Broadsheet No. 1

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Experiences of hepatitis C diagnosis:

Testing, reflecting on diagnosis and seeking advice

Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice (Broadsheet No. 1)

This broadsheet is the first in a series of four broadsheets that summarise key project findings.

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Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit *Vital voices: Personal stories of treatment for hepatitis C*.

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Recommendations

This broadsheet is the first in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

Broadsheet No. 1: Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.

- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

Broadsheet No. 2: Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.

- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.

- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.

- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

Broadsheet No. 4: Life after hepatitis C treatment: Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.

- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme.

This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA medication offers much shorter treatment durations (approximately eight to 12 weeks), far fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004).

While current data on the uptake of hepatitis C treatment among key groups (e.g. people who inject drugs and people from culturally and linguistically diverse backgrounds) are limited, meeting the WHO elimination target now looks unlikely. Rates of testing, diagnosis and linkage to care are insufficient according to target modelling (Stoové et al., 2020). System-level changes to healthcare delivery have been identified as essential to improving treatment uptake. Such changes include ensuring widespread screening and testing, more integrated and streamlined service delivery, and enhanced diagnostic and surveillance measures across specialist and mainstream services (Richmond et al., 2018; Richmond & Wallace, 2018; Scarborough et al., 2017). Importantly, even though hepatitis C is now curable, diagnosis may still be experienced as confronting and personally difficult because of its association with injecting drug use–related stigma (Rhodes & Treloar, 2008). In earlier studies of interferon-based treatment (e.g. Fraser & Seear, 2011), diagnosis produced a wide range of responses ranging from avoidance and deferral of treatment to active engagement with medical information, knowledge and treatment. While DAA treatment is relatively easy to complete and highly effective, the issues relating to diagnosis previously identified continue to be relevant to some people, affecting rates of diagnosis and treatment uptake (Henderson et al., 2017).

Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

The project used a purposive data collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A$50 cash or an A$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment. Interview material from selected codes was carefully analysed by members of the research team to develop website content. Topic sections for the website were developed in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed these broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the first of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience; for example, 'Dave (male, 65, experience with both DAA and interferon-based treatment) said that the DAA treatment was "quite easy" to incorporate into everyday life.' For more details about participants, see the demographics table in Appendix 1.

Summary of findings

The people we interviewed for this project described many different experiences of hepatitis C testing and diagnosis. For some, testing was a regular part of their healthcare, while others only found out about the virus after tests for other health issues or when donating blood. The experiences recounted in this broadsheet also suggested that testing differs according to location. While many participants had tests and treatment in healthcare services (specialist or generalist), some had received their diagnosis in other settings, such as prisons.

Participants also provided a range of different responses to diagnosis. Several said diagnosis was a significant moment in their lives that influenced their sense of self and their social relationships (see Broadsheet No. 4, *Life after hepatitis C treatment: Health, wellbeing and the future*). Others reported that diagnosis was a minor concern for them and that they rarely thought about it, sometimes taking years before deciding to have treatment.

Overall, the experiences and perspectives reported here highlighted the vital importance of social relationships in shaping how people understand their hepatitis C diagnosis. Many participants talked about being more worried about the potential implications of their diagnosis for their loved ones than for themselves.

In the following sections this broadsheet covers experiences of hepatitis C testing, reflections on diagnosis, and experiences of receiving advice from health professionals. It concludes with recommendations based on the project findings.

Having a hepatitis C test

Participants described the process of having a hepatitis C test in a range of ways. While many had sought a test themselves, others were tested at the request of someone else, such as an intimate partner. Hepatitis C was a well-known issue for most of the people we interviewed who injected drugs, but those who acquired it through other means – mainly medical procedures – were often unaware of it before their diagnosis and had not specifically sought a test.

Robbie (male, 54, experience with both DAA and interferon-based treatment) explained that he first requested a test because he had been feeling sick.

> *At least 20 years ago […I] went to the doctor […] and had the test done, and found out that I had hep C then […] It was a long time ago […] I think I asked for it to be done because I was pretty sick at the time […] Just throwing up, crook stomach all the time, yeah, sleepy […I] had symptoms. [… I told] my grandmother [about the diagnosis] because I was living with my grandmother at the time […] She was all right, just yeah, [she said,] 'Get onto it and get to the doctor'.*

Danny (male, 32, no treatment experience, experience with spontaneous clearance) described having a 'feeling inside' that he should have a hepatitis C test after injecting drugs in prison.

> *I just had this feeling inside, and so I went to my clinic. I said, you know, 'This is what's happened, and I think that I may have hepatitis C. Can you check for me?' And my doctor said, 'Yes, I'll check for you'. [He] called me back a couple of days later and said I needed to go in and speak to him, and then he told me that, yes, I was hep C positive […] I don't know how I knew, but I just could feel that my body wasn't right. And, yeah, he told me that I was positive for hepatitis C.*

Hepatitis C tests were a routine part of Anthony's (male, 36, no treatment experience) healthcare. He said that he usually asks for them and that the virus does not worry him.

> *[I get tested] now and again. I've been tested probably maybe about eight times […] That's for everything, so once I get tested, I ask them to test for everything, you know […] Most of the time I ask to get tested […] I don't worry about [hepatitis C]… I [would] only worry about it if I got it and then [I'd decide what to do…] go[ing] forward. I don't worry about ifs and buts […] Yeah, I've had the finger prick [test] where they blood-test you. […] That was all right, but I think the other one is better because the blood testing is a bit annoying, because they had to do it so many times, you know. […] Because my blood wouldn't come out when they were testing, you know. Like, they'd prick me, but my blood wasn't coming out.*

Like many of the people interviewed for this project, Harriet (trans woman, 30, experience with both DAA and interferon-based treatment) was not planning to have a hepatitis C test but received a diagnosis after a sexual health check.

> *Well, at first I just went to get a sex screen and my nurse then told me, 'Oh, it looks like you've got hep C'. At first I thought, 'Well, what's that?' I thought it was AIDS or something, and I [asked myself] 'Do I go and commit suicide now?' And she's, like, 'No, no, everything is good. You've just got to change your diet and be healthy' and stuff like that. So, at first, when I first started, I changed my diet, started being healthy again, and then it got worse, so I did the treatment.*

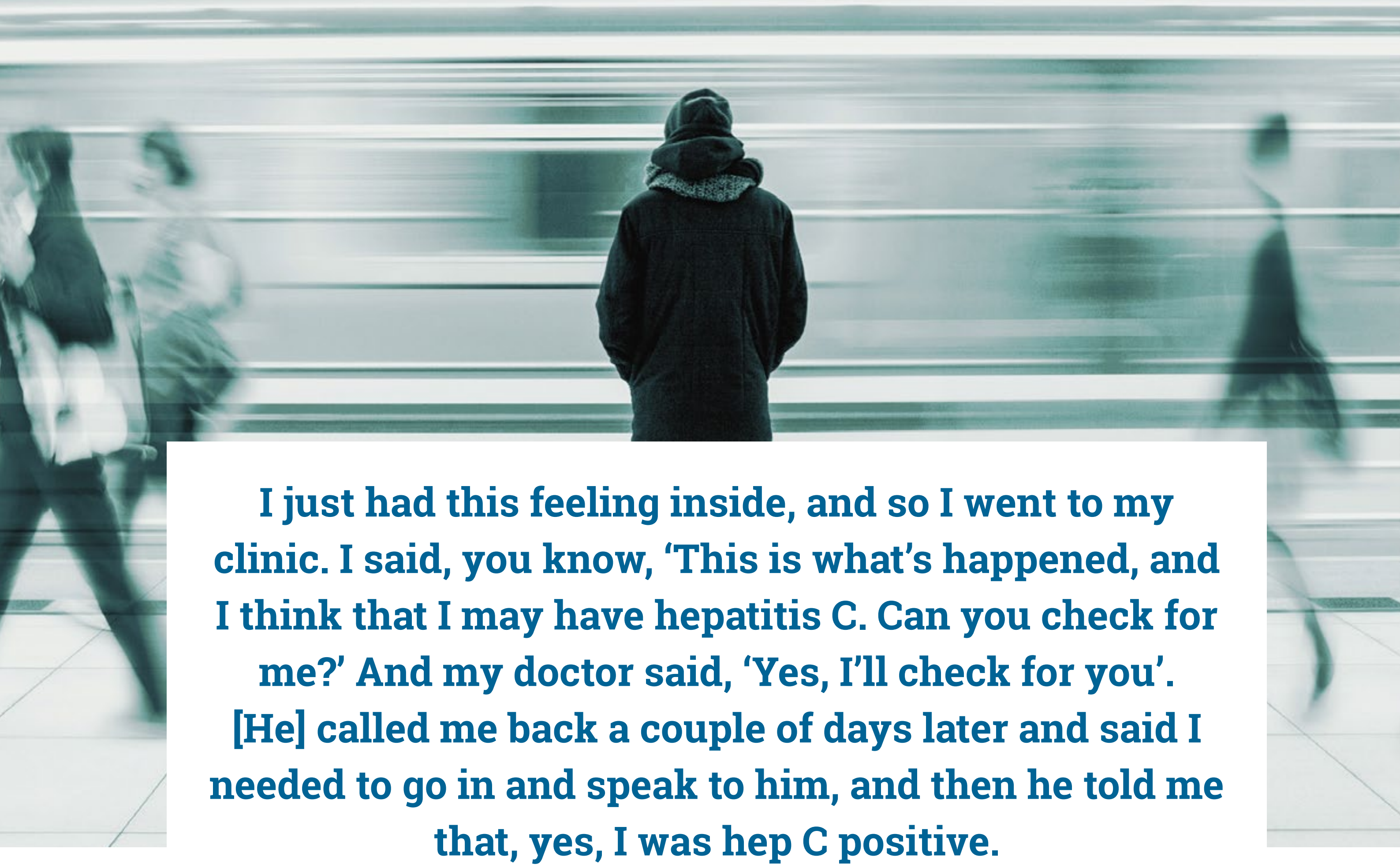
Some people had been tested at the request of others in their lives, such as intimate partners. Gracie (female, 65, experience with DAA treatment), for example, found out she had hepatitis C after a new partner asked her to have a test for HIV. She recalled thinking it was just a formality and being surprised by the diagnosis.

> *Okay. I'd just started a new relationship with a chap and I asked him if he would get tested for AIDS, and he said, 'Yes, but only if you get tested for hep C', and I said, 'Why is that?' He said, 'Because my last girlfriend had hep C and she knew and she didn't tell me', and I said, 'Oh, okay then'. So, I just went and got tested, thinking that it was just a formality, and I actually had it. I'd had a friend who had hep C and he really struggled with it, and I supported him in his struggles. He did three separate lots of interferon [treatment…] He lost so much weight. He was unable to work. He became skin and bones. He was really depressed. It was just awful to watch him struggle, trying to get rid of his disease, and then when I found out I had it too, I went, 'Oh, no! This is a worry'. So, that relationship didn't last very long, but the hep C did […] So, yeah, I remember telling my mum that I had hep C, and she said, 'Oh! Where did you get that?' and I said, 'Sharing needles', and she went, 'Oh! That's nice'. She's a poor old love, didn't know what to say, but anyway.*

Gracie was not the only participant who described being surprised by her diagnosis, with diagnosis coming as a shock to many.

Lou (female 40, experience with DAA treatment) explained that she did not think hepatitis C was in her 'orbit' until a sexual health check led her to find out that she had acquired it through a medical procedure she had as an infant.

> *So, I had started a new relationship, and we thought, 'Oh, we should do the right thing and get an STD check'. And so I got one, and that was the first time I'd had one, and the doctor… that was the results from the doctor. So that was quite a shock, and I had thought, like… [hepatitis] C just wasn't in my… just wasn't in my kind of orbit really. I remember back when I was 18, and I see a cardiologist every year because… sorry, I didn't actually say that. So, I had heart*



I just had this feeling inside, and so I went to my clinic. I said, you know, 'This is what's happened, and I think that I may have hepatitis C. Can you check for me?' And my doctor said, 'Yes, I'll check for you'. [He] called me back a couple of days later and said I needed to go in and speak to him, and then he told me that, yes, I was hep C positive.

DANNY (MALE, 32, NO TREATMENT EXPERIENCE,
EXPERIENCE WITH SPONTANEOUS CLEARANCE)

> *surgery when I was a baby, and it was from the blood transfusion at the […] hospital […] Yeah, so that was how it was acquired, as a baby in 1980. And, yeah, so I remember saying to my cardiologist when I turned 18, I said, 'Could I have got AIDS?' Because I remember there was a lot of information that had been [circulating about] people getting HIV in the '80s from blood transfusions, and he just sort of laughed me off and said, 'No, of course you don't have AIDS'. And made me feel a bit silly. Then I really never thought about it again, so yeah, it did come as a complete shock.*

Reflecting on her experience of testing over 15 years ago, Julia (female, 43, experience with DAA treatment) explained that she was not accessing healthcare regularly at the time and found out about her hepatitis C when she was having tests related to her pregnancy.

> *[I found out] probably when I was pregnant. Yeah, because before then I couldn't have given a shit. Like, there would have been years where, apart from my methadone script, I would never [have] had any meaningful interaction with healthcare. So, I would say, I probably found out when I was pregnant. I actually recall being very surprised I wasn't HIV positive. I remember asking for the test over and over when I was pregnant [and] just being shocked that I wasn't HIV positive. I didn't quite believe them […] I was all pretty overwhelmed, you know [with] everything else happening for me, and so hep C treatment, yeah, it wasn't really talked about. I do remember wondering about breastfeeding and hep C once, you know … a few months on, once I realised, you know, I was going to have a baby.*

Several of the participants interviewed for this project had experiences of testing and diagnosis while in prison. For example, Lee (male, 45, repeat diagnoses, experience with interferon-based treatment) recalled being a 'bit blasé' after being diagnosed during a period in prison.

> *When you go into custody, you are just given the option to be screened for blood-borne viruses. It was just an option, and I was 26 and I shared a lot of needles and have done lot of unsafe practices, so I was screened, and then about a month later the doctor called me in and said that I had antibodies. He explained straight away that didn't necessarily mean I had the virus, and [we did] my liver scan and that seemed all right, and then they did the PCR test and I had cleared [been cured of] the virus. So, yeah, I wasn't overly concerned when the doctor explained things straight away, and because I had a bit of prior knowledge, yeah, and I was still using drugs in prison at that stage, so I wasn't … I was a bit blasé to the whole reality of the importance of having a functioning liver.*

For some participants, testing and diagnosis occurred as a routine part of their healthcare, such as during routine sexual health screenings and pregnancy and maternal health tests. Some were diagnosed with hepatitis C on entering prison or at the request of intimate partners. Others sought testing due to symptoms and acute health problems. Being diagnosed with hepatitis C provoked a variety of responses including surprise, shame and uncertainty about the future.

Reflecting on diagnosis

The people interviewed for this project described a range of responses to their hepatitis C diagnoses. For some, the diagnosis was a significant concern, while others were unworried by it. The experiences recounted here highlighted the role of stigma in how people thought about their diagnosis. Many of the responses also pointed to the importance of family and friends (see Broadsheet No. 2: *Hepatitis C treatment uptake: Understanding treatment incentives and obstacles*).

As they explained, some participants remembered thinking about the prospect of dying after they were diagnosed with hepatitis C.

Cassandra (female, 47, experience with interferon-based treatment), for example, remembered thinking hepatitis C was a terminal illness when she was diagnosed in the early 1990s. As she learnt more about the virus, she realised this was incorrect.

