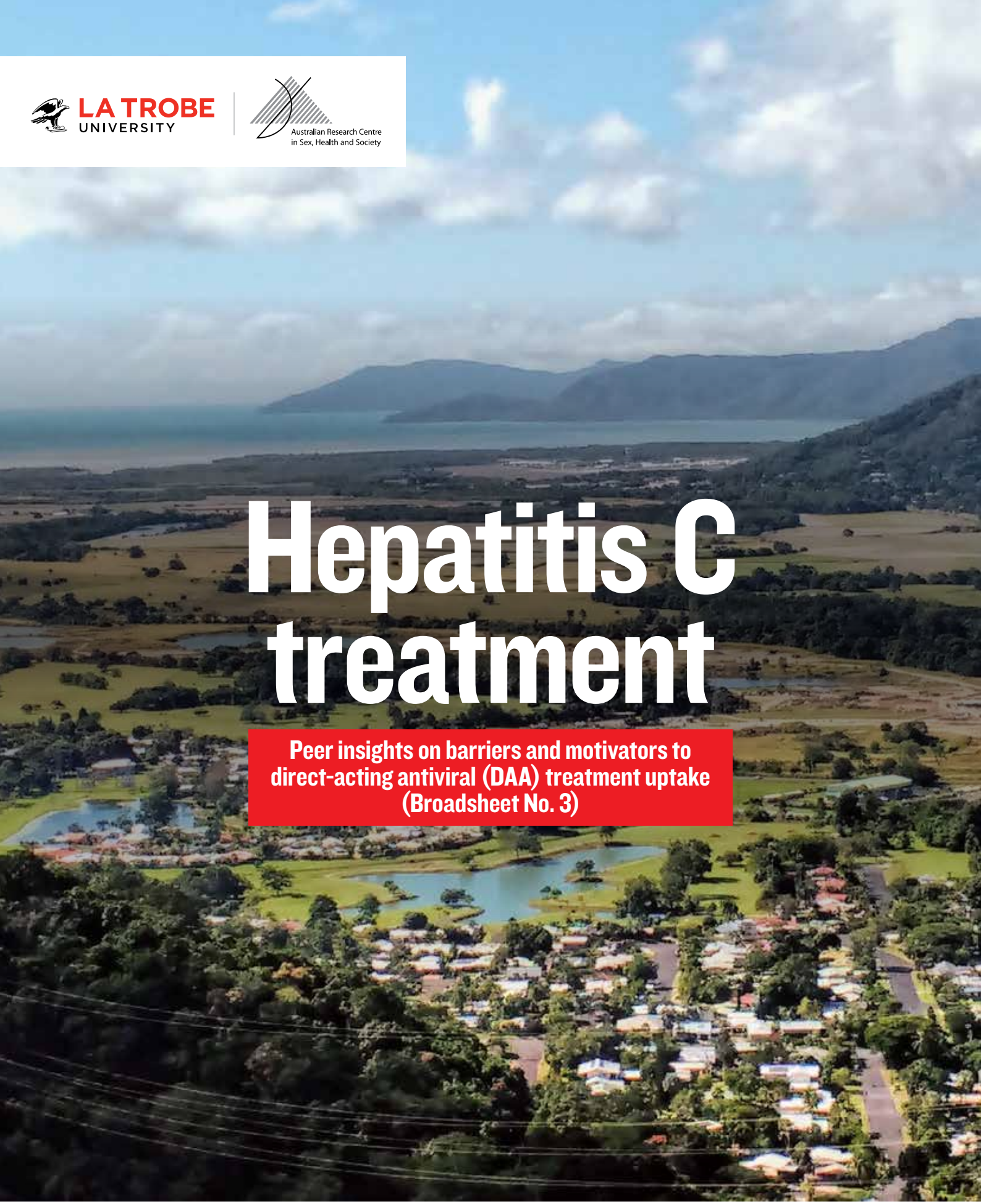


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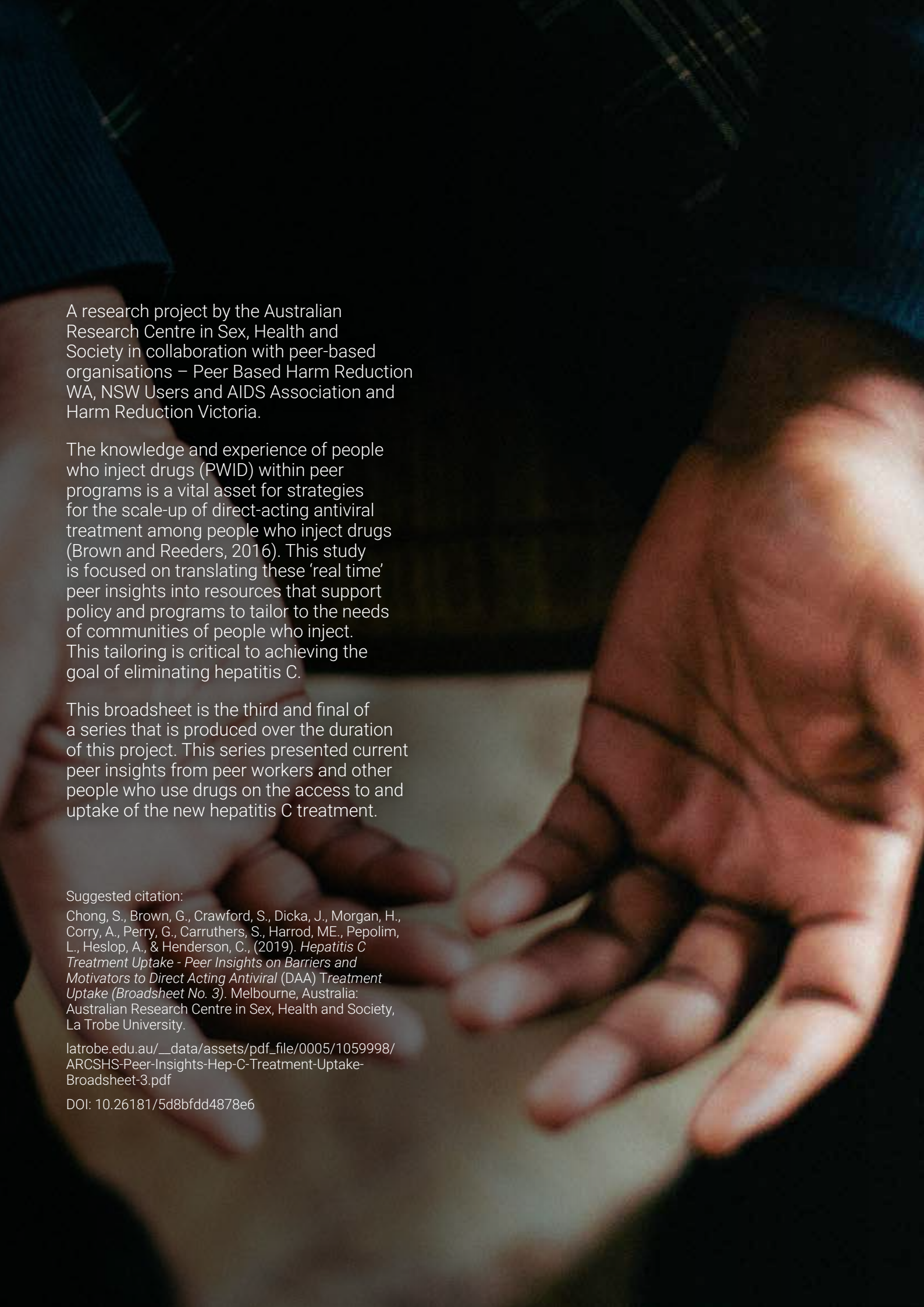
Hepatitis C treatment

Peer insights on barriers and motivators to direct-acting antiviral (DAA) treatment uptake (Broadsheet No. 3)

HARM REDUCTION VICTORIA

NUAA

peer based harm reduction wa



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 direct-acting antiviral treatment among people who inject drugs (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 third and final of a series that is produced over the duration of this project. This series presented current peer insights from peer workers and other people who use drugs on the access to and uptake of the new hepatitis C treatment.

Suggested citation:

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latrobe.edu.au/__data/assets/pdf_file/0005/1059998/ARCSHS-Peer-Insights-Hep-C-Treatment-Uptake-Broadsheet-3.pdf

DOI: 10.26181/5d8bfdd4878e6

Background

The breakthrough in hepatitis C treatment with direct-acting antiviral medicines and their listing on the Pharmaceutical Benefits Scheme promised a trajectory to achieve national prevalence and transmission targets. The uptake of treatment, however among people who inject was promising at the outset, but evidence has emerged that, uptake is plateauing and, in some areas, slowing (Burnet Institute and Kirby Institute, 2019).

