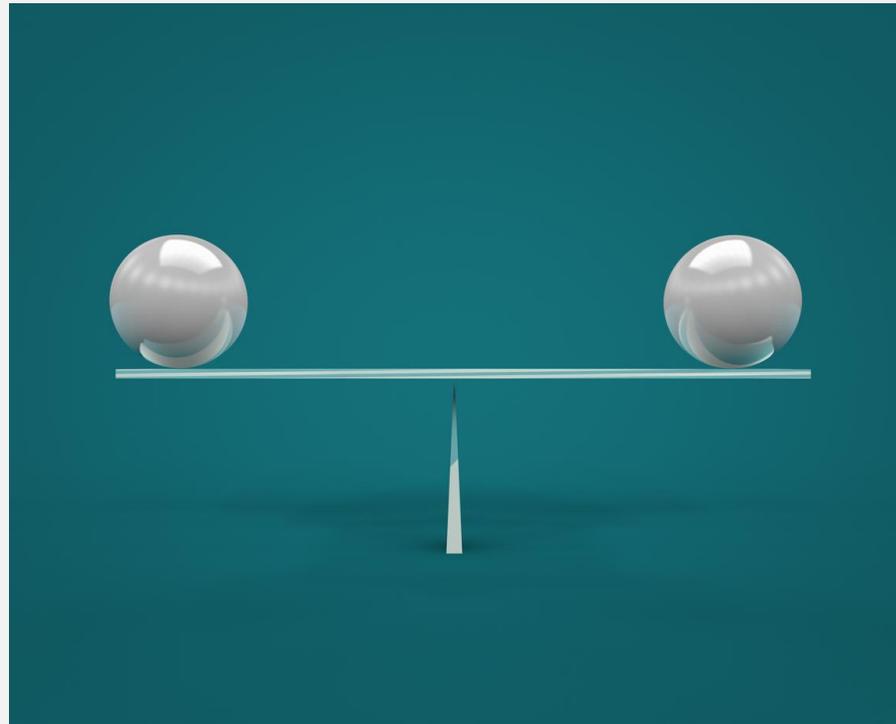
- Clinicians using inaccessible language, not attending to, or dismissing, information provided by the patient, disregard of boundaries, public disclosure of personal information
- *“I had to reintroduce myself, my entire history, to somebody who should have access to that information already but doesn’t bother to read about it before they actually talk to me... It was re-addressing my entire life story to one person, which I don’t think is appropriate or should have to happen”*



# GOOD HEALTH CARE

- Overwhelmingly, the people we interviewed wanted what everyone wants – competent, patient-centred care

*Mate we're not here to judge you, we're here to fix you*



## LISTENING



- *“Willingness to pause”*
- *“She will ask me how I’m going and actually stay silent and let me answer the question”*
- *“It feels like a collaboration”*
- *“They put my health issues first, not my drug taking”*
- *“So substance use comes up but very much at my initiative... the drug use isn’t the problem, whatever I say is the problem is the problem”*

## COLLABORATION/BALANCE

- *“I recently fractured my hand punching a wall ... the ER doctor who looked at it was just incredibly non-judgemental. It was like ‘how did you do this’ and I’m like ‘I punched the wall’ and he was like, ‘Oh, yep, I’ve done that before. Broke this knuckle.’ He then talked about the circumstances, and I said that I was drunk and he just kind of checked how much I’d been drinking... That was towards the end of August, it was the second month of lockdown and it was just nightmarish. And he just went ‘yup, I understand you’re drinking a lot. I was drinking a lot too. But that’s a bit much to do for a long time but if that’s what you need to cope, that’s okay just make sure it doesn’t continue forever.’ And that made me feel so at ease... And the same with the x-ray tech, she also said that she’s punched a wall. I don’t know if people at Canterbury-Bankstown Hospital are taught to tell people that they’ve done the same thing to make everyone feel comfortable or it’s just staffed by people who are really into angry wall punching. Fuck, it made me feel at ease.”*

## DISCUSSION

- Everyone that uses drugs has a reason for their drug use
- As long as we continue to position drug use as “wrong” and “evil” and something that should be stopped stigma will persist
- Denies the agency and expertise of people who use drugs
- Results in inherent power imbalances and poor-quality clinical care