> *It was [the early '90s], I actually went on to a methadone program […] and we had to have a blood test done, and then that's how I found out that I had hepatitis C […] I don't think they [health professionals] knew much about it back then too, you know, yeah […] It was quite frightening […] Yeah, it was almost like, for me, because I didn't know much about it, it was almost like being given a death sentence, if you know what I mean? You know, it's almost like being told I am HIV positive back then, but as [the] years went on, realising it wasn't [a death sentence] made it a lot better.*

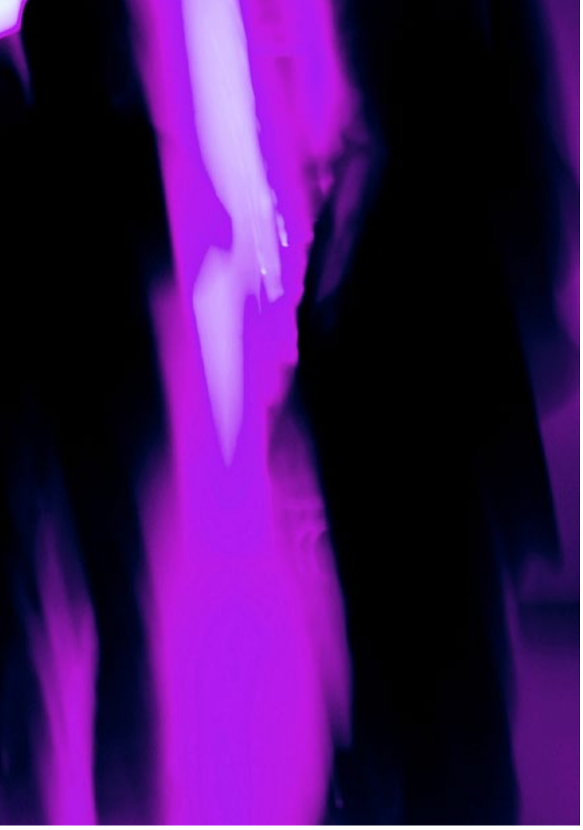
Many participants discussed the connection between hepatitis C and injecting drug consumption. Some of those who did not acquire hepatitis C through injecting said that it was important to them to explain this to others.

Brooke (female, 58, experience with interferon-based treatment) said that her diagnosis had 'emotional baggage' attached to it. She added that it is was important to her to explain to others how she acquired hepatitis C.

> *[If] I told someone I had it, it came with, you know, the description of how, why and when, because people can be very, you know what I mean, they hear one thing and that's it, it's black and white. Well, it's not black and white with hep C, because there […are those people with it who] don't use drugs. I would draw on my strength again and sort of try and educate people […] a bit about hep C, because, as I said back then, it was such a dirty word, you know, because of the stigma that surrounded it. I guess I did feel, you know, when I use that word 'dirty', because people would think the wrong thing about me [and assume that I inject drugs] when that wasn't who I was or how I got it. So, there was a lot of emotional baggage there as well.*

Heather (female, 67, experience with both DAA and interferon-based treatment) said that the relationship between hepatitis C and injecting drug consumption is a major reason some people face discrimination. She argued that treatment was a great opportunity, despite the risks some felt there were in disclosing their status and seeking care.

> *I think as long as there is an association between hepatitis C and IV drug use, then you are always going to have to deal with stigma and discrimination. As someone who has hepatitis C, and I don't think that has changed, and I think the fact that you can still have a blood test and your employer can see that you are antibody positive — so those things, I think, still hold people back a little bit and still makes them… you know, it is confronting. If you had a history of IV drug use and that's how you got it, then it's still a lot of confronting of those concepts still. In terms of your own health, I think it's [treatment]*



> *a very simple process and you can just, you know, you can just do three months' treatment, perhaps get some other medical help support, you know, emotional support maybe, and things like that that you may have needed as well. It's a great opportunity to do a lot for people in that time.*

As indicated above, some of the people interviewed were also affected by HIV. They explained how their experiences with HIV shaped their responses to hepatitis C.

Derek (male, 52, repeat diagnoses, experience with spontaneous clearance and interferon-based treatment) described how he felt after being diagnosed with hepatitis C and HIV at the same time. He explained that attending the hospital for both issues created extra complications.

> *It was a double whammy. But it [hep C] was not a concern compared to the other issue [HIV] and I must have an interesting immune system because my body overcame it [hep C] the first time of its own volition, and I was left to continue on my journey with the other situation. So, that was the first time I came across it, and to be quite honest, at that time I think the fear was just as great around hepatitis C as it was around HIV. So, dealing with health professionals, […] you had to go to two different areas of the hospital, and you were treated the same in both, but the fear was not about the other item. In each section it was about their own section item [either hepatitis C or HIV].*

For some participants, concerns about their diagnosis were connected to their relationships with others such as partners or children.

Amelia (female, 41, experience with DAA treatment), for example, was especially worried about the welfare of her unborn child.

> *I guess when I initially heard him [the doctor] say, 'You're positive for hep C', my stomach dropped, but him making it sound like a positive thing, not a negative thing, changed my feelings. Because it was all in the appointment […] I was like, 'Oh shit', you know, [asking,] 'Where do we go from here? Am I going to die?' You know, I still sort of had those feelings, but then by the end of that appointment, [my doctor] said, 'You know it's been… it's the best time to have hep C right now, because you know of the Zepatier [a DAA treatment], it's got this success rate and blah, blah, blah' and all this stuff. I was like, 'Well, if [that's what] you reckon?' I still had half a smile on my face and half a frown, you know. I guess I was more worried about, to be honest, the baby than myself. If anything, I was more worried about my son at the time, and yet again, [my doctor] eased my mind with that. So then I was just like, 'Okay, sweet, we can get [the treatment] started once I've had the baby'.*

Before the arrival of DAA treatment, those participants facing interferon-based treatment held different attitudes towards their hepatitis C diagnosis. For some people experiencing minimal symptoms and facing other life concerns, such as homelessness or poverty, hepatitis C was not seen as a pressing issue. Instead, they saw it as something that could be dealt with in the future.

Marty (male, 65, experience with both DAA and interferon-based treatment), who was diagnosed in the late 1970s, described being unconcerned about his diagnosis.

> *I was just going, donating my blood, going home, you know, every three months, and one day I read a letter from the blood bank saying there's a rare antigen in my blood [and asking] could I duck back in and see them? And seriously I thought I might have had blood type Q and I was going to save a million people or whatever, I had no idea. So, I've gone back […] saw a doctor, blah, blah, blah, and he said, 'Look, mate. We got to tell you. You've got non-A, non-B hepatitis'. Which now obviously is hepatitis C. And I went, 'Oh okay, that's fine', and it meant nothing to me, because I wasn't sick, nothing, nothing. He said, 'But the only thing is, you can't donate blood any more'. Like I say, it was just out of sight, so it just didn't mean anything.*

Like Marty, Chris (male, 60, experience with DAA treatment) also said that he did not worry much about hepatitis C because he had no ill effects at the time. Chris postponed his treatment until DAA medication was available.

> *[When I found out I had hepatitis C] I did nothing. I didn't want to do anything, and I was always saying to my doctor, 'It doesn't worry me… it doesn't affect me, and that interferon is so awful, why would you bother? In the future, we will see what happens'. In the future the 12-week Harvoni cure came up and I jumped at it.*

In contrast to Chris, some participants felt they should avoid their family and friends after learning of their hepatitis C diagnosis (see Broadsheet 4: *Life after hepatitis C treatment: Health, wellbeing and the future*).

Danny (male, 32, no treatment experience, experience with spontaneous clearance) recalled isolating at home after receiving his diagnosis.

> *I put myself in a bubble where I stayed home and didn't communicate with anybody from the outside world. When I went back for my second test, when I thought I was hep C positive, I went […] and got my heroin or whatever, and I came home and I used by myself. At that stage, I bought a whole bunch of syringes so that I would not have that problem [of running out of equipment] again. But like, yeah, I just, I knew that I was going to be sick from it.*

Participants varied in their responses to diagnosis, with some concerned that hepatitis C was a serious or potentially terminal illness, and others unworried by it. Stigma impacted on attitudes to diagnosis, shaping how people thought about hepatitis C and disclosure to others. Some were concerned about the attitudes of others and the potential impact of the virus on the health of friends and family members.

Receiving advice from health professionals

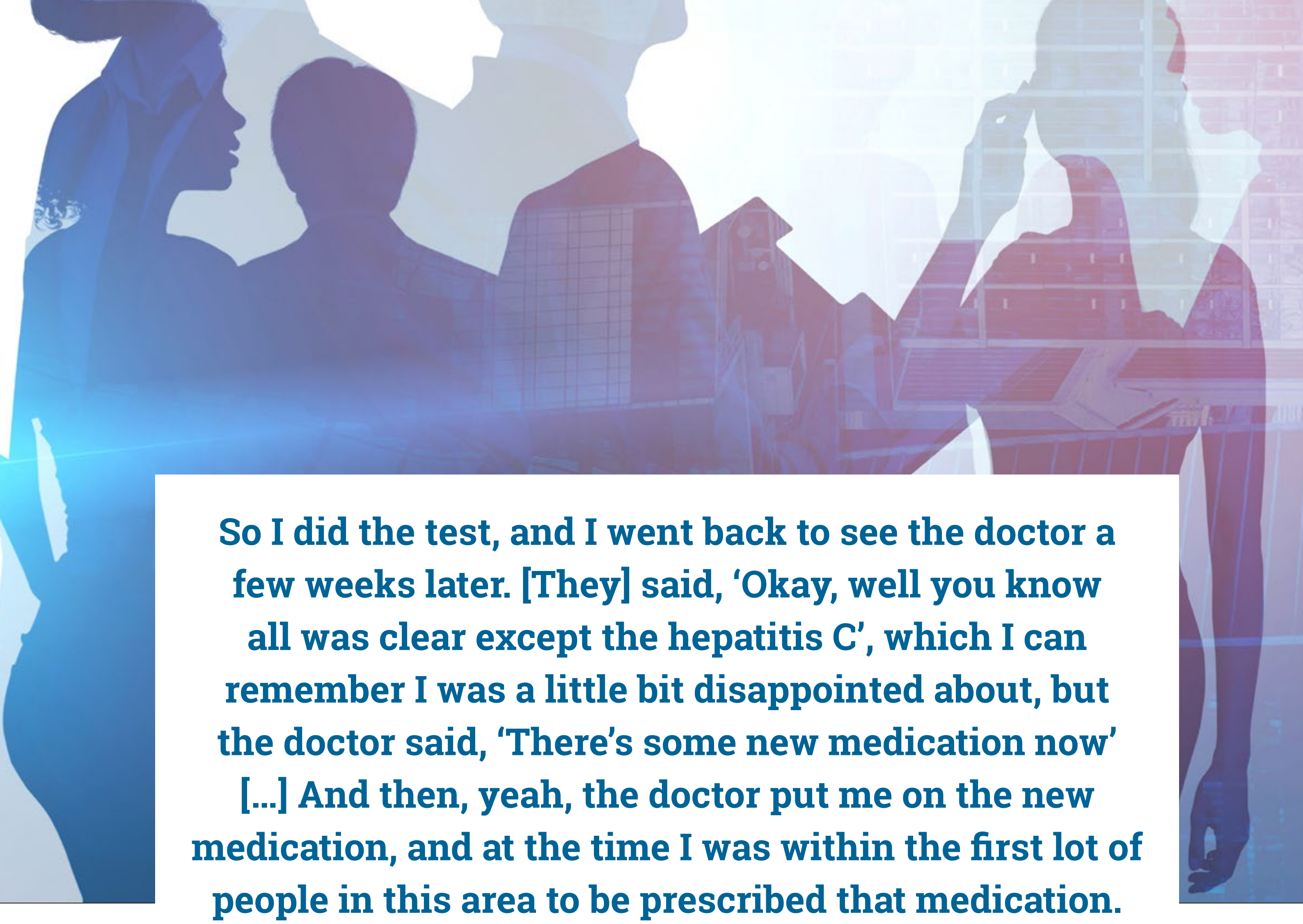
The people who participated in this research described receiving different kinds of advice from health professionals at the time of their diagnosis. For some participants, the advice was helpful, while others said they would have preferred to receive more information or different kinds of information.

Cal (male, 50, incomplete treatment experience) was 17 when he was diagnosed with hepatitis C, and he said that he should have had his mother with him at the time. He recalled the doctor saying that he had 20 years left to live, but he thought this may have been a strategy to scare him.

> *[The doctor explained that] it attacks your liver. And I'm trying to take this in, but, like, on the other hand, I'm freaking out and, like, totally freaking out. I should have had Mum with me probably, but I didn't know that was going to happen, you know, and, like, because of my drinking and because I smoked as well, but because I was a heavy drinker […] he said, 'Because you're drinking as well, it's not good for your liver, you know, both in combination, you know'. That's why he sort of said [that I had] 20 years [left to live]. I don't know whether he was trying to scare me out of drinking at that age or what, you know, but yeah, he didn't really explain too much. I wasn't really listening too much after that point, you know, because I was just sort of freaking out. I just wanted my mum, sort of thing.*

Rod (male, 41, repeat diagnoses, experience with DAA treatment]) remembered that his first diagnosing doctor was not well informed about hepatitis C. Some years later, he had another test and was advised to postpone treatment until DAA medication became available.

> *Yeah, I got diagnosed with hep C, like, about 20 years ago, and I don't think the doctor knew too much about it. He said that […] the blood tests came back with hep C, but [that it was] inactive, and he told me, like, I had something in my blood that was fighting against it. So I just thought that I couldn't catch it, and then I got tested again a couple of years later and they told me that I had caught it now, but not to do anything about it because I was healthy and that better treatment will come out in the future […] Then I've had heaps of tests over the years, like hep C. My FibroScans*



So I did the test, and I went back to see the doctor a few weeks later. [They] said, 'Okay, well you know all was clear except the hepatitis C', which I can remember I was a little bit disappointed about, but the doctor said, 'There's some new medication now' [...] And then, yeah, the doctor put me on the new medication, and at the time I was within the first lot of people in this area to be prescribed that medication.

TERENCE (MALE, 34, EXPERIENCE WITH DAA TREATMENT)

> *were pretty healthy, and they just kept telling me to wait because there will be better treatments sooner or later.*

Terence (male, 34, experience with DAA treatment), who was diagnosed much more recently than Cal and Rod (in 2017), explained that the doctor informed him about the DAA treatment at the same time as delivering his results.

> *So, at the time, I was going through a rehabilitation program, and I was encouraged by the facilitators to go and book in and see a doctor. So I did that, and I went on some alcohol withdrawal medication and some stuff and, you know, I was in and out of the doctor's all the time, and the doctor said, 'It's been a while since we've done a blood-borne virus test' for HIV, hep C, hep B and that sort of stuff. So I did the test, and I went back to see the doctor a few weeks later. [They] said, 'Okay, well you know all was clear except the hepatitis C', which I can remember I was a little bit disappointed about, but the doctor said, 'There's some new medication now' [...] And then, yeah, the doctor put me on the new medication, and at the time I was within the first lot of people in this area to be prescribed that medication.*

Sana (female, 71, experience with DAA treatment) explained that she may have acquired hepatitis C while still living in India, during a medical procedure for an arm injury. She described having blood tests in India around 2008 that suggested she had a 'blood infection' but was told to not 'worry about it'.

> *[I had] to do some checks and everything, medical things, for the visa purposes [... and] went to the local doctor there to just get all the tests done [...] They said, 'You've got a little infection in your blood', but then they didn't [explain] what sort of infection. They said, 'Don't worry about it, it's okay', because, you know, in India, sometimes they are like that. Yeah, doctor to doctor, it depends. Yeah. Some [things] they take serious[ly], some they don't take serious[ly] [...] One time [I had] like a little accident where [my] arm just got squished fully [...] luck[il]y it wasn't the bone. So, it's just like the muscles and everything [... and I] was hospitalised for nearly a month, I think. During that process, I had a blood transfusion and so many injections and everything, and we're thinking [my family and I], like, maybe [I acquired hepatitis C] from one of those injections or blood transfusions.*

The advice participants received from health professionals varied in quality, but more recent diagnoses since the arrival of DAA treatment tended to be more straightforward. Even then, however, some advice provoked anxiety and fear rather than reassurance, and some health professionals provided insufficient information about the implications of a hepatitis C diagnosis, DAA treatment and life after cure.

Conclusion and recommendations

The experiences described in the interviews collected for this project spanned a long period, during which treatment for and information about hepatitis C changed significantly. Perhaps unsurprisingly, our data suggested that health professionals' knowledge of and advice about hepatitis C and treatment has improved over time, with patients reporting improved, less-stigmatising experiences of diagnosis.

However, experiences of hepatitis C testing and diagnosis varied according to location and context (e.g. specialist or generalist healthcare services, or other settings such as prisons), and were shaped by individual levels of contact and familiarity with relevant healthcare services.

Being diagnosed with hepatitis C produced a range of responses, including surprise, sadness, shame as well as uncertainty the future and about transmitting the virus to others. Although healthcare encounters have generally improved with the development of DAA treatment, stigmatising or insufficient advice from health professionals can be upsetting and contribute to treatment delays.

Significantly, for some, diagnosis was a crucial moment in their lives that influenced their sense of self and social connection and their social relationships. Some participants mentioned that they would have preferred the option of having family and friends present for support when being diagnosed.

