

Hepatitis C treatment

Peer insights on barriers and motivators to
Direct-Acting Antiviral (DAA) treatment uptake
(Broadsheet No. 2)



A research project by the Australian Research Centre in Sex, Health and Society in collaboration with peer-based organisations – Peer Based Harm Reduction WA, NSW Users and AIDS Association and Harm Reduction Victoria.

The knowledge and experience of people who inject drugs (PWID) within peer programs is a vital asset for strategies for the scale-up of DAA treatment among people who inject drugs (Brown and Reeder, 2016). This study is focused on translating these “real time” peer insights into resources that support policy and programs to tailor to the needs of communities of people who inject. This tailoring is critical to achieving the goal of eliminating hepatitis C.

This broadsheet is the second of a series that will be produced over the duration of the project. This series will present current peer insights from the peer workers and other members of the people who inject drugs community on the access to and uptake of the new hepatitis C treatment.

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Background

The breakthrough in hepatitis C treatment with direct-acting antiviral medicines and their listing on the Pharmaceutical Benefits Scheme sets the trajectory to achieve national prevalence and transmission targets. The uptake of treatment among people who inject was promising at the outset, but evidence is emerging that uptake is plateauing and in some areas slowing.

The diffusion of innovation theory (Dol) describes five categories of people that illustrate the rate of adoption of new technology or ideas (often referred to as innovators (2.5%), early adopters (13.5%), early majority (34%), late majority (34%) and late mass (16%)) (Rogers, 2010). The current uptake of DAA treatments would indicate that we have reached the innovators and early adopters, but the rate of uptake is now slowing, and different strategies may be needed to reach the early majority, late majority and late mass (Scott, Iser, Thompson, Doyle, & Hellard, 2016). The Dol theory is useful in highlighting the role of innovators in creating momentum or willingness to take up treatment among early adopters, how social and structural barriers impact on different people, and the potential role of the late majority and late mass in reducing the momentum and willingness among the early majority.

To achieve prevalence and transmission targets of the Fourth National Hepatitis C Strategy 2014–2017 (Department of Health, 2014), people who inject drugs with HCV need to be reached to increase their access to, and uptake of, DAA treatment. However, different strategies may be required to engage people who inject drugs who are reluctant or sceptical about the new DAA treatment or may have barriers to accessing treatment (i.e. the early majority and late majority).

An innovative 18-month (February 2018 – July 2019) project was developed in collaboration with three peer-led organisations - Harm Reduction Victoria, NSW Users and AIDS Association, Peer Based Harm Reduction WA. Peer-led drug user organisations have on-the-ground insights from their networks of people who inject about current attitudes, beliefs and experiences related to the access and scale up of direct acting antiviral treatment among people who inject drugs.

Method

This study is using a qualitative approach to investigate the evolving experiences, perspectives, barriers and enablers for people who inject regarding the access, scale up and provision of the DAA treatments.

Recruitment

This study is conducting focus groups and semi-structured interviews at regular intervals with peer workers (staff and trained volunteers) from the three collaborating organisations. The staff and trained volunteers were informed of the study by their organisations and those who were interested met with researchers to obtain more information.

The second round (of three) focus groups was conducted in October and November 2018 in Perth, Melbourne and Sydney with

approximately 25 participants consisting of both staff and peer workers, many of whom had also participated in the earlier focus groups, from the collaborating organisations. Participants discussed their experiences and those of their peer networks. Peer networks ranged in size from a few people to more than 50.

Outcomes

The DAA treatment environment is evolving and rapid turnaround of interim project findings to the peer-led organisations, community, clinical, and policy sectors is essential. Short broadsheet reports describing the evolving experiences of people who inject, and the implications of these experiences for refinement or reorientation of strategies to scale-up treatment access, are being developed throughout the study. In addition, further analysis will be undertaken using the Dol theory to generate a deeper understanding of how to increase access and uptake of treatment among the early majority and late majority.