The diffusion of innovation theory (DOI) describes five categories of people that illustrate the rate of adoption of new technology or ideas (participants often referred to as innovators, early adopters, early majority, late majority, and late mass) (Rogers, 2010). The current uptake of direct-acting antiviral (DAA) treatments would indicate that we have reached those who are 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 DOI 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 project was developed in collaboration with three peer-led organisations – Harm Reduction Victoria, NSW Users and AIDS Association and Peer Based Harm Reduction WA – implemented from February 2018. Peer-led drug user organisations have on-the ground insights from their peer networks of people who inject about current attitudes, beliefs and experiences related to the access and scale up of direct-acting antiviral treatment.

Method

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

Recruitment

This study conducted 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 convened with researchers to obtain more information. This third and final round of focus groups and interviews were conducted in the rural and regional areas of Victoria, New South Wales and Western Australia with approximately 23 participants consisting of both staff and peer workers. Participants discussed their experiences and those of their peer networks. Peer networks ranged in size from a few individuals to more than 50 people.

Outcomes

The DAA treatment environment is evolving. The 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, were developed throughout the study. In addition, further analysis will be undertaken using the DOI theory to generate a deeper understanding of how to increase access and uptake of treatment among the 'early majority' and 'late majority' groups.

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

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Rogers, E. M. (2010). *Diffusion of innovations*. (4th Edition). New York: Free Press.

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 broadsheet, peer workers and peer volunteers located in country and regional areas in Victoria, WA and NSW, shared their insights on hepatitis C treatment uptake among their networks. These perspectives suggest that people who inject and live in non-metro areas encounter similar impediments and motivators to their counterparts in capital cities and urban areas. However, it also appears there are different barriers and facilitators specific to small town settings that are experienced by people who inject who live in these locations.

The common hurdles or barriers included: inconsistencies in their peers' knowledge and uncertainties about availability and access to treatment; peers' current health status (e.g., on opioid substitution therapy); privacy and confidentiality regarding hepatitis C diagnosis; and stigmatising and discriminatory practices at health services. However, there were also good practices identified by participants which have encouraged their peers to seek DAA treatment. These include the health services, such as non-peer-led NSEPs (needle syringe exchange program) and hospitals that provide 'no-fuss', judgement-free and efficient testing and treatment services. These positive experiences of people who inject are promoted within their community.

Nonetheless, 'small towns' are unique settings that present particular challenges for the injecting community and, in turn, for the promotion and uptake of DAA treatment. In two of the regional sites, peer workers from metropolitan offices coordinated outreach with their networks through regular visits (e.g., monthly), and liaised with the local NSP hosted by a community health centre. At the third site a 'branch' NSP of a peer-led harm reduction organisation was set up. The insights and experiences of peer workers and peer volunteers at these locales are captured in the following sections:

- **Hepatitis C awareness, testing and treatment**
- **"Small town talk"**
- **"Keep it fresh, keep it clean"**
- **"We need positive messages about Hepatitis C treatment"**
- **Health service provision and access**
- **Valuing peer workers and volunteers**
- **Promising practices**

In the last section, the overall project recommendations and lessons learned are presented.

Hepatitis C awareness, testing and treatment

"They reckon it's a lot easier now than before. It's just a pill, I think."

Among participants' peer networks most injectors are aware that a 'new' treatment for hepatitis C is available and some individuals in these groups have completed treatment.

"I've met a few of the other people in the other networks, so everyone is aware that the Hep C treatment is good to what it used to be. A man who hasn't himself had hep C, he was a user, and he was saying that he's aware that the treatment is easy to access... In the room at the time there were 3 other users and they were all agreeing that they now know that it's changed and it's a lot easier to access as from back 20 – 30 years ago"– *Interview 2*

However, peer workers cautioned that awareness and knowledge about DAA treatment varies. Some injectors were still uncertain about treatment side effects, eligibility, and cost, and the 'fear' of the interferon treatment still lingers.

"I just say the old treatment is nothing like the new treatment, (peers) more afraid of the side effects they had with the old treatment, and wondering if that's what they're going to get with the new treatment" *– Focus Group (FG) 2*

A few participants observed that DAA treatment is not well publicised and information is not widely available at the health services they frequent, i.e. methadone clinics and community health centres.