The experiences and perspectives reported here also highlighted the varied ways social relationships shape how people understand their hepatitis C diagnosis, with many more concerned about the potential implications of their diagnosis for friends and family rather than for themselves.

Key recommendations based on these findings

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.
- The delivery of a hepatitis C diagnosis should be conducted with sensitivity about stigma and the potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis, and depending upon how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

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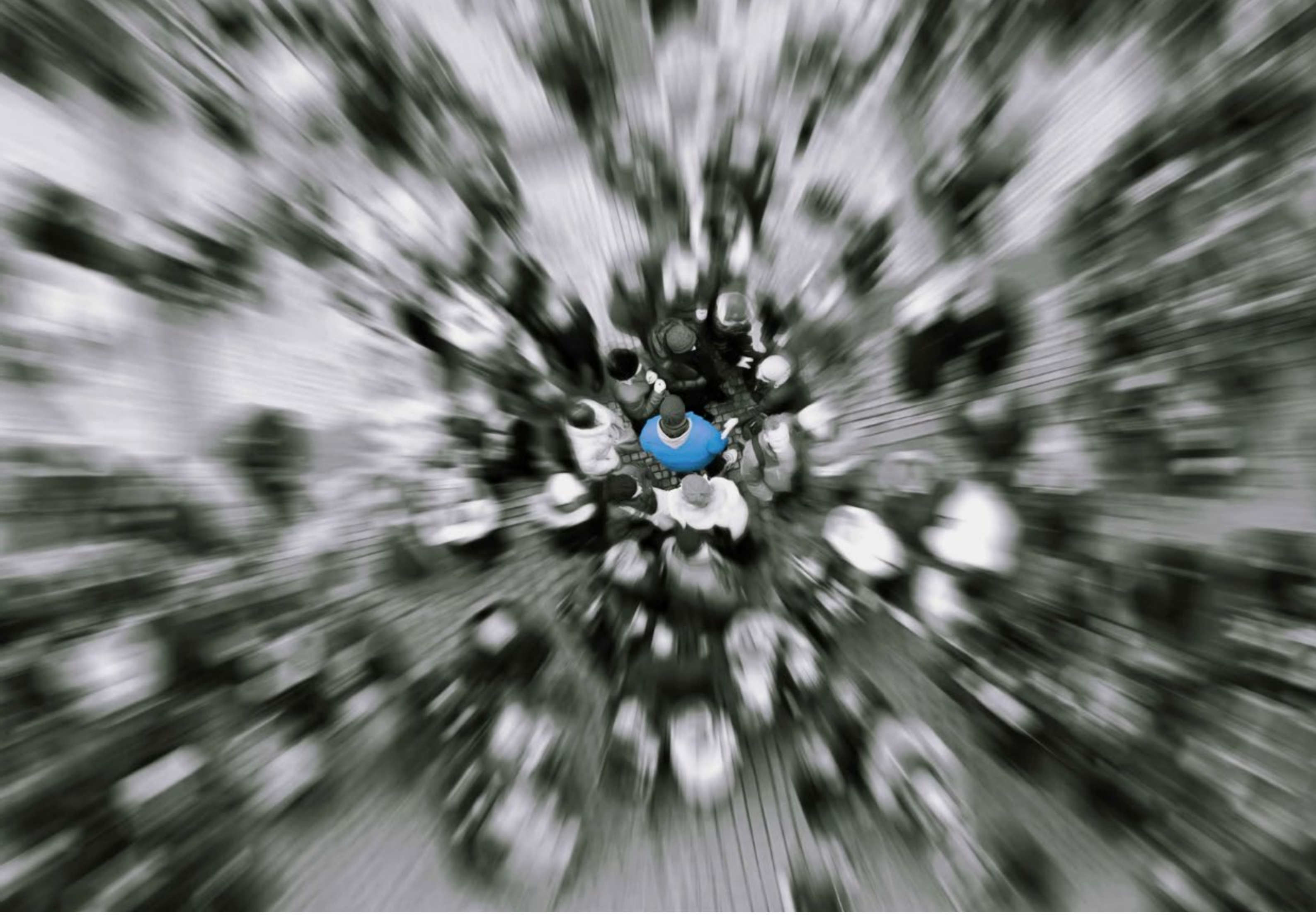
Appendix 1:
Participants

Participant information	Number
Gender	
Men	27
Women	21
Trans women	1
Non-binary	1
State	
Victoria	27
New South Wales	23
Age	
30-39	10
40-49	21
50-59	9
60-69	8
70-79	2
Type of treatment	
DAA treatment	19
Interferon-based treatment	9
Both DAA and interferon-based treatments	9
No treatment experience	13
Employment status	
Working or studying	15
Not working or studying	31
Retired	4

Participant information	Number
Education level	
Incomplete secondary	22
Complete secondary	12
Post-secondary	6
Tertiary	10
Cultural and ethnic background*	
Australian	32
Aboriginal Australian	5
New Zealander	2
North African and Middle Eastern	1
North American	1
North-West European	2
Southern and Eastern European	6
Southern and Central Asian	1
Sexuality	
Heterosexual	41
LGBQ+	9

* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.



Appendix 2:
Articles in press and under review

Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness.* https://doi.org/10.1111/1467-9566.13467

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.

La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the 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 and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world's largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to 'gamagoen yarrbat' – to soar.

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Broadsheet No. 2

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

Hepatitis C treatment uptake: Understanding treatment incentives and obstacles (Broadsheet No. 2)

This broadsheet is the second in a series of four broadsheets that summarise key project findings.

Copies of this broadsheet or of any other publications from this project may be obtained by contacting:

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Broadsheet No. 2

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit *Vital voices: Personal stories of treatment for hepatitis C*.

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Recommendations

This broadsheet is the second in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

Broadsheet No. 1: Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.
- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

Broadsheet No. 2: Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.
- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.
- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.
- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

Broadsheet No. 4: Life after hepatitis C treatment: Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme.

This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA medication offers much shorter treatment durations (approximately eight to 12 weeks), far fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004).

Research on hepatitis C treatment access before and after the availability of DAA treatments has identified a series of social issues shaping and often impeding uptake. For example, Harris and Rhodes' (2013) review of literature on access to interferon-based treatments explored 'individual' and 'social' level impediments. Individual level impediments include mental health issues, co-morbidities, the possibility of reinfection and concerns about side effects. Social level impediments include stigma, housing availability, geography, gender and cultural background, and criminalisation of people who consume drugs.

More recent research, conducted after the advent of DAAs, indicates that many of the same issues continue to impede access to treatment (Bryant et al., 2019; Gunn et al., 2021; Harris et al., 2021; Madden et al., 2018; Wright et al., 2019). Heard et al. (2021) argue that barriers at the 'personal' level include mental and physical health conditions, at the 'provider' level include stigma in healthcare settings, and at the 'system' level include complex treatment pathways and cost. They also identify enablers at the personal level such as the support of social networks, at the provider level such as trusting and respectful general practitioners, and at the system level such as fully subsidised costs and simple treatment pathways. While DAAs have far fewer side effects than interferon-based treatments, concerns about side effects also continue to shape treatment access and experiences (Bryant et al., 2019; Wright et al., 2019).

While barriers to treatment are well documented in the literature, less has been written about how people living with hepatitis C make decisions about treatment. Several studies indicate the social and relational nature of treatment decisions. Regarding the interferon-based treatment, Treloar et al. (2016) found that those in couples make decisions together. In relation to DAA treatment, Goutzamanis et al. (2021) find that local and peer-based advocacy are key to sharing information about treatment. People undergoing treatment may also be an important source of information and referral (Reygosa et al., 2021). Mattingly et al. (2019) discuss the role of altruism in treatment decisions, with fear of harming others forming part of the decision-making process. They also note that people considering treatment want to have confidence that treatment will be effective (Mattingly et al., 2019).

This broadsheet builds on and contributes to this growing literature by exploring how participants describe making decisions about treatment and the issues and social relations that complicate completing treatment.

Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was entitled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

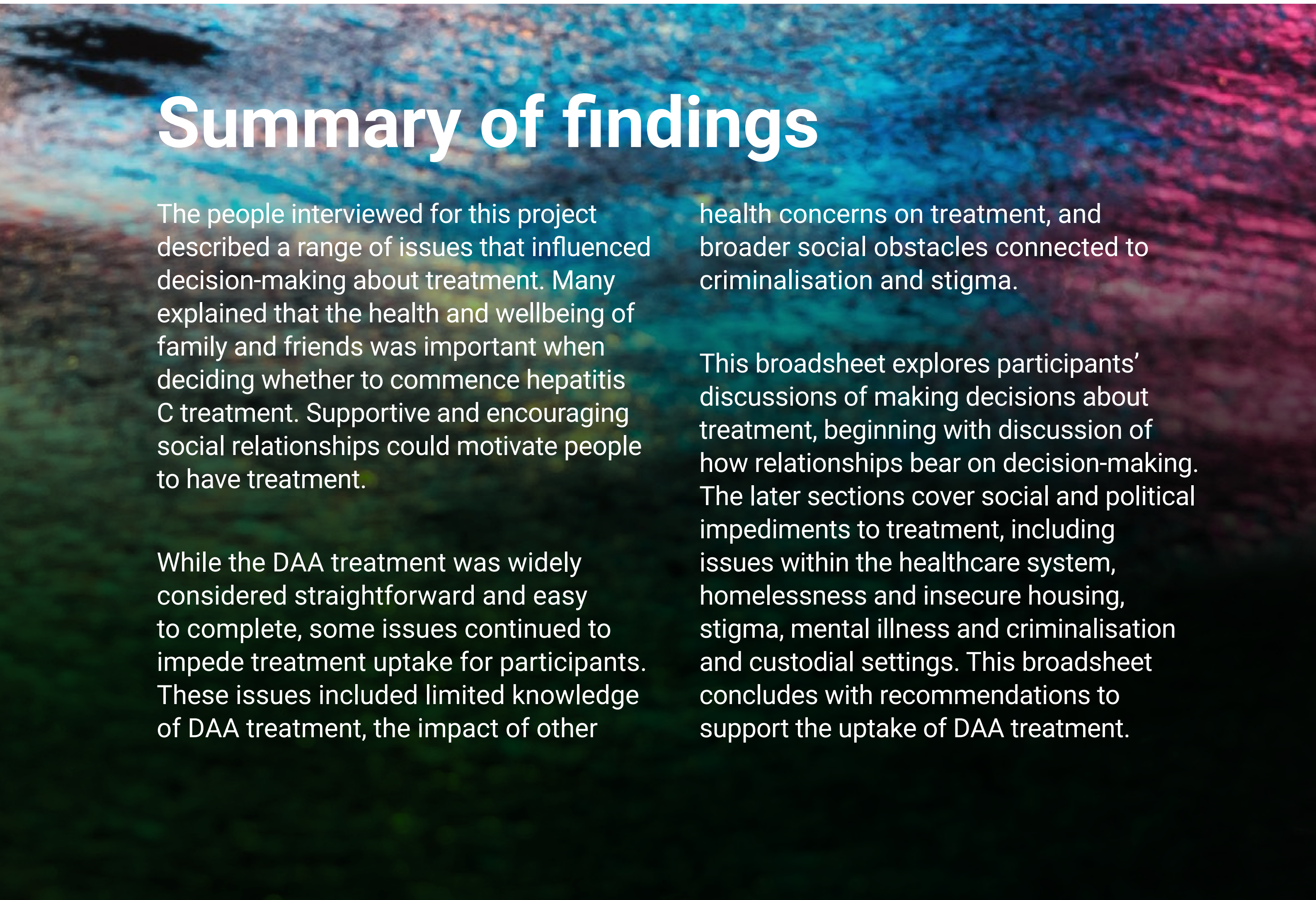
The project used a purposive data collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A$50 cash or an A$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment. Interview material from selected codes was carefully analysed by members of the research team to develop website content for this online resource. Topic sections for the website were developed in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed four broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the second of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience; for example, 'Dave (male, 65, experience with both DAA and interferon-based treatment) said that the DAA treatment was "quite easy" to incorporate into everyday life.' For more details about participants, see the demographics table in Appendix 1.



Summary of findings

The people interviewed for this project described a range of issues that influenced decision-making about treatment. Many explained that the health and wellbeing of family and friends was important when deciding whether to commence hepatitis C treatment. Supportive and encouraging social relationships could motivate people to have treatment.

While the DAA treatment was widely considered straightforward and easy to complete, some issues continued to impede treatment uptake for participants. These issues included limited knowledge of DAA treatment, the impact of other health concerns on treatment, and broader social obstacles connected to criminalisation and stigma.

This broadsheet explores participants' discussions of making decisions about treatment, beginning with discussion of how relationships bear on decision-making. The later sections cover social and political impediments to treatment, including issues within the healthcare system, homelessness and insecure housing, stigma, mental illness and criminalisation and custodial settings. This broadsheet concludes with recommendations to support the uptake of DAA treatment.

Family, friends and intimate relationships

Participants described different ways relationships influenced their decisions about hepatitis C treatment. Many focussed on the importance of family, partners and friends in their lives. For many, supportive relationships and caring for the health and wellbeing of others were significant considerations when thinking about treatment.

As Miguel (male, 48, experience with DAA treatment) explained, his mother's success with DAA treatment influenced his decision to have it too.

> *[I had hep C for] 10 years or maybe a decade or more […] until […] Mum one day rings me and says, 'There's a treatment [available, my] doctor reckons', and then a couple of weeks later she's on the tablets, and within three or four months she [has been cured of] it, and we were like, 'Oh wow […] we've got a cure', and I thought, 'It's too good to be true', and yeah, I did it too. So […] my mum found out about her treatment and then obviously it worked, and I found out through my doctor that I too could do that, and after we checked up the liver count, this whole thing, yeah, I got the drugs. So as soon as the treatment started, I started kind [of] feeling not much difference, but positively and, you know, like a fresh new start kind of feeling.*

Explaining how her family shaped her treatment experience, Carol (female, 58, repeat diagnoses, experience with DAA treatment) said that her sister helped her understand test results and that her grandchildren were part of her motivation for treatment.

> *I think the biggest [reason I had treatment] would have been when my grandson… when my eldest son and his wife got pregnant with their child. You know what I mean, so, like, I didn't want to take any chances […] so I spoke to […] the Hepatitis line. Well, the thing is that, like, my niece, she had hep C too […] and just talking to my sister about the antibodies and stuff like that, I worked it all out. I did copies of my blood tests now and my liver scans, so that I can compare them or have a look at the different results.*

Wanting to have children in the future was one of the key reasons Kylie (female, 46, experience with DAA treatment) decided to have treatment.

> *Well, I wanted to have children down the track, so […] I wanted to make sure that… I really didn't think you could have children if you had hepatitis [C]. Of course, you can [have children], but I always thought the child would be born with it […] My child still had to get blood-tested… as soon as he was born, they took him away and blood-tested him and then let me know that he didn't have [hep C], thank God.*

Parenting responsibilities and concerns about children were especially significant to many of the interview participants. Concerns about the welfare of children were an important aspect of decision-making about treatment for these participants. In some cases, children were described as a reason to have treatment.