This project has received ethics approval from the La Trobe University Human Research Ethics Committee – approval reference HEC18069.

References

- Department of Health, A. (2014). Fourth National Hepatitis C Strategy 2014–2017. Canberra: Commonwealth of Australia.
- Brown, G. and D. Reeders (2016). What Works and Why - PWID Peer Service Provision and Policy Participation System Logic and Draft Indicators. Melbourne, Australian Research Centre in Sex, Health and Society; La Trobe University.
- Rogers, E. M. (2010). Diffusion of innovations. Simon and Schuster.
- Scott, N., Iser, D. M., Thompson, A. J., Doyle, J. S., & Hellard, M. E. (2016). Cost-effectiveness of treating chronic hepatitis C virus with direct-acting antivirals in people who inject drugs in Australia. *Journal of gastroenterology and hepatology*, 31(4), 872-882.

Summary of findings

In this second round of focus groups participants delved deeper into the insights of their network of people who inject drugs. Particularly their peers' individual experiences which offer unique perspectives on their navigation of hepatitis C testing and treatment. While known barriers to DAA treatment continue to exist, it is increasingly evident that for some people who inject drugs general awareness messages about hepatitis C treatment are no longer 'sticking'. Different approaches and communication emphasising the benefits and relevance of treatment at the individual level are needed to convince this group to test and commence treatment. And it is necessary that conflicting advice and messaging, and stigmatising experiences encountered by people who inject drugs be minimised to avoid undermining scale-up strategies. Fortunately, there are practices of health services that have demonstrated progress in engaging people who inject drugs into the DAA treatment cascade.

Hepatitis C testing – is it better to know than to not know?

In the first broadsheet, poor vein health, perceived high treatment costs and hepatitis C stigma were highlighted by focus group participants as the major deterrents to testing for the virus. These barriers were again discussed and in addition many participants offered another perspective to explain the hurdles faced by many people who inject drugs to undergo a hepatitis C test.

“A whole Pandora’s Box of conversations you don’t want to have”

The prospect of testing positive for hepatitis C was depicted as overwhelming by many participants. A major stressor and predicament for a person who injects is the unavoidable and confronting conversations or situations that they are likely to encounter when they disclose their hepatitis C status.

“the diagnosis comes ... there’re certain people that you have to tell ... it’s hard ... it still hurts [to face the negative reactions] – FG 1

“those are your intimate relationships, the ones that matter, and just having to have that conversation, even if everyone knows [about the individual’s drug-use] ... you have to be having the conversation which is just draining on everyone” – FG 1

Re-living stigma and discrimination

One main consequence of a hepatitis C diagnosis, apart from the clinical implications for people who inject, is yet another cycle of stigma and discrimination experiences. These occur in settings such as pharmacies, health services, and family homes. A common reaction among people external to the drug use community is their conflation of hepatitis C with injecting drug use.

“when people find out [the PWID has hepatitis C] ... they’ve got the problem, you are actually a junkie ... that’s all the stigma” - FG 1

“ ... not just a druggy, you actually use needles or share them” and “ ... using needles carelessly” – FG 1

A few participants described the upsetting encounters when visiting immediate family members who were aware of their hepatitis C status. ‘Special’ crockery and utensils were set-aside for the individual’s use, separate from the rest of the family.

In one focus group participants discussed hepatitis C notification and it became apparent that its processes were not well understood or conflated with drug dependence notification, e.g. (different jurisdictions have varying procedures for notifying hepatitis C cases and opioid substitution therapy registration). The confusion and uncertainty appear to relate to people who inject (mis) understanding of the purpose of identifying information for hepatitis C.

“Some people are scared that it [hepatitis C] will impact on future prospects ... child protection, employment ... once it’s recorded it’s recorded.” – FG 3

“Lots of people [who inject drugs] say that they are not deserving of [treatment]”

People who inject who have hepatitis C or may have been at risk of transmission traverse a spectrum of barriers and motivators in diagnostic testing and commencing DAA treatment. The focus group participants shared their individual and peers' experiences of the deep-rooted obstacles within themselves that are akin to a 'cloud' of doubts that hover over them.

