

TURNING OUTWARD

USING COMMUNITY CONVERSATIONS WITH PEOPLE WHO INJECT DRUGS IN SOUTHERN SYDNEY TO UNDERSTAND THE FACTORS INFLUENCING THEIR HEALTH AND WELLBEING

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WHAT DID WE DO?

The HIV and Related Programs (HARP) Unit, Kirketon Road Centre (KRC) and St George Drug and Alcohol services conducted five in-depth conversations with people who inject drugs (PWID) in South Eastern Sydney Local Health District (SESLHD).

Three conversations with 22 PWID were held August - November 2017. Sixteen people attended a feedback session in March 2018 to check we heard them correctly before actions or further conversations took place.

Two conversations with 17 participants were held October - November 2018.

Participants were paid to attend all conversations and food was supplied.

WHY DID WE DO IT?

PWID are a priority for hepatitis C initiatives in the **NSW Hepatitis C Strategy 2016-2020**.

Conversations sought to explore how best to engage and retain PWID in treatment and ensure they receive health care they need in the way that they need it.

The Harwood Institute© approach of "turning outwards" was used to focus on what matters to them rather than services.

The approach is rooted in five core ideas: community ownership; strategies that fit community; sustainable enabling environment; a focus on impact and belief; and narratives.

The conversations built trust, community understanding and guided actions.

Participants expressed high-levels of satisfaction with the process and the opportunity to 'have their say'.

WHAT DID WE HEAR?

ASPIRATIONS

"We'd like the community not to be afraid of us. We're not all evil."

Participants want a community that is safe, inclusive and non-judgemental and that provides opportunities for meaningful participation.

A community that treats drug use as a health issue, rather than a legal issue.

CONCERNS

Stigma and discrimination

This was the most significant barrier to health seeking intentions and behaviours.

Stigma and discrimination from police and healthcare workers has the most significant impact on service access:

Police harassment

Police harassment and discrimination outside needle syringe programs (NSP), Opioid Treatment Programs (OTPs) and local train stations was common:

Health worker discrimination

Participants felt identifying as a person who uses drugs affects health service access including the types of treatment offered:

Lack of access to safe, acceptable and appropriate services

Issues that made health services not acceptable and accessible include: limited services in some areas; not knowing what services offer; service exclusion criteria, restrictive opening hours; lack of staff time; staff attitudes and behaviours, a lack of peer support and workers such as social workers.

Low literacy and computer skills compounded the barriers.

"We are judged as 'loser drug addicts', as 'junkies'. It's so hard to change people's perceptions There is so much judgement on us"

"Once a drug addict always a drug addict, no wonder people give up"

"Your day is ruined, you've missed your appointment and you haven't done anything wrong, you feel like a criminal"

"It's scary going to [the OTP clinic] that is why I jumped off the program before...they [police] hold you up and then you miss your dosing"

"Some [health workers] say we have wasted our lives and don't deserve to be looked after."

"If [health care workers] already know you use drugs, when you need painkillers, they won't give them to you."

"How are people meant to rebuild their lives without access to treatment?"

"We need specialist doctors who understand there are reasons why people use drugs."

ACTIONS

Actions and agencies that would make a difference

Participants trusted few people and organisations to be involved in actions to support the community.

NSPs and the NSW Users and AIDS Association (NUAA) were identified as the most trustworthy. Some non-government organisations providing practical assistance were identified.

The actions participants identified as crucial to moving the community forward were:

1. Education for community, police, health workers and PWID

Education to break down stigma and stereotypes and increase understanding about drug use and the reasons people use.

Particularly important for police and health care workers, including GPs.

"if you can re-educate people in medical health – there is just as many uneducated in health sector as the police system that can really do damage to your life"

Education for PWID about rights, responsibilities, safe injecting and disposal to reduce negative consequences of "irresponsible drug use" on the community.

"we need education on both sides – us as well as them"

2. Paid consumer roles

Education to break down stigma and stereotypes and increase understanding about drug use and the reasons people use.

Particularly important for police and health care workers, including GPs.

"More consumer roles"

Peer-led programs and consumer roles would give PWID a 'voice'; increase appropriateness, acceptability and accessibility of services.

The importance of interacting with peers in services was emphasised.

3. Better access to non-judgemental health services

Participants want access to appropriate and acceptable services provided free of charge.

They felt NSPs should provide a broader range of health services (such as primary care, mental health, dental care and drug and alcohol clinics).

A hepatitis C clinic run at the NSP was highlighted:

"That hep C we are doing here [NSP] is excellent. I would never have got that done if they didn't do it here. I could have gone to the medical centre but they are judgemental"

They want outreach programs to 'hotspots' in the area to provide NSP and health support and referrals as needed.

WHAT HAS BEEN ACHIEVED?

"Quick wins" were identified and enacted to build trust such as:

- Privacy screen erected at the NSP entrance and vending machine.
- Providing computer and internet access at services.

Consumer advisory group is operating at the NSP to ensure the PWID "have their say" and are engaged in health service planning and delivery.

Nurse and peer-led hepatitis C clinics are being offered in drug and alcohol and NSP settings.

Developed and delivered a one-day Hepatitis C workshop including stigma and discrimination to 90+ SESLHD health care workers in 12 months.

Incentivised HETI Stigma, Discrimination & Injecting Drug Use module resulted in 500+ health care workers completing it in 12 months compared to just 43 in the 12 months prior.

WHAT NEXT?

Explore models for paid peer-programs with clinical services and the injecting community.

Conversations with police are planned to engage them in actions to improve outcomes for PWID.

Reviewing services provided via NSPs and via 'outreach' to communities.

Feedback session to inform participants of progress and obtain further feedback.