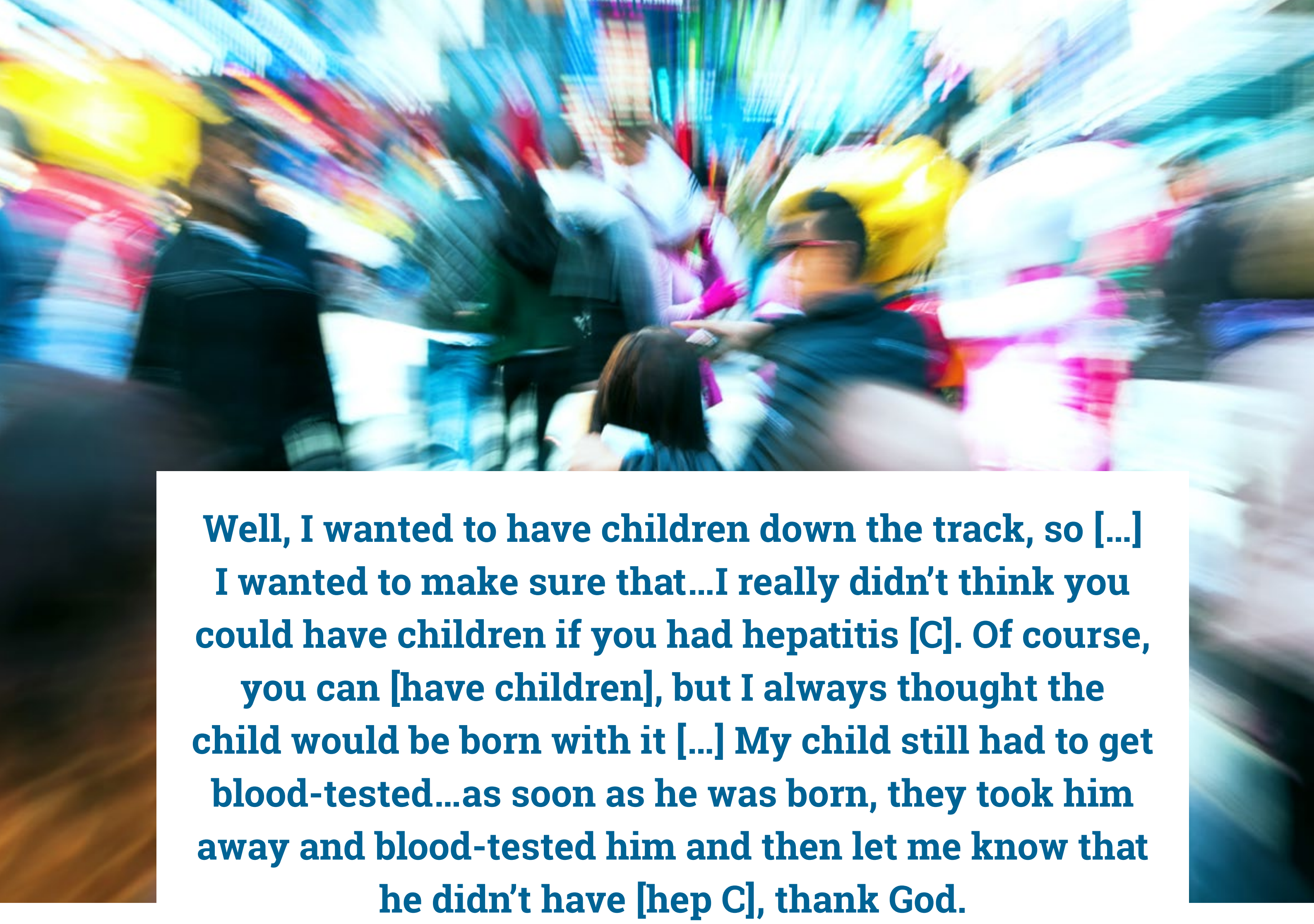
Several participants explained that their intimate relationships were an important part of their hepatitis C treatment decisions. While partners were often described as an important source of support, for some they were discouraging and unhelpful. Overall, worries about the impact of hepatitis C on intimate relationships were common among the people we interviewed. Several participants, for example, expressed concern that having hepatitis C meant that they could not have intimate relationships or that potential partners might be put off. Paulie (male, 45, experience with DAA treatment) said that treatment relieved him of the need to disclose his hepatitis C to potential intimate partners.

> *Yeah, [treatment] made me happy and content, so that way I don't have to go around, yeah, always getting in contact with some people, you know, new people or in a relationship or having sexual affairs, I don't have to say, 'Excuse me, you know, I've got hep C, just so you know.' Like, I just don't have to say it [any more] because I'm [cured], so it takes away that agitation [… When I found out I was cured,] yeah, I was very overwhelmed, I was happy, I was vibrant. I was just happy that I don't have to disclose to people who I get in contact with and, yeah, because there's no need to because I've […been cured of] the virus or disease.*

For many, much of the significance of treatment was about being able to have intimate relationships (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*). Seeking support from intimate partners and friends was important for many, but experiences varied. Some described receiving support and help and others described unhelpful and unsupportive relationships.

Many of the participants said they often spoke with friends about hepatitis C treatment. While friends were generally described as a vital source of support, participants said they were careful about who they spoke to about hepatitis C. On speaking to close friends about her hepatitis C, Regina (female, 69, experience with DAA treatment) found out some of them had also had it. She said that even though she did not usually tell other people 'everything', it was 'nice' to find out that they also knew about hepatitis C.

> *Well, the only people I have told have been close friends, and the interesting thing was, one of the close friends*



Well, I wanted to have children down the track, so […] I wanted to make sure that…I really didn't think you could have children if you had hepatitis [C]. Of course, you can [have children], but I always thought the child would be born with it […] My child still had to get blood-tested…as soon as he was born, they took him away and blood-tested him and then let me know that he didn't have [hep C], thank God.

KYLIE (FEMALE, 46, EXPERIENCE WITH DAA TREATMENT)

> *[…] it turns out, he also had hep C, but he got […cured] a long, long time ago with interferon. I told another friend whose husband also has it, but […] I don't know his story at all […] I think it […] came up in conversation or something along those lines. It wasn't an 'Oh, I'm going to disclose this to someone' [type of moment]. It would have come up in conversation, I think […] They were people my age who lived through the same era, you know, who lived through the same time, so it was the same thing [… It was] actually quite good. It's nice to know that other people know [about it], but it doesn't really matter to me. You know, I'm not one of these people who's big on, you know, telling people everything.*

Some participants also detailed how friends helped them overcome challenges that emerged while they were having treatment. In explaining the reasons they spoke to others about hepatitis C, some of our participants said that they wanted other people to consider getting tested or having treatment.

Given his disappointing experience with interferon-based treatment, Robbie (male, 54, experience with both DAA and interferon-based treatment) said that he recommends the DAA treatment to other people living with hepatitis C.

> *Yeah, I was spewing [disappointed] that [the interferon] didn't work. The doctor didn't really explain a great deal, just that it didn't work and, yeah, that I have to follow it up [again in the future]. So then I heard of this new treatment many years later, just the tablets, and went to the doctor and saw him about it, and he put me on the program […] I tell others about the program, if I hear they have hep C or anything like that, to do the program and see how they go, because it, yeah, worked for me [… I tell them that] all this is is a matter of taking a tablet.*

As Terence (male, 34, experience with DAA treatment) explained, while friends could be supportive, some people were not enthusiastic about the prospect of also having hepatitis C tests and treatment.

> *I told friends of mine [about my hepatitis C and treatment…] Yeah, my friend was really supportive, and I spoke to someone who I used to inject drugs with and sort of said that 'I tested positive for hepatitis C and, you know, I'm not able to definitively pinpoint the origin of it, but I think it's a good idea [for you] to get tested [too].' Yeah, they sort of weren't too keen on the idea.*

Participant interviews show the importance of family relationships in influencing how people make decisions about treatment. They also suggest that people affected by hepatitis C often encounter a range of responses when speaking with friends about the virus or treatment. While intimate partners and friends could shape decisions to seek treatment and be a source of support during treatment, some friends were less encouraging.

Issues in the healthcare system

Several people said they had difficulty finding out about and starting hepatitis C treatment because of issues in the healthcare system. They felt that treatment was not promoted very widely, and they described several other barriers to hepatitis C testing and treatment. Additionally, some indicated that even though they had heard of DAA treatment, they were not sure of the details, including how to start it. As Laura (female, 30, no treatment experience) said, 'I didn't even know there was a new treatment until you mentioned it […] Yeah, it's all confusing'.

Dana (female, 53, no treatment experience) explained that between 2012 and 2016 she had regular blood tests for hepatitis C and other tests for STIs. She did not remember receiving much information about hepatitis C during this period.

> *Being an IV drug user [who had] shared equipment in the past and [who was] also a working girl for a little while there too in [sex work…], I just needed to get checked and make sure I didn't have it […] Yeah, I think we had to go once a month […] or maybe three months for blood [tests] and one month for STD thing[s], I think [… The] only thing I think I ever received is a little brochure once, and it was about hepatitis, and then it had a few numbers or letters under it, like, I think it was A, B, C or something, I don't know. And all it said was that it can be transmitted [… through] sharing of [injecting] instruments and sexual[ly], and to be aware.*

Also speaking about the issue of awareness about treatment, Mikey (male, 40, no treatment experience) said that social and community organisations need to provide more information about hepatitis C to their clients.

> *All through the Salvation Army crisis housing and stuff, you never hear anything about hep C ever, and I feel like it's something that, yeah, people should be aware of […] hep C […] like, I wouldn't be surprised [if I acquired it in the future], and I probably would go and read about the current treatments, because my information is outdated, I think […] I didn't even realise that there was a new treatment, actually. I had no idea [… I haven't noticed] anything that would advertise this new treatment, [and] I would have noticed.*

In a few cases, participants described difficulty starting treatment due to vein damage. Hepatitis C testing in preparation for treatment may be hard to carry out due to difficulty accessing veins and may require special expertise and equipment that is not readily available.

Mem (female, 41, experience with DAA treatment) said that because an ultrasound is needed to guide her blood tests and collect blood, it took nearly 12 months to start treatment.

> *I believe I probably went for treatment [and] it took me nearly 12 months to be able to get bloods out [...] I have an issue with bloods, getting them out of my body, so I need an ultrasound guided [test], with a machine, to get bloods out. So [… there was] a year or so in between knowing [I] had the hep C and getting treatment, because when I've gone to go up to either the hospital or the doctor to get bloods out, if they didn't have an ultrasound machine, I [was] knocked back. So then it's just perpetuated the problem.*

Carol (female, 58, experience with DAA treatment) tried to access DAA treatment relatively early (in 2016) and said that living regionally and having difficulty accessing suitable appointment times could result in missing out on treatment.

> *I had an appointment that didn't suit, so I had to change it, and if you do that more than twice, you are off the list, more or less […] Yeah, but I suppose they've got a lot of people to deal with, you know what I mean. You've got to respect that as well […] You can't be messing them about.*

In addition to a lack of information about hepatitis C treatment within healthcare and other services, and limitations in services in regional areas, follow-up support and access to the appropriate diagnostic and testing equipment were also identified as impacting on treatment decisions.

Insecure housing, stigma and mental illness

Several participants spoke about the ways broader issues such as insecure housing, stigma and mental illness could act as barriers to hepatitis C treatment. While treatment was generally described as easy to take (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*), these broader social issues can contribute to difficulty beginning and completing it.

Alexander (male, 45, experience with DAA treatment) said being homeless made it difficult to complete his treatment.

> *I still currently have hep C. I was on treatment for a while. I got halfway through but circumstances [around] where I was, like, staying at the time changed and it was really hard for me to keep up with the medications […] I was taking the medication every morning because I was actually staying at [a supported short-term crisis accommodation], but then when my time was up there and I left, it was hard for me to keep up with the medication, because I was homeless again. So, although it's a very simple task, my memory is not the best and it was a bit hard for me to keep up with it […] Just being transient, like, I was never in the same place, I'd never wake up in the same place every day. So, it was hard for me to, sort of, remember to take the tablets, because I had other things on my mind.*

Referring to stigma, Lou (female, 40, experience with DAA treatment) said she worried about privacy at the local pharmacy during treatment, as she was known in the local community.

> *It was all pretty easy, really […] By that stage, I had started to notice there was lots of posters coming up in waiting rooms and around the hospital about, you know, 'hep C treatment: this clinic now treats hepatitis C'. It had come onto the Pharmaceutical Benefits Scheme, people were quite excited by that. So, the way it worked is that I had to go to Melbourne to get the prescription […] and then there was a few barriers, like again, the local community. I didn't want to come down to this pharmacy and get it, because, you know, I'm in here all the time. You are standing around talking to your neighbours and friends while you are waiting for your prescription to be filled, all of that silly stuff, which probably wouldn't bother me any more, but did back then.*

Some participants were living with mental health conditions that made it difficult to have hepatitis C treatment. The most common conditions spoken about by our participants were depression and anxiety, with several describing how managing these can make it hard to get and complete treatment.

Rose (female, 36, no treatment experience) explained how depression and anxiety reduced her motivation to have hepatitis C treatment.

> *Yeah. I've tried so hard to start the treatment. How many years… a lot of years on and off where I didn't give two shits. I couldn't wait to die, you know what I mean? So I was like, 'I don't care, I'm not going to do nothing' […] Why? Because [my] depression and anxiety and all that [make this] a big uphill… an up[hill] and downhill process for me, and every day it changes, like, I can't catch a break. I'm happy, down, happy, not happy.*

Evan (male, 45, no treatment experience) explained that while he was unsure whether he agreed with his mental health diagnoses, his mental health was the focus of his meetings with his doctor. That meant that, for him, hepatitis C was only one of a number of health issues needing attention.

> *Yeah, mental health [...] Yeah, it was always severe depression and personality disorder, but I think I would argue that one and just say, we all have up and some downs. But let's say, it's usually been about that […] I remember when I was 23 or 24 […] it seemed to be mostly what we were dealing with every time I'd go see him – apart from doing my prescribing when it needed to be done.*

The interviews show that those seeking and completing treatment for hepatitis C are affected by a range of issues, including many beyond individual control. Broader issues such as insecure housing, stigma and mental illness can act as barriers to hepatitis C treatment and need to be addressed in efforts to improve treatment uptake.

Minimal symptoms and confusion about treatment side effects

Several people described delaying treatment because they had not experienced any significant hepatitis C symptoms. Some participants who were diagnosed when interferon-based therapy was the only treatment option also described waiting until DAA treatment was available. Other participants described confusion about the differences between the old and new treatments.

Marty (male, 65, experience with both DAA and interferon-based treatment) said he delayed having treatment because he did not experience any hepatitis C symptoms.

> *I served probably 18 years in jail. That's not one sentence, that's just altogether. Now, in jail, I also knew I had hepatitis C […] because they did blood tests and my ALTs[1] and ASTs[2] were pretty high, but all they could do was tell me that I had the virus. There was nothing they could do. But again, it didn't feel or seem serious because I didn't, at that stage, have any ill effects. So, that's all I sort of knew, you know. Your ALTs are high, your ASTs are high, all that sort of stuff. Anyway, fast-forward, and still no ill effects in jail. Even though I was becoming aware of it because there was an old-timers' wing, like unit, that they had turned into a hepatitis treatment sort of section (and it was interferon), but the amount of thought I gave it was minimal […] I wasn't serious then, because there was no ill effects.*

Laura (female, 30, no treatment experience) recounted concerns about side effects associated with the interferon-based treatment and explained that they are one of the reasons she had not had treatment yet.

> *Straight away I'm like, 'But I heard that it can send you into a really deep depression, and I'm not in that really good headspace right now' […] Exactly the first thought that came into my head was that […] Like, at one point, [treatment is] going to help me heal, but at the same point, I don't want to, you know, put my kids through that and I don't want to… you know, I don't want my kids taken [away from me] because I'm that depressed that I can't clean my house […] I didn't even know there was a new treatment until you [the interviewer] mentioned it […] Yeah, it's all confusing.*

While DAAs are not associated with significant side effects, these findings show that the negative reputation of past treatments may linger and continue to discourage people from seeking treatment. Also, people may delay treatment because of an absence of symptoms.