“I've had a bunch of pathology done, I've just been having these issues in my head all week, and it's the anticipation of conflict even if there isn't one, that's also a huge barrier just to be organised, that motivation to get your ducks in a row, organised. It takes a massive amount of internal organisation and self-talk

to just get yourself in the right head space, because with all the support services and all the education and all the access and everything that we have, there's still this internal thing that if I'm, as I said, feeling f--- up and feeling wrong that I just, it's so hard I can't do it you know.” – FG 1

These doubts are often exacerbated by other debilitating feelings that further delay the attempts of current injectors to seek treatment.

“when you miss an appointment then you feel like crap because someone's gone and done all this stuff for you, trying to get you in and you miss it and then you feel bad because someone's done work for you and you haven't turned up and it's like I can't put them through that again, guilt” – FG 1

“It doesn't take much to just derail you because like I said we've all got a lot of this ... negative self-talk going on and internal conflict” – FG 1

The pessimism and negative self-image were described across all the three focus groups. To counter the low esteem and to support current injectors seeking DAA treatment the peer workers provided some approaches used to reassure and encourage PWID. For instance, a peer worker would relieve the PWID's anxiety by expressing:

“Look it doesn't matter if you've missed a week of medication, don't give up, you're still going to be successful” – FG 2

“You haven't put anybody out, it's OK, we understand s--- happens, you know we want to see you again, we want to see you succeed” – FG 1

The participants agreed that it is helpful and comforting to the PWID and one participant shared their experience:

“It empowers you strangely when someone [says] “this isn't a total crisis, it isn't totally f--- because you've done this [e.g. missed medication or appointment].” – FG 1



Life matters

Several peer workers stated that over a prolonged period they have emphasised the impact of structural and systemic barriers on the uptake of DAA treatment to policy-makers, researchers, and health service providers at various hepatitis C and drug-use related platforms.

Specifically, for many people who inject drugs, meeting daily essentials, i.e. suitable accommodation and obtaining food is a constant struggle. These priorities will override other perceived non-immediate needs including seeking medical attention.

“Given like you know food, your drugs, your habit drugs, that’s your instinctive [need], that’s what you need to do, and like you know focussing on a course of [DAA] treatment for something that seems kind of obscure because it’s not ... helping you straight away” – FG 3

“I think the less stability in your life the less inclined you are to maybe access [DAA treatment]. If you are out of control and I’ve been there, people tell you stuff and you are like “Yeah yeah OK next time” – FG 3

Harm reduction organisations are increasingly expected to play a central role in engaging and supporting current injectors into treatment (in line with the new emphasis on hepatitis C elimination). This impacts on the peer workforce. Peer-led organisations themselves have had to develop innovative strategies to address the consequences of systemic barriers to facilitate the uptake of the DAA treatment. This is drawing significantly on their limited resources and adding a layer of pressure on staff to deal with the complex nature of the social and systemic barriers to treatment encountered by their service users. Peer workers expressed their exasperation that these core concerns are rarely addressed in any meaningful way by stakeholders including government departments.

“But that thing about people having too much other shit going on to focus on hep C, I kind of feel like I keep saying that to people and like at meetings and stuff, but it’s just like it seems like it’s too big of a problem for people to go “Well OK let’s focus on trying to sort some of that stuff out” instead of just talking like literally about hep C” – FG 3

These broader structural issues are especially concerning as they continue to constrain peer programs capacity to support their most affected and vulnerable service users uptake of DAA treatment.



DAA treatment awareness and information

There's indication that among some networks the general awareness of DAA has reached saturation. For some people this level of information has been enough to take up treatment. However, focus group participants report although awareness of hepatitis treatment has increased since the introduction of the DAA therapy this was concentrated amongst their peer networks and other PWID who regularly access harm reduction services.

