

Hepatitis C treatment

Peer insights on barriers and motivators to
Direct-Acting Antiviral (DAA) treatment uptake



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 to strategies for the scale-up of DAA treatment among PWID (Brown and Reeders, 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 first 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 community on the access to and uptake of the new hepatitis C treatment. This broadsheet provides background to the study and presents an overview of the attitudes, beliefs and experiences of PWID related to the access and scale-up of direct acting antiviral treatment among this community.

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 onset but evidence is emerging that uptake is plateauing and in some areas slowing.

The diffusion of innovation theory (Dol) approximates that there are 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 creating momentum or willingness to take up treatment among the 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), PWID with hepatitis C 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 PWID.

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 first round (of three) focus groups were conducted in May and June in Perth, Melbourne and Sydney with approximately 30 participants consisting of both staff and peer workers 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, will be 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 – PWUD 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 emerging key themes from the focus group discussions

Attitudes, understandings and beliefs about the DAA treatments

People who inject have different experiences in their engagement with treatment. These differences relate to whether they have undergone treatment, or know of peers' experiences with treatment, and how much treatment information they have.

"Treatment is gloriously simple and available", but not for all

The focus group participants who had undergone treatment described that they were relieved that treatment was straightforward, (i.e. short course of pills), with limited side effects, and minimal interference with daily activities. For the most part, this was the experience that was shared with peers. However, peer workers reported that some people in their networks had been told that there were no side-effects but did experience side-effects. While this would not deter them from promoting the treatments to their peers, they expressed a need for treatment information from health services and promotional resources to be more accurate or nuanced, i.e. to include details of common side-effects.

"That's the feedback I got was it was a mild but noticeable headache, it wasn't imagination it wasn't so disruptive that it stopped them being able to do anything, just that noticeable thing and you know, I'm sure all of them were happy to trade off that for getting the treatment through." – FG:1

"There's a heck of a lot of people that are hep C positive that are just living with it because they think that because they're still using they're not going to be able to [go on treatment], or you know like I said they still know about the old treatment, and there's that fear" – FG:3

Periphery of treatment services and information

Peer workers also reported that there are people who inject that have little knowledge about treatment due to not having access to needle and syringe programs (NSPs), peer workers or harm reduction services, or that may access those services but do not engage or connect with treatment information.

Getting on DAA treatment

The focus groups highlighted the stumbling blocks that impeded PWID from accessing treatment information and treatment. While many current and former injectors in their networks were aware of treatment, peer workers noted inconsistencies in their peers' knowledge and uncertainties about availability and access to treatment.

Eligibility and cost

A recurring question raised within their peer networks was whether people who disclosed they were a current drug user would still be prescribed treatment. Similar concerns were raised about whether being on an opioid substitution therapy program would preclude them from accessing treatment. There was also concern about affordability, and the cost of treatment was generally not known or perceived to be expensive. There was a perception that if people did not have a Medicare card this would exclude them from subsidised health services.

"You've got to pay for the script, if you're on a pension it's about \$6 or something, but however we will pay it for clients who can't afford it." – FG:1

Vein health

For many PWID having their blood drawn for tests caused great anxiety due to previously painful and difficult experiences. This was a major deterrent, and PWID would 'search for' or stick to nurses or medical workers who were skilled in venipuncture. A peer worker mentioned if their preferred nurse was not available they would rather return at another time than to endure a potentially uncomfortable procedure.

"I think especially for older people who've been using for a long time and our veins are pretty shot, is that you like I mean I don't go and get blood tests as often as I should because I get anxiety about it you know every time" – FG:1

Stigma and discrimination

The continued encounters with prejudice and discriminatory behaviour by many people who inject in their daily lives, including

with some health services, were identified as a major deterrent to them interacting or engaging with treatment providers. The peer workers spoke of stigma attached to hepatitis C – that it is a disease associated with injecting – and the pervasive negative stereotypes attached to PWID.

"I think it's still like if you say that you've got hepatitis C it's then assumed that you're an injecting drug user" – FG:1

Hepatitis C stigma can also occur within the PWID community. One person described being socially isolated and losing friends.

"Like people found out because I was sick, for 9 months, and people knew and because I had to drive to Gosford Hospital which was sort of a 45-50-minute drive most days, people would find out, why are you going all that way, the minute they found out that it was to do with hep C I lost a lot of friends" – FG:3

Not on treatment, or not wanting to be on treatment

A theme that emerged from the focus groups centred on people who inject who opted not to take-up treatment or had not yet started treatment. The reasons pointed to systemic and structural issues.

Transient and homeless

Peer workers highlighted that many current injectors in their networks have to address basic needs, specifically shelter and food that take up most of their daily hours. The implications were that not having an address made it difficult to access support, health services or have a safe space to store their medication should they begin treatment.

‘I’m doing OK ..., don’t need to worry about it [hepatitis C and treatment]’

This was a common response peer workers received when hepatitis C and treatment were brought up during their outreach work. Also, it was observed that PWID were less likely to engage with health services and less inclined to accept treatment related messages if they

were not experiencing symptoms. Particularly if their day-to-day priority and routine was taken up by having to meet basic life or drug use needs.