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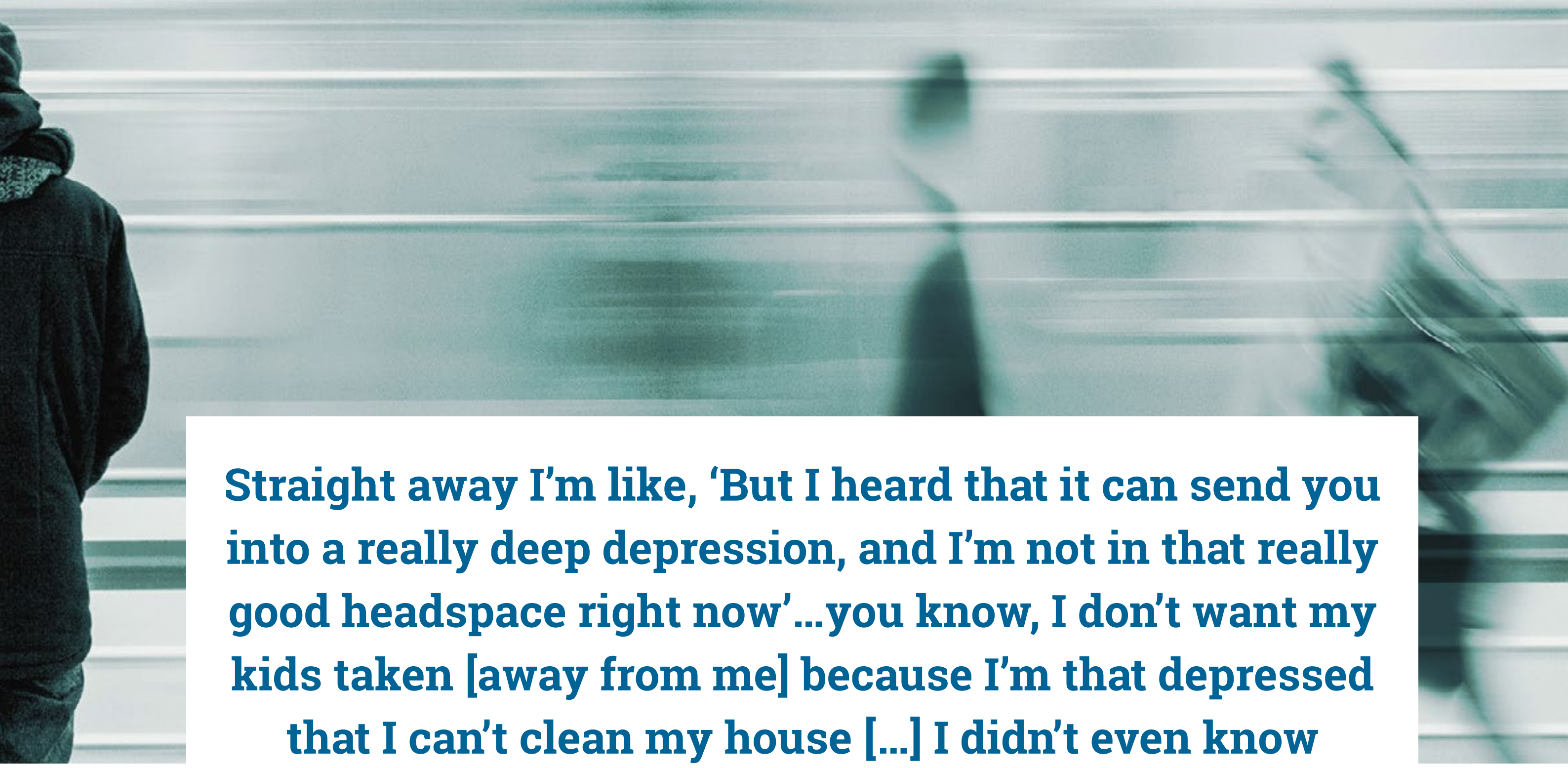
1 Alanine transaminase, or ALT, is an enzyme found in the liver that helps turn proteins into energy for the liver cells. When the liver is damaged – for example, by hepatitis C – ALT is released into the bloodstream and levels of it in the body increase.

2 Aspartate transaminase, or AST, is an enzyme that helps the body process amino acids. When the liver is damaged – for example, by hepatitis C – AST is released into the bloodstream and levels of it in the body increase.



> **Straight away I'm like, 'But I heard that it can send you into a really deep depression, and I'm not in that really good headspace right now'…you know, I don't want my kids taken [away from me] because I'm that depressed that I can't clean my house […] I didn't even know there was a new treatment until you [the interviewer] mentioned it […] Yeah, it's all confusing.**

LAURA (FEMALE, 30, NO TREATMENT EXPERIENCE)

Experiences of making decisions about hepatitis C treatment

Criminalisation and custodial settings

While there are several ways to get DAA treatment in Australia, some obstacles remain even for those who wish to have it. For several people interviewed for the project on which this broadsheet is based, criminalisation and imprisonment made accessing and completing treatment difficult.

Cal (male, 50, no treatment experience) described how he wanted to have treatment to 'make the best' of his time in prison but found it hard to complete treatment because of cycles of imprisonment and bail (conditional release).

> *Yeah, [I wanted to start treatment while I was in prison in] 2014 […] I thought, 'I am going to make the best of this and start treatment' because I could have been in there for a while. Then I ended up being bailed. But I wanted to continue on [the treatment after I left prison but…] I ran into a few hurdles […] I was staying at […] the homeless place where I was bailed to and, yeah, […] they were making life hard for me. I don't know whether it was over the charge that I was on from the court or, you know, but right from the start, I was copping hassles with them, and […] they kicked me out [… This made me] breach my bail and so I ended up just going, 'What's the point?', you know, and I didn't chase it up [any] more.*

Referring to the conditions inside prison, Dominic (male, 36, experience with DAA treatment) explained that while he had hoped to have treatment during his sentence, medical care was scarce.

> *I actually did want to do it [treatment] when I was locked up, but it would be a miracle if you get to see a doctor when you're inside, a miracle […] The medical system inside is a nightmare […] It's just hard to even get them to take you to see a doctor. It's hard to get a Panadol if you've got a migraine […] I put [hep C treatment] on the medical form and requested it and it went nowhere […] But it would have been good to do it while I was inside, because you are just locked in your cell all day and it's a perfect place to do it.*

Several participants described the criminal justice system as disrupting their efforts to look after their health and wellbeing in general, and to have treatment for hepatitis C in particular.

Conclusion and recommendations

Participants described a variety of social and political issues that shape decision-making around treatment and the ability to access or complete treatment. Friends, family and intimate partners are central to deciding to have treatment.

Many of the people we interviewed said they were motivated to start treatment out of consideration for partners or concern about transmitting hepatitis C to friends and family. Others wished to avoid having to disclose a positive hepatitis C status to potential partners.

People may also have treatment in order to care for the wellbeing of family members, particularly when parenting and children are concerns. Wanting to have children in the future, or managing existing parenting responsibilities, were also considerations, especially among the women we interviewed. People also described relying on family and friends for support and guidance during this period; however, many were careful about who they disclosed to.

Difficulty finding and starting hepatitis C treatment was also a key issue. Obstacles identified in the healthcare system include barriers to testing, being removed from waiting lists due to missed appointments and limitations in the quality of healthcare. This research project also found that limited information about the availability of DAA treatment and confusion about side effects contributed to treatment non-uptake. Some participants who were aware of DAA treatment did not know how to access it.

Other significant issues such as insecure housing, stigma and mental illness continue to make accessing and completing treatment difficult and sometimes impossible. Importantly, criminalisation and obstacles arising from custodial settings also make it difficult for people to access healthcare and address health concerns.

Key recommendations based on these findings

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.

- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.

- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

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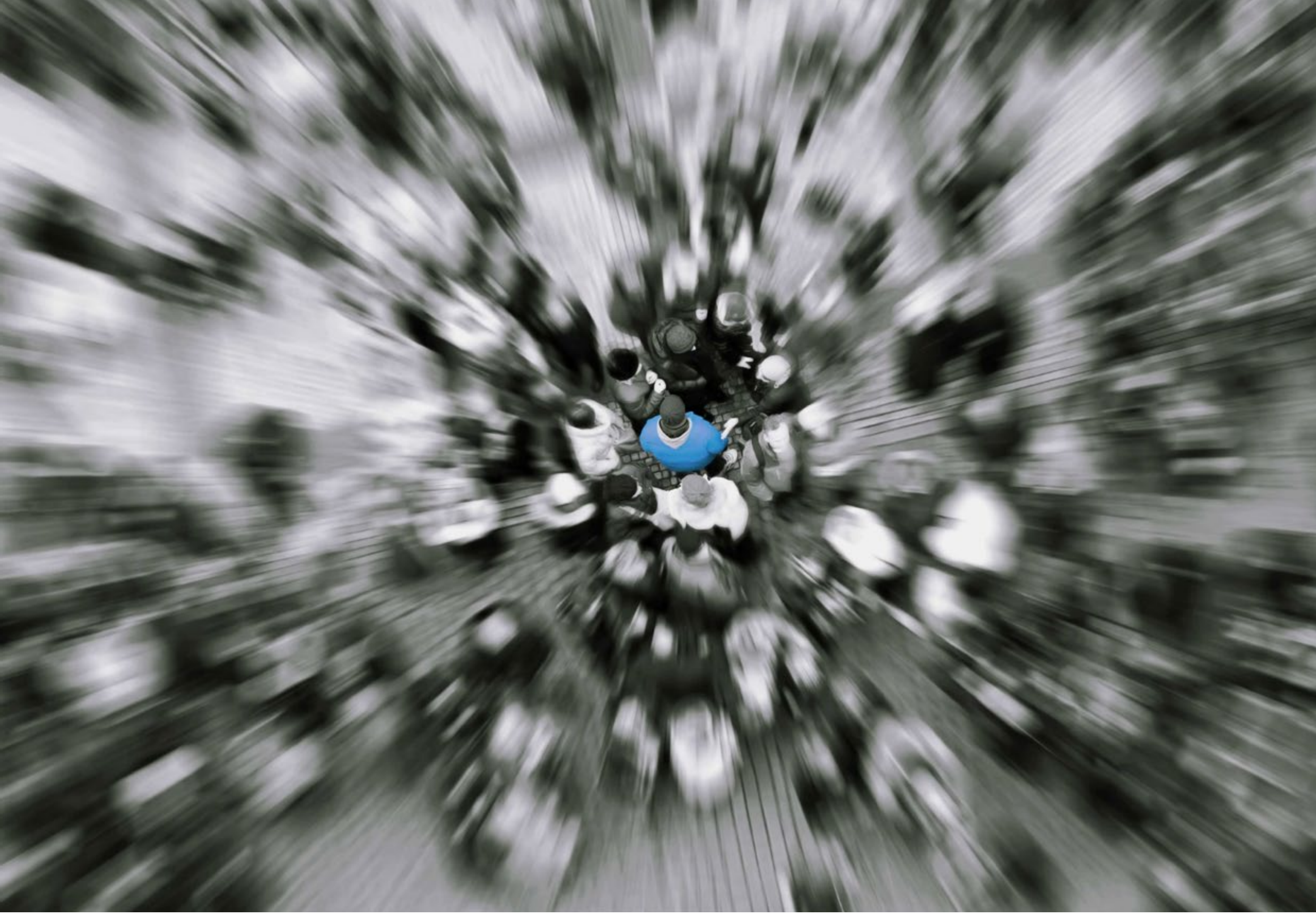
Appendix 1: Participants

Participant information	Number
Gender	
Men	27
Women	21
Trans women	1
Non-binary	1
State	
Victoria	27
New South Wales	23
Age	
30-39	10
40-49	21
50-59	9
60-69	8
70-79	2
Type of treatment	
DAA treatment	19
Interferon-based treatment	9
Both DAA and interferon-based treatments	9
No treatment experience	13
Employment status	
Working or studying	15
Not working or studying	31
Retired	4

Participant information	Number
Education level	
Incomplete secondary	22
Complete secondary	12
Post-secondary	6
Tertiary	10
Cultural and ethnic background*	
Australian	32
Aboriginal Australian	5
New Zealander	2
North African and Middle Eastern	1
North American	1
North-West European	2
Southern and Eastern European	6
Southern and Central Asian	1
Sexuality	
Heterosexual	41
LGBQ+	9

* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.



Appendix 2: Articles in press and under review

Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness.* https://doi.org/10.1111/1467-9566.13467

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.

La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the 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 and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world’s largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to ‘gamagoen yarrbat’ – to soar.

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Broadsheet No. 3

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Experiences of DAA treatment and hepatitis C cure:

Treatment knowledge, interactions with health professionals and questions after cure

LA TROBE UNIVERSITY
Australian Research Centre in Sex, Health and Society
UNSW SYDNEY
CSRH Centre for Social Research in Health
VICTORIA State Government
VITAL voices

Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure (Broadsheet No. 3)

This broadsheet is the third in a series of four that summarise key project findings.

Copies of this broadsheet or of any other publications from this project may be obtained by contacting:

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Broadsheet No. 3

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit *Vital voices: Personal stories of treatment for hepatitis C*.

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Recommendations

This broadsheet is the third in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

Broadsheet No. 1: Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.
- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

Broadsheet No. 2: Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.
- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.
- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.
- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

Broadsheet No. 4: Life after hepatitis C treatment: Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme. This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA treatment offers much shorter treatment durations (approximately eight to 12 weeks), far fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004). Along with significant differences between old and new treatments in prescribing and availability, the new medications have transformed the clinical management of hepatitis C (Bajis et al., 2017; Richmond et al., 2018).

Optimism surrounds the relative ease and simplicity of the new medications, the 'miracle' of cure and a much longed-for future without hepatitis C (Rhodes et al., 2019). Qualitative research suggests that patients find the new DAA treatment comparatively easy and it leads to improvements across physical, emotional and mental health (Goutzamanis et al., 2021). However, a range of social issues continue to shape and often impede uptake.

In Australia, Madden et al. (2018) identify barriers to treatment such as gaps in continuity of care, stigma, poor vein health, and the challenge of finding supportive and non-judgemental care. Commenting recently on Australia, Heard et al. (2021) argue that barriers at the 'personal' level include mental and physical health conditions, at the 'provider' level include stigma in healthcare settings, and at the 'system' level include complex treatment pathways and cost-related barriers for undertaking treatment. They also identify enablers at the personal level such as the support of social networks, at the provider level such as trusting and respectful GPs, and at the system level such as fully subsidised costs and simple treatment pathways.

While DAAs have vastly fewer side effects than interferon-based treatments, concerns about side effects are also thought to continue to shape treatment access and experiences (Bryant et al., 2019; Wright et al., 2019). In this respect and others, some contend that efforts to increase uptake would benefit from fully engaging with the meanings given to treatment that circulate within affected communities (Bryant et al., 2019).

While improvements in physical health, such as an increase in energy levels, are significant (Goutzamanis et al., 2021; Mora et al., 2020), experiences of cure are also imbued with deeper meanings. Some research indicates that people affected by hepatitis C primarily value the broader effects of cure such as the relief of not having a looming chronic illness (Mora et al., 2020) and, consequently, treatment benefits need to be understood beyond clinical outcomes alone (Goutzamanis et al., 2021). In this sense, hepatitis C cure is not solely defined by sustained virological response (or SVR), the accepted definition of cure (Kirby Institute, 2018), or by improved physical health, but is invested with meanings beyond the virus and its effects. Multiple articles argue, for example, that hepatitis C cure offers a symbolic break from a past life and stigmatised subjectivity linked to a history of injecting drug consumption (e.g. Harris, 2018; Madden et al., 2018; Pourmarzi et al. 2020; Richmond et al., 2018; Vega et al. 2021; Williams et al., 2019). Reflecting the complexity of treatment experiences, some research emphasises that individuals accessing treatment often hope for outcomes beyond cure, such as new social connections and strategies to manage health and wellbeing (Madden et al., 2018).

Our research contributes to this literature by exploring the way that participants described their qualitative experience of treatment. We show that participants had concerns about DAA treatment when they were not given sufficient information about what treatment involved or post-treatment life.

Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

The project used a purposive data collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A$50 cash or an A$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment.

Interview material from selected codes was carefully analysed by members of the research team to develop website content for this online resource. Topic sections for the website were developed in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed four broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the third of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience, for example, 'Dave (male, 65, experience with both DAA and interferon-based treatment) said that the DAA treatment was "quite easy" to incorporate into everyday life.' For more details about participants, see the demographics table in Appendix 1.

Summary of findings

The people we interviewed for this project described positive experiences of DAA treatment. The ease and simplicity of DAA treatment, along with the high success rates, were highly valued by participants and central to their treatment experiences. While many participants recounted positive interactions with health professionals, some described wanting more information about hepatitis C itself, treatments and potential health issues that might occur in the future after cure. Overall, descriptions of being cured indicate that treatment was generally a positive experience, connected to improved health and wellbeing and feelings of optimism about the future.

In the following sections, this broadsheet covers participants' perspectives on and experiences of DAA treatment, their reflections on the role of health professionals in treatment experiences, their need for further information, and experiences of cure.

The new treatment: Simple and easy

Participants with experience of DAA treatment generally described it as 'simple' or 'easy' to take. Comments were almost wholly positive, and often focussed on the treatment's minimal side effects or how easy it was to include it in daily routines.

Dave (male, 65, experience with both DAA and interferon-based treatment) said that DAA treatment was 'quite easy' to incorporate into everyday life, and he encouraged others to have it too.

> *It was just a bottle of tablets that was sitting next to my vitamins, which I had every morning. I took them at seven [pm], every night I took them at seven, so quite easy […] I have friends who still have hepatitis C and I try and encourage them to get treatment […] Good hep C treatment [should be] available to everybody whether they are using drugs or not […] It should be freely available to everybody.*

Sam (male, 35, experience with DAA treatment) offered a similar assessment when he said treatment could not have been 'any easier'.