“[DAA treatment] was a real turning point for hep C, people were really excited and jazzed up about it, everyone is kind of a bit over it I think novelty has worn off ...” – FG 3

While awareness may have increased there remains some degree of scepticism about the benefits of treatment among the injecting community. Peer workers called for added health promotion approaches to communicating DAA treatment information. While current messaging informing on the DAA treatment should continue the focus could shift to the benefits of being cured of hepatitis C. As one participant declared, **“I felt like I was re-born [after being cured]”** – FG 2, emphasising their improved quality of life. People who inject drugs need accurate evidence from people they see as like themselves that hepatitis C treatment will benefit them directly, and not encounter conflicting messages from different sources. In addition, peer workers suggested information be made available on holistic well-being, e.g. liver health and nutrition, along with DAA information.

Clear, consistent and relatable messages on DAA treatment are necessary across the peer, community and health service organisations. Peer workers report continued misconceptions and conflicting advice about eligibility, cost and access to treatment among their networks.

“some Doctors not wanting to give you the treatment because you are still using” – FG 4

“I've heard Doctors say too that like people that are doing the Hep C treatment you know you only get one chance type thing” – FG 3

Inconsistent information creates misunderstanding and undermines the credibility of clinicians and health promotion messengers and is another deterrent to commencing treatment. This further reinforces PWIDs' perception that accessing health care is fraught with barriers and stigmatising attitudes.





Health service provision and access

The experiences of people who inject of being stigmatised and discriminated against while seeking medical assistance at health service sites, including at GPs, hospitals, dental clinics, community health centres and pharmacies, were recurring themes in the focus groups. Participants reported that these negative encounters adversely influence theirs and their peers' health seeking behaviour, and most will avoid contact with health services unless they are seriously ill.

“One bad experience can scare people ... like the fear of experiencing stigma can stop people from doing something [hepatitis C test and/or treatment]” – FG 3

“You don't have to go through your history again and again ... I feel like if I go to another GP about something non-related I just sometimes get the impression that if they know that I'm a current drug-user that that they are going to have that perception that I'm in there looking for something” – FG 2

“The doctors just need to be told to [treat us as] human beings ... not to judge us and if someone's got hepatitis C give them the duty of care, give them exactly what they need, and so give them the medications so they don't have to go wandering looking for a place like a peer-based NSP out in the middle of woop woop.” – FG 1

Some peer workers related their personal and peers' realities of navigating the complexities of the health care system and managing their confidentiality and the stigma regarding their injecting drug use. Participants described that for some people who inject, they do not feel comfortable disclosing their drug use as they are concerned they will not receive optimal health care.

Conversely, the peer workers emphasised that positive experiences with non-judgemental and considerate health workers are likely to encourage repeat visits by current injectors. These 'untroublesome' and empathetic service providers are promoted among the network of injectors and as one participant stated, **“if you have got a good doctor, you will travel!” – FG 4**. The quote below describes a primary health care (PHC) provider held in high regard:

“PHC is sort of great, PHC and NUAA are the same [providing similar services to the injecting drug community] but NUAA has had the peer people that have been through it [injecting drug use], PHC haven't, they've got staff that are professional staff but they've learnt as a text book way, but they are non-judgemental, they're just as compassionate as what we are, and they are very very good ... they haven't been peer-based, they haven't been through it, they haven't been addicts, but they make you feel comfortable” – FG 1

A few peer workers suggested a holistic approach to the provision of care that would be of benefit to their peer networks. For instance, in addition to NSP related amenities a health care site could offer information, linkages and referrals to welfare services, housing or shelter assistance, counselling and so on.

“One stop shop, a building like this, social workers, mental health ...” - FG 3

Peer Workforce

The focus group participants clearly communicated that non-peer NSPs are perceived as more 'user-friendly' if an identified peer worker is part of their workforce.