"If they're (methadone clinics) going to be fair dinkum about hep C they should have pamphlets in there and handing them to people as they're getting dosed. You know to show them, they don't do that, they just put up a little pamphlet, hep C treatment available, nothing about (details of DAAs, where to access treatment, etc.)" *– FG 1*

In addition to the gaps in information and knowledge, the peer workers mentioned that it is not uncommon for current injectors, who may have been exposed to or have hepatitis C, to have other life priorities that delay their testing and/or access of treatment.

"Yeah, (for) some people, work's one (barrier), caring for children is another... A lot of times with health problems people are like "I'm fine I don't need to take that, I don't need to do this", or they're in denial (about possibly having hepatitis C). The only people that will ask about (treatment) are the ones that actually want to do it. If they're not interested, they will walk past the sign that says "We do hep C treatment", they'll shut down the conversation when you are trying to talk about it" *– Interview 3*

"The younger ones still are a bit scared, freaked out, can't get their head around (treatment) and are probably scared of just people being cruel, nasty... that probably stops them from even being tested. (Younger ones) they're just dealing with their whole life just spiralling as well. But the older ones speak openly and freely about it because it's just become more and more easily treated and tested and more talked about." *– Interview 1*



"Small town talk"

Participants across the three study sites highlighted the presence of close-knit networks of people who inject who extend assistance and support to each other in day-to-day living, and in dealing with unexpected and difficult situations. Often, these 'connected' networks offer a safe space for injectors to raise the topic of hepatitis C, including testing and treatment options, without encountering stigma. This contrasts with previous peer insights (Broadsheets 1 and 2[1]) that informed in some of the peer networks hepatitis C stigma continues to occur.

"being a regional area though, people are more sort of tighter... friendlier, you have relationships with each other, you sort of trust people... (here) there is always somebody that you can call if you are in trouble. You know like they seem to be like little families kind of, like the relationships are more sort of tight … You might sit around and have like a shot, but then you put on the kettle and you have a coffee, you know you will actually sit down and communicate with those people and support each other a little bit. So people that I know would most definitely be talking about (treatment)." *– Interview 2*

On the flip side, "everybody knows everybody's business" and this can deter or stymie health seeking behaviour.

"Also in a country town it is more visible, you can see your Doctor somewhere at the pharmacy, at Coles down the road or wherever you know. It's the same when it comes to people with treatment, they don't want to go to their normal Doctor, their own GP because they don't particularly want their GP to know that they use drugs and stuff like that... It's the one downside to small towns, everybody knows your business, you never sort of fly under the radar." *– Interview 3*

1 Chong, S., Brown, G., Crawford, S., Morgan, H., Corry, A., Perry, G., Harrod, M., Pepolim, L., (2018). *Hepatitis C Treatment Uptake - Peer Insights on Barriers and Motivators to Direct Acting Antiviral (DAA) Treatment Uptake (Broadsheet No. 1).* Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.

Chong, S., Brown, G., Crawford, S., Morgan, H., Corry, A., Perry, G., Harrod, M., Pepolim, L., & Henderson, C. (2019). *Hepatitis C Treatment Uptake - Peer Insights on Barriers and Motivators to Direct Acting Antiviral (DAA) Treatment Uptake (Broadsheet No. 2).* Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.



"Keep it fresh, keep it clean"

Concerns were raised by some peer workers, who observed that certain practices and circumstances may contribute to the risk of hepatitis C transmission.

Injecting equipment is available from NSEPs (i.e., peer-led organisations and community health centres) and hospitals, either over-the-counter or from dispensing machines. A few peer workers reported that dispensing machines are at times unfilled or "they've run out" or are out-of-service. There are current injectors who avoid requesting for equipment at health service counters. This could be due to previous negative experiences, or concerns about encountering someone they know at that health service.

"You get less out this way, you probably share a fit out this way because there's none" *– FG 1*

"It's like they don't have the knowledge... and I know a couple, they both share, I think they think that they're together so it doesn't matter, but they still both share the equipment." *– Interview 2*

"I just feel like a lot of people that are more at risk of contracting hep C are the homeless because let's just say that this Centre is closed and it's the middle of the night, and people are more inclined to maybe share if they can't get clean equipment." *– Interview 3*

At the same time, there were peer workers who highlighted the safe injecting among their peer networks. Other peer workers emphasised that in their networks, current injectors are acutely aware of ensuring their injecting paraphernalia are kept clean, and to not use each other's equipment.