> *I don't think that you could get anything better than taking one tablet a day. You couldn't get it any easier than that […] For people having treatment down the road in the future, like, yeah, as long as they can stay on top of it, I don't think you could make it any easier than one tablet a day.*

For some participants, treatment was so uncomplicated, there was not much to say about the experience.

Robbie (male, 54, experience with both DAA and interferon-based treatment) had DAA treatment at the same time as his friend.

> *[My friend and I] heard about this new program, the tablets, and then the friend I'm staying with, we both got on it and both got rid of it within a month [… We heard about it] from the doctor [… who said] that there was a new treatment out and it worked for others pretty good, and if you want to try, give it a go, yeah. So we did and it worked […] Yeah, it went for three months and, yeah, I stayed on the program for the whole three months, even though [the hep C] was gone within the first month.*

Because the interferon-based treatment was known for significant negative side effects that diminished quality of life, many of the people who had DAA treatment expressed that they were relieved by and happy with their experiences with DAAs. Harriet (trans woman, 30, experience with both DAA and interferon-based treatment), for example, reported that it was 'the best thing [she] ever did for [her]self […] because there are no side effects or anything'. Similarly, Terence (male, 34, experience with DAA treatment) said that for him there were 'no side effects whatsoever', and Regina (female, 69, experience with DAA treatment) explained simply that for her there were 'no side effects, and it worked and it was fantastic'.

Commenting on the absence of side effects for him, Tristan (male, 49, repeat diagnoses, experience with both DAA and interferon-based treatment) compared DAA treatment favourably to taking headache medication.

> *I was expecting there to be some sort of side effects, but no. Just like taking an aspirin once a day and that was it […] No side effects, nothing at all. Whereas with the interferon, you'd get to the end of the week, you'd start feeling good because all the drugs are wearing off, and you'd have to stick [inject] yourself in the belly again and an hour later, you feel like dog shit for the next five days. And then it starts wearing off and you become good, and then you stick [inject] yourself again. But the new one [treatment], that is unbelievable.*

While Chris (male, 60, experience with DAA treatment) did not speak about side effects directly, he described DAA treatment as 'gentle'.

> *I didn't [know] what to expect, but it was so gentle and unassuming and unnoticeable. I just had this pill every day and that was it, and 12 weeks later it was done […] It was like the beginning of the disease [hep C] where you know you've got it, but it doesn't bother you [with any symptoms, so you] think it doesn't matter. The treatment was kind of the same, it was really benign and gentle.*

Participants described DAA treatment in very positive terms: 'gentle', 'fantastic', 'unbelievable' and 'the best', but, as discussed below, some suggested they would have liked more information about what to expect during and following treatment. Because the interferon-based treatment was known for significant negative side effects, participants were often surprised by their absence. In contrast, DAA treatment was generally without side effects and simple to take.

Need for more information about DAA treatment

Overall, DAA treatment was widely considered to be much better than the old interferon-based treatment, but some participants indicated they would have liked more information while having treatment. Key points included uncertainty about the effects of hepatitis C and about treatment policies and procedures, and in some cases, there was a desire for more information about treatment before starting it.

Steve (male, 49, experience with DAA treatment) said he was given minimal information about DAA treatment.

> *No, no, I wasn't told hardly anything. I was just handed a bottle and said, 'Here, take this once a day.' […] I instantly linked it to giving me an extra few years of quality life, you know […] I was sort of expecting to maybe feel a bit off, like, after I started taking it, but no, I didn't even notice it really.*

Alexander (male, 45, experience with DAA treatment) also described being given little information about hepatitis C and the tests he had.

> *I was on the treatment a few months ago, this new medication that they've got for hepatitis, and they did some sort of check then, but my liver exam is normally generally pretty good, even when I've been [taking] drugs […Even after the check-ups] I've [still] got no idea [what my genotype is].*

Paulie (male, 45, experience with DAA treatment) explained that while his GP advised him to have treatment, he was not informed that he could have treatment again if he was cured but acquired the disease again in the future.

> *If I got it [again], I'd like to do [treatment] again, but I don't know. Are you allowed to do it again? If I had hep C and I'd done the treatment and [been cured of] it and then I've caught it again, can you reapply and get the treatment done again, or [do] they ban you or something after you've done it once and you get it again or something? I don't know.*

Sam (male, 35, experience with DAA treatment) described his GP's approach as comforting but not informative enough.

> *I thought [being diagnosed with hepatitis C] was a life sentence, and I went and saw my GP and got tested and, yeah, like, he was pretty blasé about it, you know what I mean. He said, 'It's so easy to get cured from it, there's no reason to be getting upset.' It sort of made me feel a lot more comfortable with it, in all honesty, but in saying that, I still really didn't understand it and I didn't ask the questions… like, I didn't get the answers from him that I should have been getting. In saying that, I didn't ask questions to him to fully understand what I was dealing with […I would have liked to have known] just how it affects the body, you know, what am I going to be going through as opposed to someone who didn't have hep C. You know, how it's really going to affect my day-to-day life.*

These findings indicate that while treatment is straightforward, more detailed information about hepatitis C is often desired, including whether it can return, and what to do in the case of reinfection.

Interactions with health professionals

Many people we interviewed recounted their experiences with the health professionals who managed their hepatitis C treatment. Health professionals were instrumental in guiding people into treatment and had an important part to play in their treatment experiences overall. Many of the people we interviewed said that health professionals described DAA treatment as simple and easy, and encouraged them to consider it.

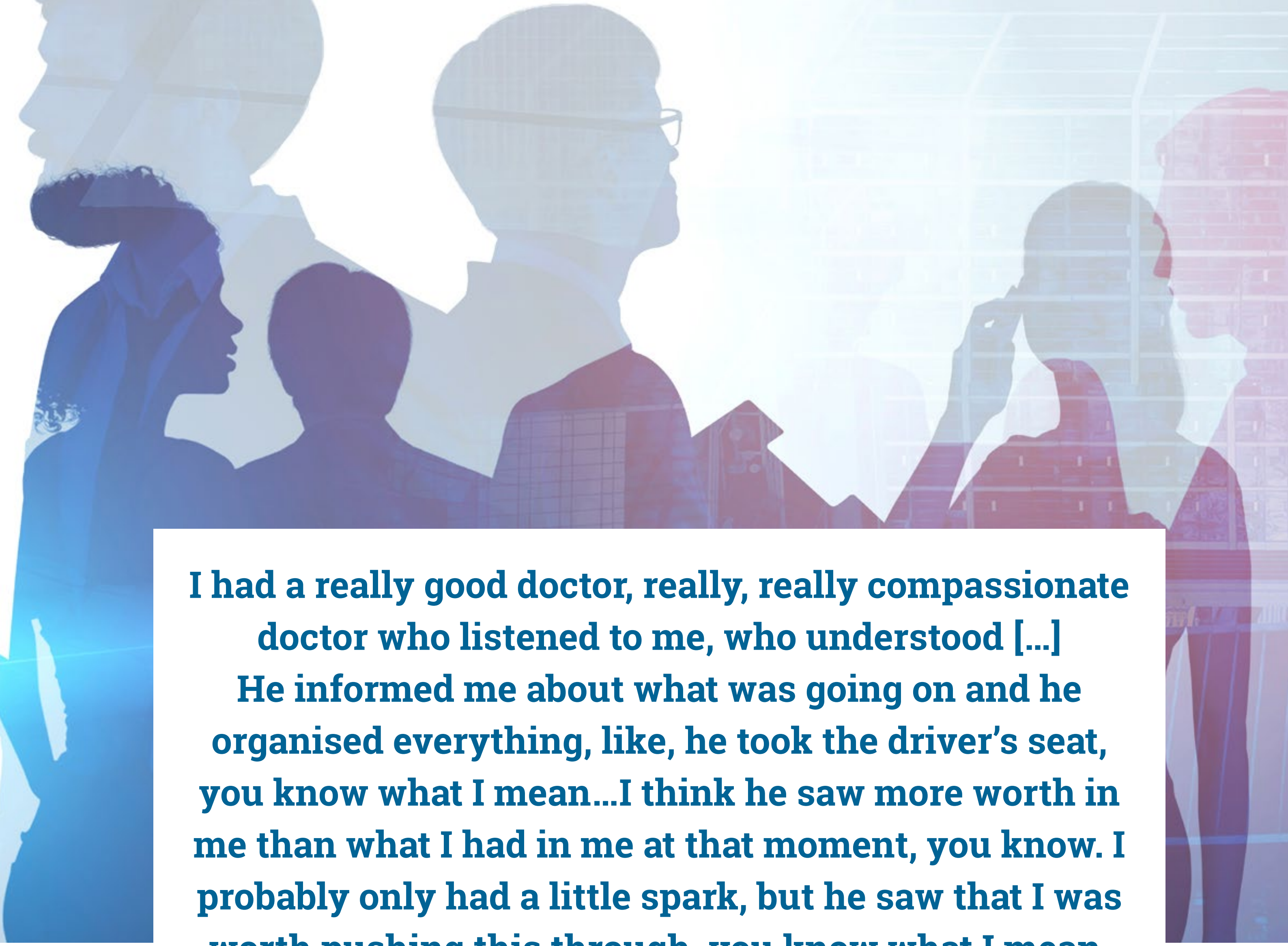
Rod (male, 41, repeat diagnoses, experience with DAA treatment) talked about how a doctor encouraged him to begin treatment.

> *I had the nurses explaining to me, like, how easy it was [… to have] treatment and I went to the [hospital liver clinic] and there was a doctor… can't think of her last name, really nice lady […] Yeah, she explained everything to me and said it was a good time for me to do it now and, yeah, [I] just stuck with her and got that done.*

Many of the interviews considered what good healthcare looks like for hepatitis C treatment. A common response was to highlight the value of knowledgeable and thorough healthcare professionals who take an active role in treatment and provide care and support.

As Gretchen (female, 68, no treatment experience, experience with spontaneous clearance) explained, she chose her current GP because he was 'knowledgeable' and did not have a negative reaction to her experience with hepatitis C.

> *I'm very sceptical of doctors. Because I've worked in the health system, I know they're not all good. So, when I changed from [my current doctor to] where I live now, about 10 years ago, I needed a good GP. I think it's good to have rapport with your doctor, not just any port in a storm. You've got to get to know each other […] Yes, and that's why I chose him, because he didn't flinch, he asked me about it [hepatitis C], he asked me stuff and he's… I'm 68, he could be about my age ... He wears boots and jeans, you know, and I thought, 'He's an old hippie', but he's very good. He's very*



I had a really good doctor, really, really compassionate doctor who listened to me, who understood […] He informed me about what was going on and he organised everything, like, he took the driver's seat, you know what I mean…I think he saw more worth in me than what I had in me at that moment, you know. I probably only had a little spark, but he saw that I was worth pushing this through, you know what I mean, and he chased it up, chased it up and chased it up.

COLIN (MALE, 44, EXPERIENCE WITH BOTH DAA AND INTERFERON-BASED TREATMENT)

> *knowledgeable and very thorough, and there was no discrimination.*

Colin (male, 44, experience with both DAA and interferon-based treatment) described the way his doctor took charge of his treatment and demonstrated he was invested in his future and wellbeing.

> *I had a really good doctor, really, really compassionate doctor who listened to me, who understood […] He informed me about what was going on and he organised everything, like, he took the driver's seat, you know what I mean, and [he] really did, you know what I mean. It was more than just bedside manner, like, he showed a vested interest, like, in me getting better, you know what I mean. I think he saw more worth in me than what I had in me at that moment, you know. I probably only had a little spark, but he saw that I was worth pushing this through, you know what I mean, and he chased it up, chased it up and chased it up.*

Sana (female, 71, experience with DAA treatment) said that the health professionals managing her treatment were 'fantastic' and very respectful. She explained further that she experienced some skin-related side effects during treatment, and the doctor was very helpful.

> *Every person during the treatment was fantastic […] Even the nurses […] the ones that work under a specialist, they are so helpful. […] They were very helpful and […] they speak nicely. When they know that I can't understand English, they speak, like, [a] little bit slowly and just on the targeted words and with a smile, facial expressions, and they give [me…] full respect [… I] got a lot of itchiness on [my] whole body during the treatment, when [I] was having that medication. So [… I] just keep applying a lot of Vaseline and, you know, high petroleum jellies and things like that. [I] asked the doctor, like, 'I'm having [itchiness]', but the doctor said, 'Yeah, it normally happens during that treatment'.*

Importantly, the information and support provided by trusted health professionals can encourage people to access treatment. Participants explained that informative, trustworthy and caring health professionals were important to their overall experience of treatment and wellbeing.

Reflections on DAA treatment and being cured

Experiences of cure

The people interviewed for this website offered a range of different perspectives on what being cured means and how it affected their everyday lives. Some explained that it led to improvements in health, vitality and wellbeing, while others expressed concerns about hepatitis C returning in the future. Overall, participants' descriptions of being cured indicate that, while it was generally a positive experience, its effects were not uniform and were shaped by personal circumstances.

Kylie (female, 46, experience with DAA treatment) said that completing treatment got rid of the frequent headaches she had previously experienced, and it also improved her mental health.

> *I shout it from the rooftops […] Yeah, it's just made me happier […] Well, [being cured] made me feel better, because I don't suffer from the headaches that I used to suffer from all the time, and I don't feel as depressed as what I did when I knew that I had hepatitis. So yeah, it's made me feel happier within myself.*

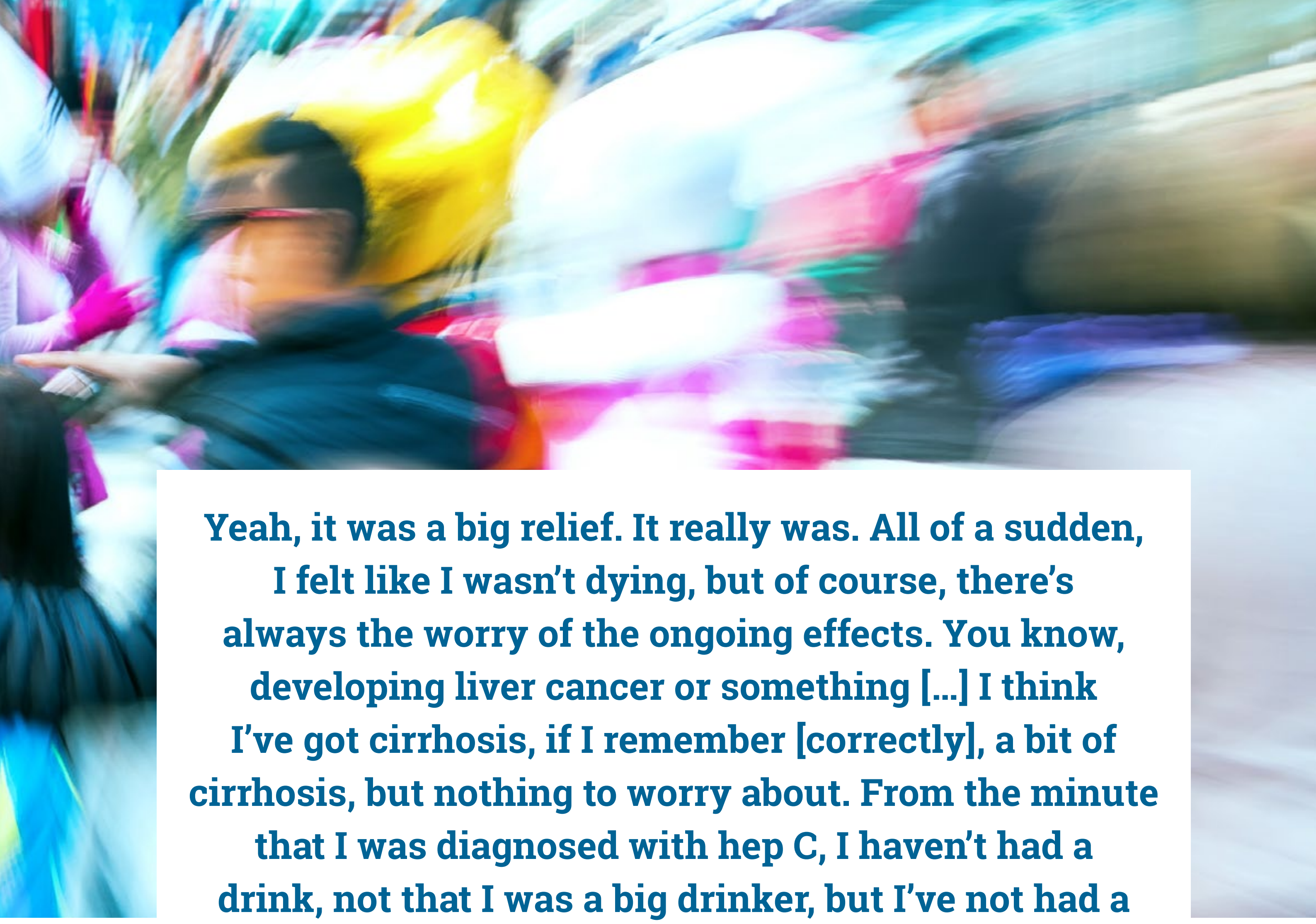
Many of the people we interviewed described feeling great emotion after being told they were cured of hepatitis C. Feelings such as relief, happiness, joy and optimism were common.