*“addiction to narcotic drugs constitutes a serious evil for the individual and is fraught with social and economic danger to mankind”*

# RECOMMENDATIONS - I

- Stop framing drug users as “avoiding” or “evading” health care – they aren’t they are reducing harm
- Quantify the problem
  - How many people die each year because of stigma?
  - What are the costs to the health system
  - Investigate stigma as a factor in every critical incident analysis
  - A complaints system with teeth
- Recognise and address the fact that these are **systems** issues

## RECOMMENDATIONS - 2

- Overwhelmingly, people did not complain about the treatment they received, they moved on
- Empower not just consumers but their representatives to participate in systems change
- Information by people who use drugs, for people who use drugs
- Change the system – decriminalize, invest in patient-centred care, revoke the UNODC conventions etc

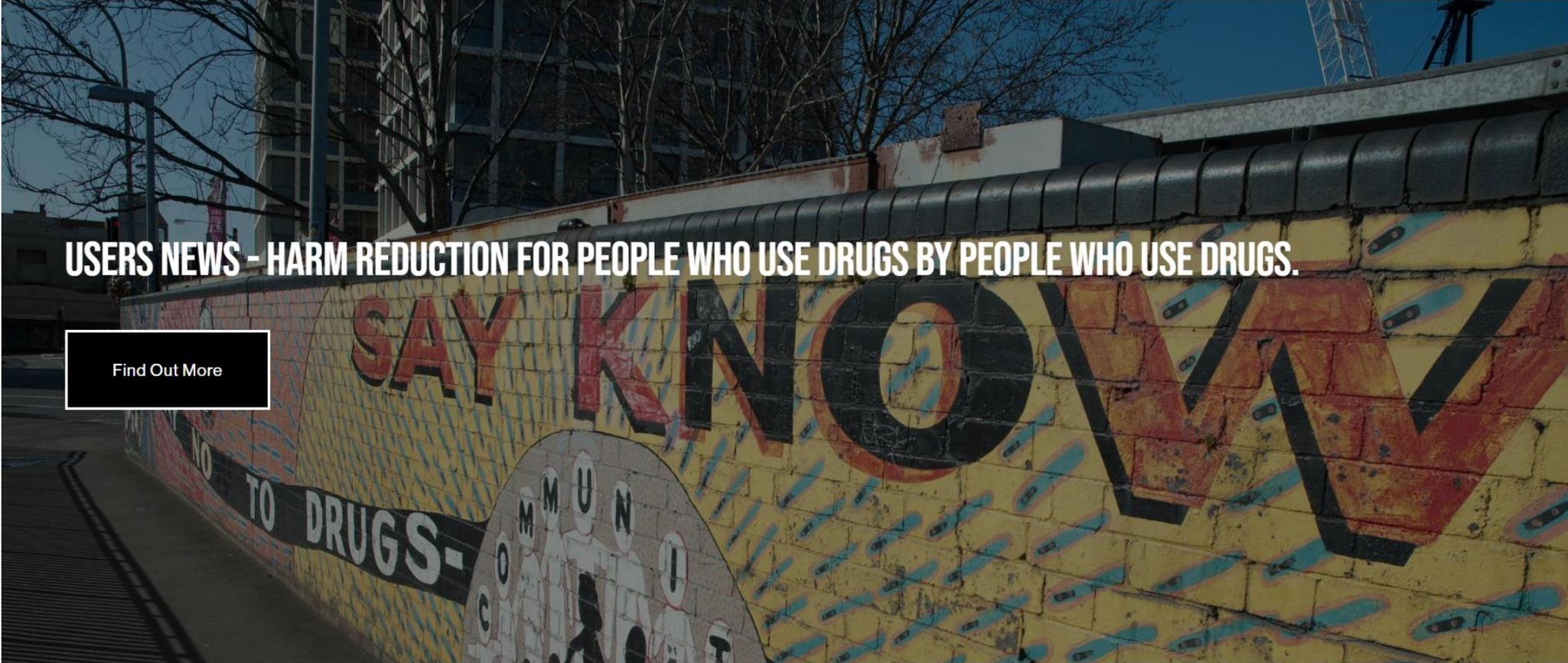




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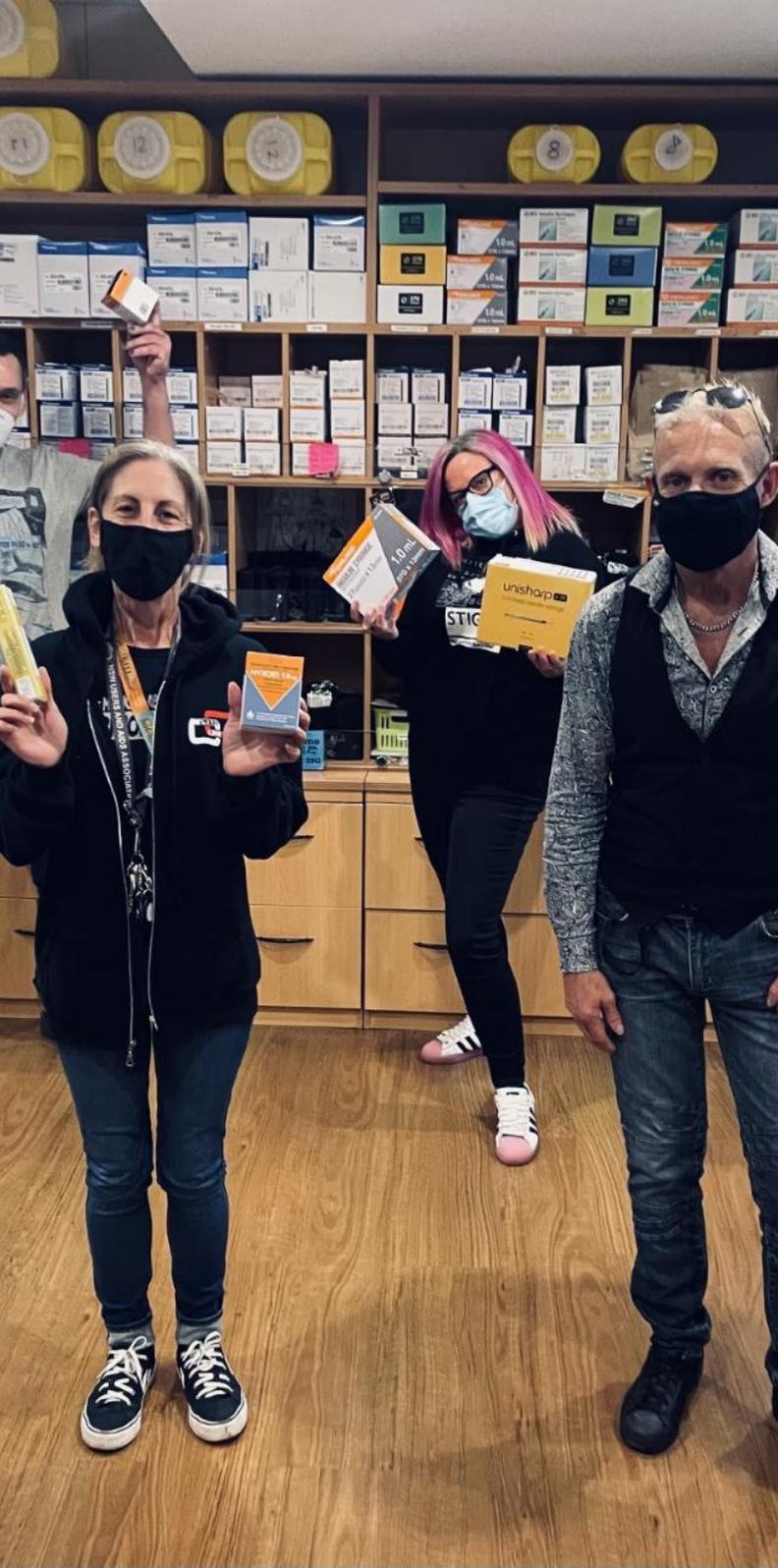


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