Privacy and confidentiality

Peer workers reported that within their networks peers were not comfortable to disclose their hepatitis C status, both within the community and outside the drug use community (see above – stigma and discrimination). There was strong motivation to prevent being linked to or associated with the disease or treatment such as avoiding being seen at hepatitis C treatment clinics. While others were concerned that they may be obligated to inform their employers if they choose to undergo treatment.

“Some people you know that have pretty good police record they’re well aware that as a drug user you can get shocking treatment at the established medical facility, hospitals and stuff, and they think that if they get [known] as a drug user, or having just a drug user’s disease that’s going to effect in the future their treatment when they’ve got other serious conditions, and they have to get help” – FG:3

Health service providers, and DAA treatment

The focus group participants described varied experiences with health care sites and workers. Many in the focus groups reported that previous negative experiences with health service providers have deterred them from seeking any medical attention unless it was unavoidable. As such, they were daunted by having to interact with health workers who may potentially provide sub-standard care or discriminate against them as people who inject.

“Now I’m too scared [to request for a hep C test] ... I’ve got a good relationship with her [sexual health clinician] and I’ve heard other people complaining about having horrible [experiences] and I don’t want to ruin that relationship. And the people who have complained about not having a great relationship, she knows them as injecting drug users so I’m not willing to take that risk to ruin the relationship” – FG:3

However, the peer workers who have undergone DAA treatment described that they received good care and were supported by the clinicians and nurses. The positive experience encouraged peer workers to spread the word about which treatment sites were friendly, comprehensive and prompt. Unsurprisingly, the DAA treatment providers such as NSPs and specific hospitals and GP clinics were pointed out by many peer workers as the go to treatment sites.

“Dead easy, they were fantastic you know, there wasn’t any kind of hold up or wait, it was really really quick. They got me straight onto it ... totally easy experience ... I’ve told so many people about my experiences at the Royal Melbourne Hospital ... they were just fantastic. I couldn’t have hoped for any kind of better care with regards to that and follow up ... I was asked about a whole range of issues ... including mental health ... I don’t know if it would be done by a local medical centre ...” – FG:2



Considerations for supporting DAA treatment access and uptake

The peer workers shared many valuable insights on the enablers and impediments to hepatitis C treatment. Focus group participants made recommendations on how to address the impediments to the access and uptake of DAA treatment. The main themes raised across all three groups are highlighted below.

Promoting hepatitis C treatment

Multi-pronged strategies are necessary to explain, educate and address misconceptions of DAA treatment. These include:

- **Prompt and user-friendly assistance and support at treatment sites** – a non-judgemental approach to people who inject and a credible record of working with PWID demonstrates assurance of quality of service provision. This could include a workforce that comprises of peer workers and an in-house phlebotomist experienced with drawing blood from damaged veins.
- **Peer workers** positioned as integral in the development of strategies to promote DAA treatment, such as in the design of resource materials and service delivery modalities, peer education, and outreach. The meaningful participation of peers signals to the injecting community that a service is informed by, and values, the expertise of people who inject.
- **Consistency and alignment** across all sectors in conveying information about the direct-acting antiviral medications. Specifically, the messaging should include who can access treatment (e.g. people who are currently injecting drugs), the treatment side-effects, the type of medicines and how they are administered, and post-treatment follow-up.

As well, information related to treatment **availability, access and affordability** is needed to promote the location of DAA treatment sites (e.g. physical and mobile clinics, peer-based venue, regional locales), operating hours, and treatment costs (e.g. PBS subsidy of treating agents, blood tests, etc).

- Existing campaigns and messages promoting treatment, such as posters or information included in fit packs, while highly visible at treatment sites, i.e. NSPs and hospitals, only reach people who access those sites. Hepatitis C health promotion material should be **wide-spread** in other health service provision sites, pharmacies and in public spaces such as train stations and entertainment outlets.

DAA treatment side-effects

Aversion to hepatitis C treatment continues to exist within the PWID community, as many recall the severe side-effects of the older Interferon-based treatments. As such, it is important that the side-effects of DAA treatment (although not as severe as previous treatment) are not glossed over by health care workers or in information resources. Also, many current injectors are unclear about what a hepatitis C 'cure' means and if this term is used it should be explained. For instance, participants described a belief that hepatitis C re-infection will not occur after being 'cured'.

Hepatitis C stigma and the PWID community

Stigma reduction is essential in the elimination of hepatitis C. The impact of stigma on access to health care services was a major discussion point among participants. Peer workers also raised the issue of hepatitis C stigma within the PWID community. Several noted that if a person who injects disclosed their positive status to their peers they were likely to encounter negative attitudes and face social isolation and experience distress. The breakthrough DAA treatment is an opportunity that could be used to address the misconceptions of hepatitis C, educate on treatment options, and potentially mitigate long-term health complications. Peer models of service delivery are essential to effectively engage with the injecting community, and to better understand the impact of hepatitis C stigma on access to testing, treatment and care. Tangible investment is vital to increase the peer workforce, and to continue to build evidence about what works and why.



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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