"About your clean equipment, so like it's sort of a thing in the drug community that if you have your clean equipment and you're injecting the correct way, you are sort of proud of yourself. You know so people sort of like to sit back and just go "I've got all my cleanies, I've got my clean tourniquet" and you sort of boast about it a little bit. People talk about their exchanges, people talk about having the clean equipment and making it a priority in your life, you know like you need to go to the exchange, you need to get your equipment." *– Interview 2*

"We need positive messages about hepatitis C treatment"

One peer worker pointed to hepatitis C posters on the office walls and exclaimed, "Look at those posters, it's all doom and gloom … some woman in the rain and some bloke in the dark."

While most hepatitis C health promotion materials are not as sombre and foreboding, many participants suggested that messaging should be positive in emphasising that hepatitis C is a disease that can be cured, and is not a "death sentence".

Peer workers recommend that hepatitis C awareness should be increased within the broader community and highlighted the necessity to mitigate prevailing stigma related to hepatitis C. The participants called for clear, simple and accurate information on hepatitis C.

In addition, the peer workers, specifically those who have undergone DAA treatment, suggested communicating the benefits of DAA therapy and the significant change to one's health and wellbeing.

"After hep C treatment it's like you get a second chance, a second chance in life almost. To me it's just perfect, I think." *– Interview 2*

Health service provision and access

The participants spoke of country and regional settings presenting unique or inherent challenges for communities of people who inject. The peer workers and volunteers credited the nurse practitioners (at each site) with providing friendly and efficient testing and treatment services. However, the clinics do not operate full-time and may have 'lost' consumers/ clients seeking services when the clinics are closed.

"If (the nurse) is not here on that day, it's like they just walk away and kind of forget about it. I think one of the challenges is that you don't have (the nurse) here every single day, so if people come in and they want to see a nurse and she's not here then what do you do? You might try to book them in for next week, but they might not want to come back next week." *– Interview 3*

At one site, the peer worker commented that the local NSEP offered limited hours as staff had to offer services at other locations. A vending machine was available to dispense injecting equipment, however health promotion opportunities with individuals who inject were lost.

A common challenge among the peer networks was the lack of mobility or access to transport. While people who inject in metro areas may experience similar impediments, in rural and regional areas the problem is further exacerbated by greater distances and limited NSEP services. One consequence is people who inject may have to rely on friends and family members to pick-up their injecting supplies. Crucially, they are not being reached, and do not have access to hepatitis C and DAA treatment information.

A major apprehension among the participants and their peer networks in seeking medical care relate to privacy and confidentially concerns, particularly for people who inject drugs and live in a country town or small community.



"The more appointments that you got the more people see you and they know something's going on and they start talking about you... It only takes one person and it's all the way around town." *– FG 1*

"A lot of the time (people who inject) don't want to go to their own doctors because their own doctor knows their issues and they don't want that doctor to know that they use drugs" *– Interview 3*

Regardless of locale, all participants reported experiences of stigmatising and discriminatory behaviour by health service providers.

"They (clinicians) look at you like a nobody... especially when they know you have hep C... even when they've got the gloves on, they still don't want to touch you" *– FG 1*

"You know we pay our money (at the pharmacy) and we are just as good as them customers and they serving them when we are in there first. We are there and standing there like idiots you know, people staring at you and they know what that lines for, they know you (are a drug-user) *– FG 1*

"People don't want to go to the hospital (to get Fit Packs) because they are that rude and discriminatory." *– Interview 3*

Despite the adverse experiences participants pointed out they have received good care by doctors who treated them well. However, this was not the norm.

"Registrar or something I think, and we told her how you know I was (an injecting drug user)... and told her about (previous negative encounter) and she could not have been any nicer, she was apologising for all the other people." *– FG 1*

Valuing peer workers and peer volunteers

Communities of people who inject rely on and provide peer support to each other, particularly in country and regional areas where harm reduction related resources and services are limited. The peer volunteers pointed out that it is not uncommon for individuals in their networks to undertake a de facto peer educator role.

"Couple of girls... they will come and pick up a heap (of sterile injecting equipment) and maybe drop-off a heap and I'll say nothing but then they might ask me something (information related to injecting) and I know they're asking about someone else, so they're out there... gives them confidence as well" *– Interview 1*

They may also be involved in tertiary distribution of sterile injecting equipment to "help-out" their peers.