According to Lou (female, 40, experience with DAA treatment), although she was not comfortable speaking with many people about her experience of hepatitis C, her treatment experience and cure led her to reflect on what was meaningful in her life and now informs her practice as a social worker.

> *I think [my cure's] probably, you know, added to the richness of what's meaningful in my life, and I think it's probably made me a better social worker. It's certainly helped me maybe, yeah, reflect on some of my own assumptions and vices that I didn't realise that I had. I think I have always thought that maybe one day I would like to be able to talk a bit more about it publicly. Perhaps that day will come, perhaps it won't, but yeah […] And […] maybe it's added to my thinking that you just don't know what's coming around the corner, so just make the most of it. It sounds a bit like a platitude, but really, just to make the most of what's in front of you right now.*

According to some of the participants, being cured also meant feeling free of worry about passing on hepatitis C to other people, and feeling more optimistic about the future.

Miguel (48, male, experience with DAA treatment) started having treatment during a period in which he was making other positive changes in his life. He



Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't dying, but of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something […] I think I've got cirrhosis, if I remember [correctly], a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink, not that I was a big drinker, but I've not had a drink of alcohol since.

FOR REGINA (FEMALE, 69, EXPERIENCE WITH DAA TREATMENT)

described being cured as offering him renewed optimism and vitality.

> *As soon as the treatment started, I started feeling not much difference, but [then I started to feel […] a fresh new start kind of feeling, you know […] At that time […] I found some work, and also [other] things were falling into place, and I [wasn't taking drugs any more]. On top of that, [I was also thinking…] that soon enough I would get rid of hep C and then I [wouldn't] have to think of it ever again. [I wouldn't have to ask,] 'If I cut myself, who's around?' [… This] stuff weighs on you, and feeling like you are less than others because you've got this disease. So yeah, I reckon […] I felt relieved and stronger and just able to look at the world with a new set of eyes. I felt I had an influence on the people around me too, because I was like, 'Okay, things are finally working out': rehab, this [new] work and now a clean bill of health. Yeah […] it worked so fast as well. The treatment was […] about three months and the doctor […] said, 'Yes it's definitely cleared up', whereas for years, we didn't have a clue [what] we were going to do. There was no cure or hope in sight, and then all of a sudden, there it is, you know what I mean?*

Some people explained that they had a different response, one not totally free of worry about their health and future, as they considered the longer-term health effects of having had hepatitis C or the potential for it to come back (see Broadsheet No. 4, *Life after hepatitis C treatment: Health, wellbeing and the future*).

For Regina (female, 69, experience with DAA treatment), being cured of hepatitis C was a 'relief', but she worried about developing liver cancer in the future.

> *Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't dying, but of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something. There's always that slight worry, but I try not to worry […] I think I've got cirrhosis, if I remember [correctly], a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink, not that I was a big drinker, but I've not had a drink of alcohol since.*

While many participants experienced cure as a joyful event that signified positive changes in health and wellbeing, and was connected to renewed optimism and energy, some continued to be concerned about the future, especially the possibility of developing hepatitis C–related health issues, including liver cancer.

Conclusion and recommendations

Most of the people interviewed for this project had overwhelmingly positive experiences of DAA treatment. Treatment was described as simple and easy, and most people experienced few side effects.

While most of the people we interviewed described positive experiences of DAA treatment, some mentioned needing further information about treatment and more support following treatment. They were left with questions about what to expect during treatment and after cure, including questions about ongoing health effects and reinfection.

Positive interactions with health professionals were found to be crucial to positive experiences of treatment. Participants described health professionals encouraging them to begin treatment and guiding them through this process. Respectful and trustworthy healthcare was highly valued by participants.

Finally, while the meanings given to cure varied, they were often connected to improved health and wellbeing, feeling positive about the future and increased vitality more generally.

Key recommendations based on these findings

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.

- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

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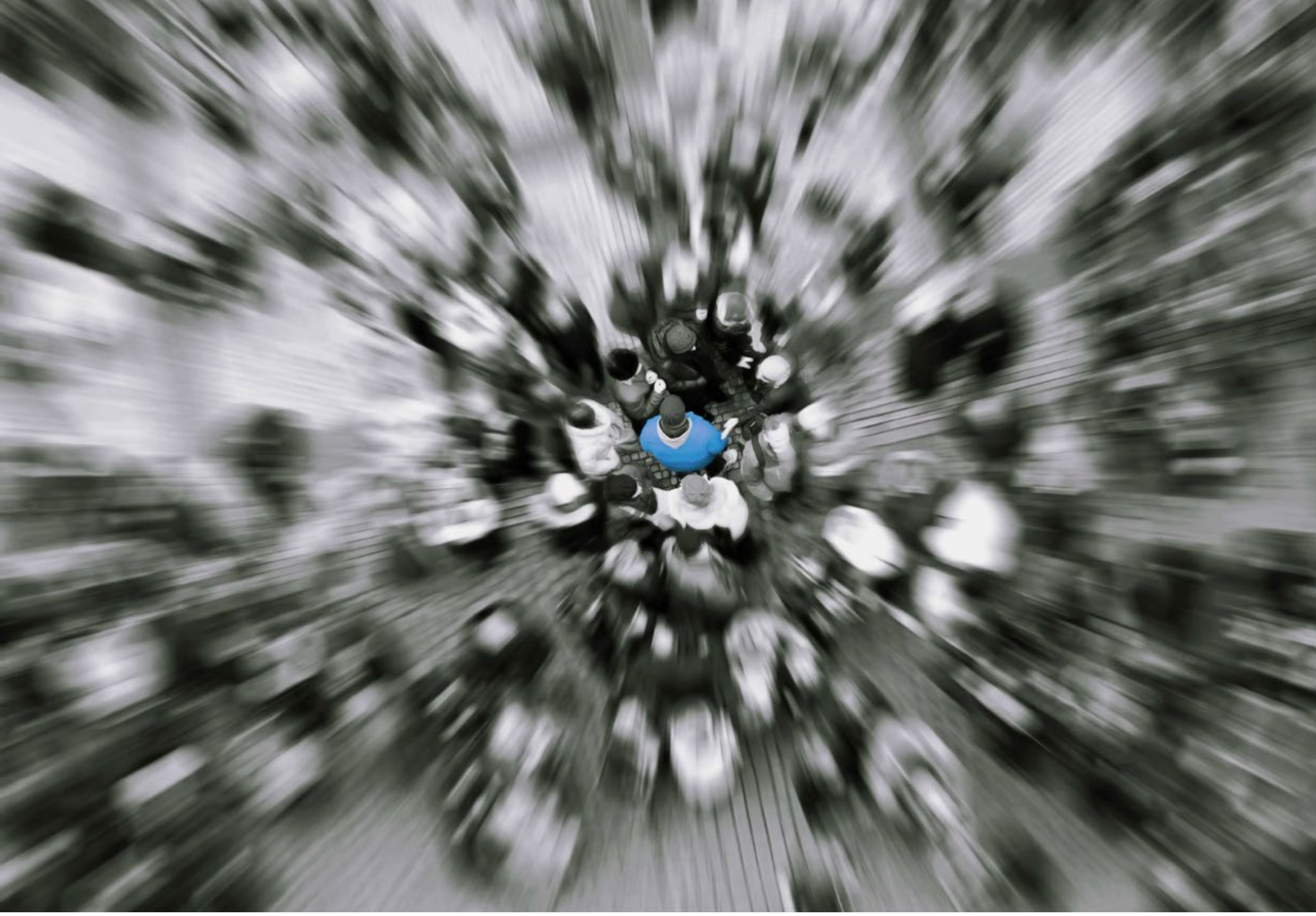
Appendix 1:
Participants

Participant information	Number
Gender	
Men	27
Women	21
Trans women	1
Non-binary	1
State	
Victoria	27
New South Wales	23
Age	
30-39	10
40-49	21
50-59	9
60-69	8
70-79	2
Type of treatment	
DAA treatment	19
Interferon-based treatment	9
Both DAA and interferon-based treatments	9
No treatment experience	13
Employment status	
Working or studying	15
Not working or studying	31
Retired	4

Participant information	Number
Education level	
Incomplete secondary	22
Complete secondary	12
Post-secondary	6
Tertiary	10
Cultural and ethnic background*	
Australian	32
Aboriginal Australian	5
New Zealander	2
North African and Middle Eastern	1
North American	1
North-West European	2
Southern and Eastern European	6
Southern and Central Asian	1
Sexuality	
Heterosexual	41
LGBQ+	9

* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.



Appendix 2:
Articles in press and under review

Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness.* https://doi.org/10.1111/1467-9566.13467

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.

La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the 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 and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world’s largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to ‘gamagoen yarrbat’ – to soar.

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Broadsheet No. 4

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Life after hepatitis C treatment:
Health, wellbeing and the future

LA TROBE UNIVERSITY
Australian Research Centre in Sex, Health and Society
UNSW SYDNEY
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VICTORIA State Government
VITAL voices

Life after hepatitis C treatment: Health, wellbeing and the future
(Broadsheet No. 4)

This broadsheet is the fourth in a series of four that summarise key project findings.

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Broadsheet No. 4

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Life after hepatitis C treatment:
Health, wellbeing
and the future

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit *Vital voices: Personal stories of treatment for hepatitis C*.

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Recommendations

This broadsheet is the fourth in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

Broadsheet No. 1: Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.

- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

Broadsheet No. 2: Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.

- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.

- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.

- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

Broadsheet No. 4: Life after hepatitis C treatment: Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.

- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme. This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA medication offers much shorter treatment durations (approximately eight to 12 weeks), far fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004).

While optimism surrounds the relative ease and simplicity of the new medications and the 'miracle' of cure (Rhodes & Lancaster, 2019), social research has complicated biomedical accounts of DAA success by drawing attention to the multiple meanings of hepatitis C cure and the complexities of post-cure life (Rhodes & Lancaster, 2019; Richmond et al., 2018). Madden et al. (2018), for example, contend that biomedical cure does not always meet the expectations or needs of people accessing treatment. As they argue, some of their participants felt let down by promises of a 'better life' following cure, and many desired further support for their liver health as well as information about liver health and ongoing risks after cure. Conversely, for other participants, experiences of cure extended beyond treatment and involved enhanced social connections and new perspectives on transmission risk (Madden et al., 2018). This broadsheet builds on and contributes to this growing literature by exploring experiences of life following treatment, including reflections on and concerns about life after cure.

Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

The project used a purposive data collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A$50 cash or an A$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment.

Summary of findings

The people interviewed for this project expressed a range of views about their health, wellbeing and vitality after hepatitis C treatment (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*). For some, treatment was a positive experience that led to feelings of optimism about the future and ongoing changes in how they managed their health and wellbeing. For others, treatment experiences did not have long-term significance, and hepatitis C was simply something they no longer considered relevant.

While treatment had cured them of hepatitis C, many participants in our project said that they had ongoing concerns about the impact of the virus on their health, and explained that they engaged in routine hepatitis C–related testing and monitoring. Some participants who inject drugs expressed concern about reinfection, and reported adapting their injecting practices to reduce this risk. Some discussed hepatitis C as one of several health issues they have continued to manage since treatment. Related to this, some said that post-treatment life could be improved by access to more support. A few people had such positive experiences of treatment that they engaged in informal and formal advocacy and peer work to improve treatment access and wellbeing for others (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*).

In the following sections, this broadsheet covers experiences of health and life in general after treatment, including how cure shapes perspectives on health and wellbeing. It also covers testing and support needs after treatment, and concerns about, and hopes and plans for, the future. It concludes with recommendations to improve support and care following hepatitis C treatment and cure.

Interview material from selected codes was carefully analysed by members of the research team to develop website content for this online resource. Topic sections for the website were developed in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed four broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the fourth of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience, for example, ‘Dave (male, 65, experience with both DAA and interferon-based treatment) said that the DAA treatment was “quite easy” to incorporate into everyday life.’ For more details about participants, see the demographics table in Appendix 1.

Looking after health and wellbeing

The people we interviewed for the project on which this broadsheet is based offered a range of different perspectives on what being cured of hepatitis C meant for their everyday lives. For some, their cure led to them having a greater focus on their health, often adopting practical strategies to look after it. For many, while welcome news, a hepatitis C cure addressed only one of a range of health issues that needed their attention. Several people said that following their cure, they started paying greater attention to their health and wellbeing. For many, this involved eating regularly and having a balanced diet, drinking less alcohol, exercising and seeing family and friends.

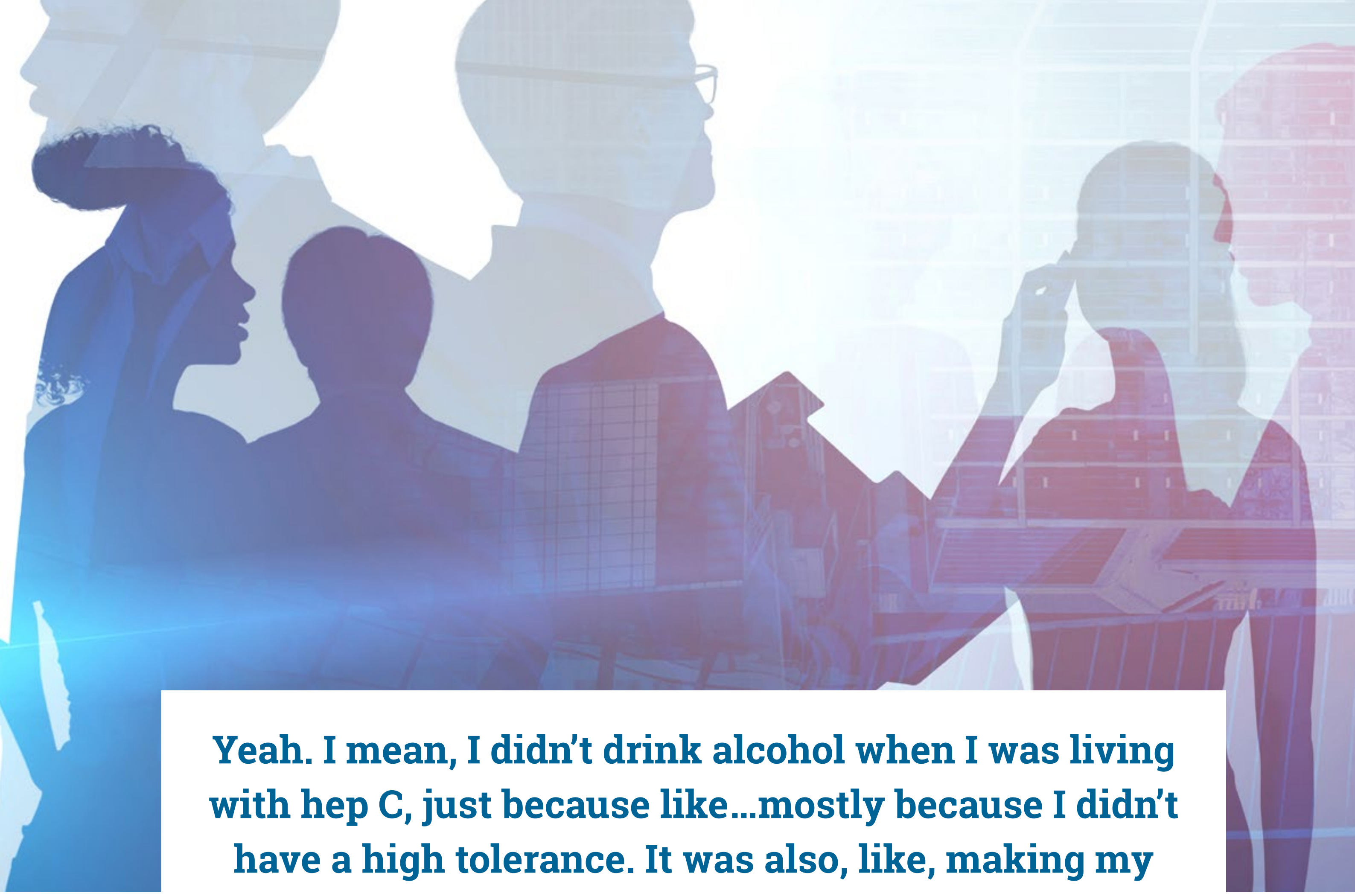
Following treatment, Sana (female, 71, experience with DAA treatment) described 'maintaining her diet' and avoiding 'salty, sugary and oily stuff'. Colin (male, 44, experience with both DAA and interferon-based treatment) said after being cured he had 'more energy […] and colour' and was 'heavily involved in yoga and exercise and [watching his] diet'. Rohan (non-binary, 38, experience with both DAA and interferon-based treatment) said that the break they took from drinking while living with hepatitis C helped them realise that it contributed to their anxiety. After their treatment, Rohan considered returning to drinking, but they decided to stop altogether.

