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NEW AND EMERGING METHODS FOR IMPROVING THE HEALTHCARE OF PEOPLE WHO USE DRUGS:

Results and recommendations
from a national consultation



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ACKNOWLEDGEMENT OF COUNTRY

La Trobe University acknowledges our campuses are located on the lands of many Traditional Custodians in Victoria and New South Wales. We recognise their ongoing connection to the land and value their unique contribution to the University and wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching, learning, research and partnerships across all our campuses.



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Ethics

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Background

- Addiction is the most heavily stigmatised condition in the world (WHO, 2019);
- Drug-related stigma is extremely commonplace in numerous settings, but most marked in healthcare settings;
- Low levels of trust in health care systems (Newman et al., 2020; Treloar et al., 2016), often expect to be treated adversely (Farrugia et al., 2021) and are concerned about privacy, surveillance, and access to sensitive and private health information (Lenton et al., 2025; Tertulino et al., 2024; Mulcahy et al., 2023; Stablein et al., 2015);
- Agreement that trust in healthcare systems must be restored, healthcare outcomes must be improved, and drug-related stigma must be eradicated.

Using data to find people who use drugs

There is a push underway to detect, locate and predict people who use drugs in response to:

- Healthcare concerns, such as increasing overdose deaths in Australia (Cerdá et al., 2021)
- Medical breakthroughs, such as the advent of cure for hepatitis C and public health goals of elimination

‘Novel’ data-driven interventions:

- Tested 1000s of blood samples of racialised populations that were collected in an Australian hospital emergency department, screening for hepatitis C (Prince et al., 2021)
- Data linkage, machine learning techniques and proxy measures to identify people who use (or may use) drugs, such as traits like ‘neuroticism,’ ‘extraversion,’ and ‘agreeableness’ (Qiao et al., 2019).



METHODS

National consultation (N=13)

- Community advocacy of people who use drugs
- Design, development, or implementation of new and emerging methods
- Health and privacy law
- Drug policy

Findings: New & emerging methods

Category	Description
Surveillance systems	Public health and epidemiological surveillance systems. Example: State notification systems: HIV, hepatitis B and C
Data linkage	- National and state data linkage: eg: Electronic health data systems, My Health records and Single Digit Patient Records - Population - wide data linkage projects on mental health outcomes - Longitudinal cohort studies of people who use drugs with linked health data
Prescription and medication monitoring	- Real-time prescription monitoring systems: SafeScript - Pharmacotherapy/Opioid replacement therapies: Facial recognition - National medicine dispensing and subsidy datasets
Drug early warning and harm reduction systems	- Emergency department - based early warning systems - Syringe residue testing projects - Peer-led rapid reporting systems
Administrative and disability datasets	- National disability support datasets - Linked datasets on disability and health
Epidemiological modelling	Predictive identification of people who use drugs from health datasets

There's actually now a big rollout nationwide about projects to link, interlink primary healthcare and acute care data. That is de-identified data, so it's for data-linkage projects. (P2)

Perceived benefits

In theory, with machine learning, you can do a predictive algorithm of saying whether somebody is more likely to suffer a particular illness based on their history [...] they can do predictive algorithms of bad health outcomes. So, that can be really good [...] if used well and wisely. (P01)

I think the more people know about how our data is being used, the more accountability and transparency, hopefully that's putting some pressure on using these things in ways to reduce stigma. (P02)

PERCEIVED RISKS AND CONCERNS

STIGMA

Lack of consent

There was a level of consent there to [...] that information could be used in a deidentified manner, but deidentifying data and having a person's health information used in AI learning, is not the same thing. (P13)



PERCEIVED RISKS AND CONCERNS

Trust

How do you facilitate trust in a system that has a long track record of mistreating vulnerable people? I think it is worth thinking about not just novel ways of finding and accessing these people, but novel ways of also protecting them and constructing or facilitating the groundwork for a relationship of trust [...] I think is often overlooked in these circumstances and maybe something that has to be brought into the frame rather than just how are we going to find these people using novel data methods? How are we going to convince them that they can trust whoever it is that might be offering this particular service or trust the program that we're doing. You know, what work do we have to do to inspire that trust? (P07)

PERCEIVED RISKS AND CONCERNS

Biases in AI

AI methods by definition are a system that learns [...] and is supposed to become smarter and better over time as more data accumulates, it learns its lessons from previous things and self-refines what it does, but if the fundamental for that learning are based on particular biases in data, then you [...] it just becomes like a data-driven hegemony in terms of it just reinforces the same. (P12)

The biases embedded in the ways we address things like child abuse as individual problems, as reduceable to sort of features of the individual rather than the society in which they live and the families they raise, you know their social and economic conditions they are raised in and the challenges they might face. (P03)

PERCEIVED RISKS AND CONCERNS

Healthcare as site for experimentation

I think there's a legality question. I think there's a kind of, I'll call it like a research ethics question, which is around a tendency towards non-consent based forms of research for reasons I think that are revealing in themselves. I think that there are really [...] genuine and significant data security, privacy, cybersecurity issues [and] criminalisation and policing issues with all of these things [and...] accidental effects and [...] non-accidental effects, or more direct effects. (P08)

I mean it's true that there are many people who inject drugs who use emergency departments kind of as their GP because that's all they've got, but I still don't think it's necessarily the right place to do [experimental work]. I think that needle and syringe programs and lots of other places, the street, yeah. There's lots of other places that that could be done. It's just that that's an easy place for a research or a healthcare focused kind of sector to think about it [But...] They're in there because they are there for an emergency. (P05)

PERCEIVED RISKS AND CONCERNS

Legal and human rights issues

So, there needs to be research that prioritises a human rights approach or whatever it may be, a critical consideration of the value of these programs because there's a huge push in my experience within government to come up with novel ways of doing their job that are technology facilitated. So, unless there's critical scholarship on it, I have a nasty suspicion based on previous experience that there might be real problems as well as missed opportunities. (P07)

I think it's very important that people know what their rights are when interacting with services, yeah, of all sorts and yeah, it'd be good to have even maybe some dedicated resource or something for people who use drugs about, you know, which unpacks and addresses data concerns. (P04)

Centring affected communities

It's about empowering our community and our organisations to tell our own story with our own data and indicators, not those that are used to write about us. So, for instance, a measure of [any] research strategy is actually developing a peer-based set of wellbeing indicators that peers identify as relevant to measuring their health and wellbeing. Yeah. So, those sorts of things. (P04)

There is a gap between people who want to get involved in this work. So, there's an acceptance that it's important, but we've had difficulty recruiting people into these discussions because I think people feel that they don't have the technical knowledge to sit at the table. (P02)

Conclusion



- Data-driven methods can improve healthcare outcomes and support early intervention, but operate in contexts of stigma and low trust.
- These approaches are not neutral; they risk reinforcing stigma, surveillance, and mistrust without strong safeguards.
- Ethical and human rights concerns are heightened, particularly around consent, transparency, and legal compliance.
- Risks can be mitigated through careful governance and design grounded in human rights and data justice.
- Lived experience leadership, transparency, and ongoing ethical research are critical to equitable implementation.

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THANK YOU