"I knew one or two users where it was easy for me to just do their swap because of whatever reason, had no car or lived out of town... in the past I've gone to houses where someone's got raided or they've had to move house and I'll go "Right I'm coming for all dirties" and I'll have them in the boot of my car, the yellow boxes."" *– Interview 1*

The sterile injecting equipment packages contain information about hepatitis C testing and treatment, and peer volunteers will broach the topic with their networks.

"I always talk to my consumers about the new hep C treatments and safe using and vein care and if you can't get a proper vein to come here and get your veins looked at, and sometimes I even drive them here (local NSEP) to get their veins looked at." *– FG 2*

The peer workers also emphasised the importance of engaging their clients/consumers in conversations about other aspects of their lives in order to ascertain if there is additional support that could be provided to them.

"I think besides giving them equipment you do really want to stand there and have a bit of a chat because you want to find out sort of what's going on for that individual... when they come in I try and stand there and find out what's happening, things that are going on for them and try to support what's going on or give referrals to doctors or pharmacies or try to assist those people." *– Interview 2*

The peer workers from all three organisations raised the challenges of conducting peer outreach with communities of people who inject in rural and regional areas. These included injecting drug use and hepatitis C stigma being amplified in small communities, disparate and smaller pools of potential peer workers and volunteers to recruit from, and the significant time and effort necessary to recruit and maintain the peer workforce located a distance from the organisation's main office in the city.

Promising practices

This project's three peer-led collaborating organisations have undertaken varied approaches to reach communities of people who inject in rural and regional settings. This work is reliant on human resources and funding at an organisational level, and the capacity and availability of peer volunteers and their networks.

The following are brief examples of the adaptations being made by the peer-led organisations to provide outreach services on hepatitis C testing and DAA treatment services.

- To understand the injecting community's needs and gather peer insights, regular (e.g. monthly) or periodic health promotion workshops are conducted by metro-based peer workers with well-networked peer volunteers at regional sites. Developments in hepatitis C treatment and services are shared, and peer volunteers are provided with sterile injecting equipment which is available to their peer networks. In addition, the peer worker connects and liaises with the local NSEP staff or team as part of the outreach.
- Regional towns often lack NSEP services. An initiative to promote better outreach to these towns is the mobile van NSEP service, which travels to regional towns every few weeks. In addition to harm reduction interventions, hepatitis C treatment services are offered by a nurse practitioner.
- For many people who inject, face-to-face connection with their peers in rural and regional areas can be limited due to their personal circumstances and remoteness. An informal online group support platform, e.g. via Facebook, was described as one way to address the social isolation and provide opportunity for peer-to-peer learning, e.g. safe injecting practices.

"Mainly it's about information about or anything to do with using, keeping it clean... to use clean needles because we don't want them to contract hep C when we're trying to just get the word out there to you know get treated and stuff." *– Interview 1*

Project recommendations

On many levels, the insights of peer workers and volunteers and their networks in country and regional areas reflect those of their city and urban counterparts. There are, however, unique perspectives and experiences offered by those living outside of major metropolitan areas. These inform, and have been included in, the following overall project recommendations.

We found that the impact of generalised hepatitis C treatment awareness campaigns have diminished over time (i.e., since the introduction of the DAA), and that conflicting advice and messaging detracted from testing and DAA treatment efforts. In addition, stigmatising experiences encountered by people who inject were undermining scale-up programs. Specific to rural and regional areas, which offer limited services and outreach for hepatitis C treatment, the additional programming required to conduct an effective peer program in smaller and spread-out populations present further pressures to peer-led organisations.

We propose the following:

- Different and targeted approaches and communication emphasising the benefits and relevance of DAA treatment are needed, to enhance confidence and re-invigorate interest in DAA treatment.
- Consistency and alignment across all sectors with regard to DAA treatment information, e.g. eligibility, cost, side effects, 'cure' definition, particularly in regional and country areas, is crucial.
- Good practice by health workers, including non-judgmental, prompt, and user-friendly assistance and support, are vital and need to be publicised and promoted amongst peer networks.
- Inter-sectoral collaboration to address complex social and systemic barriers to treatment (e.g., unstable housing and food insecurity) is critical.
- Regional and country areas require strategic investment to strengthen health services and peer-led initiatives to scale-up DAA treatment.
- Embedding a peer workforce at an NSEP site would demonstrate commitment to engaging with the injecting community. Organisational leadership, structure and resourcing are essential to support integration of peer approaches.







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 education to PWID who are not able to, or would not, access existing services.

/ Contact:
PO Box 12720 A'Beckett Street,
Melbourne, Victoria 8006
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-borne 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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