“They've been in the same environment [drug use] so they can relate. I can come up to you and I don't even know you but I know that you have used because you are in this organisation, so I can be honest with you, I don't even know you from a bar of soap, but I can be honest within myself to talk to you and I know that you're not going to piss in my pocket and hate me and look at me and throw daggers at me while I'm asking you a simple question about an issue of drugs. So that's probably the best part. That's the difference.” – FG 1

Embedding a peer workforce signals that an NSP is committed to engaging with the injecting community.

“a service get themselves a peer worker ... respected as part of the team ... to show the [injecting drug use] community this isn't a place where you are going to get looked down on because people from your community are staff and they're respected members of our staff” – FG 3

However, employing one peer worker at a service delivery level without the appropriate leadership and resourcing by the organisation can undermine hepatitis C initiatives. Organisational policies and governance structures should demonstrate commitment to peer approaches. It is also important for organisations to work towards developing the capacity of all staff to be able to provide inclusive and non-judgemental services to people who inject. In addition, the development of a local area practice support network facilitated by a peer-led harm reduction organisation where peer workers in non-peer organisations can link in with each other would strengthen the workforce.



Harm Reduction Victoria (HRVic)

Harm Reduction Victoria is the peer-based drug user organisation for the state of Victoria, specialising in peer education and health promotion. Recognising that drug use happens in the community, HRVic does not condone or condemn drug use, instead working to reduce associated harms and realise a world where everyone has the same opportunities and life chances, regardless of their drug of choice.

Programs

The Peer Network Program, participating in the Peer Insight project, trains networks of PWID around Victoria to provide peer-to-peer NSP services and model safer drug use in their communities. As a complement to mainstream NSP services, PNP volunteers are licensed as outreach workers of HRVic's NSP and provide sterile injecting equipment and educating to PWID who are not able to or would not access existing services.

/ Contact:
128 Peel St, North Melbourne, VIC 3051
P: (03) 9329 1500

/ Learn more:
hrvic.org.au



Peer Based Harm Reduction WA

Peer Based Harm Reduction WA (formally WASUA), is a community based harm reduction organisation based in Western Australia. The organisation provides an advocating voice for people who use drugs and strives to deliver services which reduce the transmission of blood born viruses and sexually transmitted infections associated with drug use. At its core is a peer-based model of engagement, working with people with lived experience of drug use in supporting and delivery of health promotion initiatives. For participants who choose to use drugs, this ensures they receive a rounded perspective which details not only the risks of drug use, but also how to take drugs in an informed and safe way if they so choose to.

Programs

Needle Syringe Exchange Program, Health Clinic, Hepatitis C case management, Overdose Prevention and Management (OPAM), Peer Naloxone Project, Outreach Program.

/ Contact:
Suite 21 & 22, 7 Aberdeen Street,
Perth, WA 6000
P: (08) 9325 8387

/ Learn more:
harmreductionwa.org

The NSW Users and AIDS Association (NUAA)

Proudly governed and directed by people with a lived experience of drug use, the NSW Users and AIDS Association (NUAA) is the peak drug user organisation in NSW. This association provides a range of services for people who use drugs, including harm reduction strategies, education and advocacy for improved services and approaches to drug use within the population. The NSW Users and AIDS Association receives state government funding and leads the way in reducing the harm from illicit drug use in NSW.

Programs

Needle and Syringe Program (NSP) – providing access to a safe injection room and equipment for people who inject drugs.

PeerLink – NUAA's peer education project which trains peer educators with a lived experience of drug use in educating other people who use drugs.

/ Contact:
Level 5, 414 Elizabeth St, NSW 2010
P: (02) 8354 7300
P: 1800 644 413 (free call)

/ Learn more:
nuaa.org.au

ARCSHS

The Australian Research Centre in Sex, Health and Society (ARCSHS) is a centre for social research into sexuality, health and the social dimensions of human relationships. It works collaboratively and in partnership with communities, community-based organisations, government and professionals in relevant fields to produce research that advances knowledge and promotes positive change in policy, practice and people's lives.

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