> *Yeah. I mean, I didn't drink alcohol when I was living with hep C, just because like…mostly because I didn't have a high tolerance. It was also, like, making my liver, that was already under pressure, having to work, and, like, I got a really bad taste and kind of a bit of a reflux when I was drinking alcohol. So, when I [was cured of] it, I was like, 'Oh, cool. I can drink again now.' […] What I realised is that actually, like, alcohol causes me anxiety, yeah, and I always thought, like, when I was younger, I was, like, smoking cannabis and drinking and I was just, like […] 'Oh, it's the cannabis', and actually, no, cannabis doesn't give me anxiety, it's the alcohol. So, I just don't really drink, because I don't like the anxiety after it.*

Another common theme in our interviews was the need to continue managing other ongoing health issues after being cured of hepatitis C. For several participants, hepatitis C had been only one of a range of serious health issues they had to manage.

Dave (male, 65, experience with both DAA and interferon-based treatment) described concerns shared by several participants when he explained that he had other health conditions still needing treatment.

> *I do have an old back injury, but that's not going to change. It's being treated, I am living with it. I am doing physio for it, so yes, I need a hip replacement, but other than that, I am quite healthy. My dental health, my teeth are looked after quite well. I regularly see the*



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>
> ROHAN (NON-BINARY, 38, EXPERIENCE WITH BOTH DAA AND INTERFERON-BASED TREATMENT)

> *optometrist every two years and get an update for my glasses. I went through physio for my back and stuff, and I exercise quite regularly. I do my exercises reasonably regularly […] I look after my health. I don't drink a lot. I am not using IV drugs. I will have a joint at a party [but] I won't go looking for it. I am in the process of giving up smoking again.*

Carol (female, 58, repeat diagnoses, experience with DAA treatment) was cured of hepatitis C but described still needing to pay attention to her diabetes and diet.

> *I have a little bit of trouble in my legs, but […that's] part of being type 2 diabetes […] I still do what I was doing then [during treatment]. I try and walk, I've got a [dog], so we walk every day […] I still like to eat a little bit of… like, you've got to live, you know what I mean? There's no point in eating fruit and vegetables and being depressed because you would feel like you've got no quality of life […] It's just listening to your tummy and doing what's best without sort of going overboard. At the moment, we are carving out cheese. Like, I had a little run on cheese, and I find cheese with a high fat content, it's got to go. Milk chocolate's got to go.*

Participants varied in how they approached life after treatment, but many described paying greater attention to diet and exercise, and more generally prioritising their health and wellbeing. While treating hepatitis C was a priority for many, other persistent health issues were also a concern that required ongoing management and care following cure.

Testing and support after treatment

Most participants did not report ongoing liver problems or the need for regular tests for their liver health. However, for some, ongoing testing and support was a feature of everyday life following treatment. Some of these tests were due to long-term hepatitis C–related matters such as monitoring of liver health, including liver disease and cirrhosis. For others, regular blood tests were undertaken due to the ongoing risk of acquiring hepatitis C again.

Post-treatment healthcare was delivered through general practitioners, liver specialists, and other health professionals. Terence (male, 34, experience with DAA treatment) explained that his doctor encouraged him to have regular liver monitoring and gave him information about reinfection and support.

> *My doctor was very good with that stuff and encouraged me to get a liver function test at least every 12 months. Yeah, he gave me some information and, yeah, sort of invited me back anytime I needed any further assistance or information. [He said] that I could come back and then also sort of went through the whole, you know, 'Just because you've [been cured of] it, it doesn't mean that you can't catch it again' sort of thing. Like, [he said,] 'If you return to injecting drug practices or put yourself in other high-risk situations, yeah, you can still contract the virus. Like, the treatment doesn't give you any immunity to it.' So yeah, they were good in that aspect.*

In contrast, some participants described little testing after treatment. Chris (male, 60, experience with DAA treatment), for example, explained that he 'didn't really have any other [tests or follow-up]' after his cure was confirmed. He also explained that he had to initiate all follow-up tests related to his hepatitis C.

While tests confirmed that Lou's (female, 40, experience with DAA treatment) liver was healthy, she described wanting more information than she received about issues to consider after being cured.

> *I said, 'So what do I need to do from here? Do I see you again in a few years? What happens?' And he was just again, that dismissive, 'No, everything is fine, don't worry about it again, everything's fine.' […] Yeah, it would be helpful to know certainly about, you know, any signs or symptoms of anything changing. It would be helpful to know if, you know, if there were any screening programs that would be recommended to me. It would be helpful to know what is best practice in terms of, you know, the ongoing management of somebody who's had the illness for so long. I feel like I don't know much about that. I feel like all of that information is geared around, yeah, how to prevent yourself from getting it again through safe needle use, yeah.*

For some participants, blood-borne virus and liver testing and management of chronic health issues were ongoing features of post-cure life. Notably, for others, the support they received after treatment did not provide enough information about life and health after cure.

Reflections on life after hepatitis C

Reflecting on life after treatment

Of the people we interviewed, being cured of hepatitis C affected their lives in different ways. For some, being cured was a significant event connected to a range of other shifts in their lives. For others, cure was less significant, as many other aspects of their lives remained the same. Together these experiences indicated that while treatment is an important event for many, it addresses only one of a range of issues and concerns in life for people affected by hepatitis C.

Being cured of hepatitis C was 'life-changing' for Marty (male, 65, experience with both DAA and interferon-based treatment). He said he had a success story to tell others, and since completing treatment he had been doing formal advocacy work with a hepatitis advocacy organisation.

> *From that day when the virus was cured, that was life-changing, because I had a story to tell others of success […] I went to a federal inquiry into living with hepatitis [C] in Australia. After I told my story, a politician called Ken Wyatt[1] came straight over to me, shook my hand, gave me a hug, he's a Koori fella, [and] gave me his card […] Then, I went down to Canberra during this time. I saw Sussan Ley[2] personally. The Pharmaceutical Benefits Advisory Committee[3] came up to Sydney to see me, not to have a cup of tea or see her [Sussan Ley], to see me […] When you've got the Pharmaceutical [Benefits] Advisory Committee coming up from Canberra to see me, you know, there's a bit of ego there, but there's also a bit of authenticity for me, you know, like, 'Fuck! You know, these people are interested in me, you know, interested in my story.'*

Colin (male, 44, experience with both DAA and interferon-based treatment) explained that his life has changed significantly since being cured of hepatitis C. For him, being cured meant he felt able to pursue an intimate relationship, and it was also connected to a range of other positive changes in his life.

> *I hadn't had any intimate partners for a long time, because I lost a partner when I was 20 and wasn't in a relationship, actually, had nothing for about 18 years, you know. And then with the hep C, I just thought I was just dirty, you know what I mean, and it was too much of a risk. Like, I had it in my head [that] it was too risky, and stuff like this or whatever, to transmit it on to a partner, and no-one deserves that sort of thing, you know. Getting it off your back, like, I guess as far as intimate partners [go], like, I need connection in my life with someone, you know. I need to share my life with someone, and that made that hell of a lot easier to, I guess, go and pursue that. And I think my family have only been back in my life probably four or five years, you know, and they have definitely… like, they have seen the change and the effort that I put in, you know what I mean. I have worked incredibly hard to get to where I am at.*

Since completing treatment, Dave's (male, 65, experience with both DAA and interferon-based treatment) life has changed in several significant ways. He spoke about getting involved in a campaign promoting hepatitis C treatment, but also said that he continued to face other health issues.

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[1] Ken Wyatt is a former assistant minister for health in the Australian Government.

[2] Sussan Ley is a former minister for health in the Australian Government.

[3] The Pharmaceutical Benefits Advisory Committee is an independent expert body providing advice to the Australian Government about which drugs and medicinal products should be listed on the Pharmaceutical Benefits Scheme and subsidised by the government.

> *I have made a lot of connections with people who I'd never thought would [meet] in my life, and a lot of that has come through working [on a campaign to increase treatment uptake]. I am meeting politicians […] I am talking to people about sort of expanding drug treatment facilities. I am a team leader of a group of people with lived experience who are part of the campaign. I am also co-editor of […] a newsletter [for a service… I also edit a […] Facebook page [on treatment]. None of that would happen if I hadn't stopped using [drugs], and none of that would have happened if I hadn't sort of [been] cured [of] hepatitis C […] Yeah, getting rid of hep C and putting down the IV drug use has greatly changed my life […] I realised how old I am, you know. There is not another 50 or 60 years in front of me. I am sort of going to have to accept that, you know, and my body is sort of breaking down. I am going to need another hip replacement in a few years' time, on the other hip. I have a back injury […] I crushed a lot of vertebrae in my back, but I can work around that sort of stuff, you know […] My life has changed completely.*

Terence (male, 34, experience with DAA treatment) explained that while being cured had a positive impact, it occurred at the same time as a series of other positive shifts in his life.

> *I suppose emotionally I felt better [once I was cured]. Physically, I would probably say yes, that [the cure] contributed [positively], but I was going through a lot of changes in lifestyle as well at the time. Yeah, when I [was cured of] the virus, that was a huge emotional baggage lifted from my shoulders [… I also] probably just start[ed] to make better choices in life. Yeah, that's about it really […] I decided to go and study instead of work. Typically, I'd worked in the meat industry and labouring and stuff like that, so yeah, it was pretty big for me. I didn't really go to high school, probably got a Year 7 education, and I decided around that time in my life that education was something that I wanted to pursue, so yeah, I signed up for a course at university.*

In contrast, Sean (male, 42, repeat diagnoses, experience with DAA treatment) said his life had not improved a great deal since being cured of hepatitis C.

> *[My life hasn't changed], not because of not having hep C, no […] My life isn't that great, and I couldn't give two shits whether I have it or not, you know. Yeah, I've got a pretty bleak outlook, you know […] I've just got a lot of stuff going on. You know, [my ex-partner], she's my wife, I'm married to her, and I don't even know where she is […] No idea where she is. I just know that she's a mess and I can't find her.*

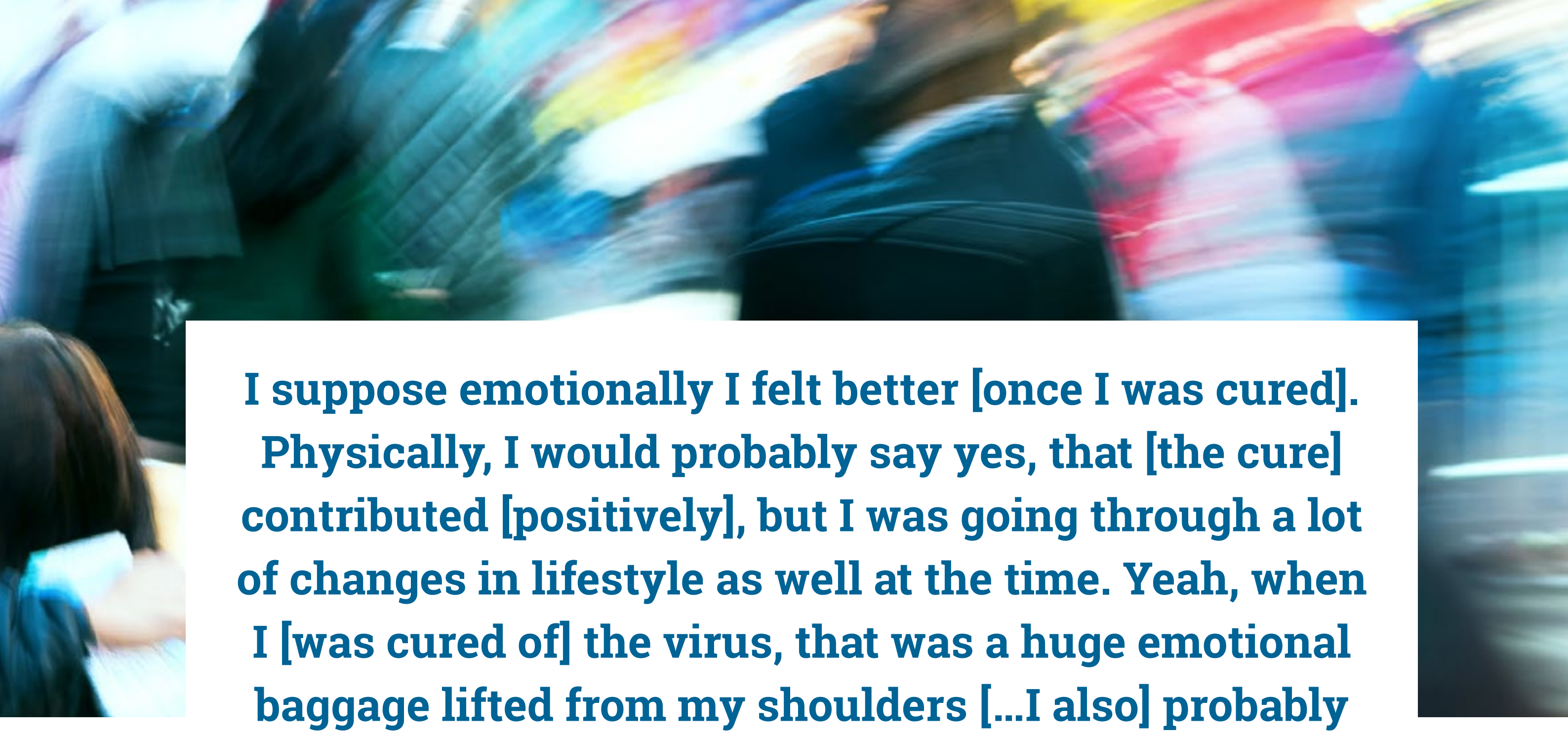
While Gracie (female, 65, experience with DAA treatment) said that her life had not changed dramatically since completing treatment, she was glad to be cured of hepatitis C and felt relatively content.

> *I struggled with hep C for 20 years, and miraculously the new medication worked with me, but I struggled sometimes in those 20 years, especially when I was thinking about entering sexual relationships and stuff about disclosure and whatever […] There's nothing I really want to do that hep C… if I was a young woman and sexually active, this would've been a massive improvement in my life, but I'm not, I don't care, and everything's cool.*

Kylie (female, 46, experience with DAA treatment) said that while being cured of hepatitis C made her 'happier', she still faced drug use–related discrimination due to her appearance and residence.

> *It's funny, I've always been skinny but I'm a lot skinnier now, because I can't have a lot of weight on my legs because of injuries [from a car accident] and, like, my son's friends say to him – I don't even look like I take drugs – but they say to him, 'Oh, your mum is still on drugs, she's so skinny' […] It's upsetting a little bit, like, that he has to deal with things like that, but he said it comes with the fact that as soon as you say you are in the housing commission house, everyone is supposed to be on drugs in [a] housing commission house, which is bullshit.*

Our findings show that the effects of hepatitis C cure emerged differently for people depending on life circumstances, how long they had been living with hepatitis C, the concerns they dealt with in their lives and the challenges of stigma and discrimination. For some, cure was a significant event connected to an improved sense of self, confidence and optimism about the future. For others, it was less significant, because stigma, discrimination and material concerns were still present and requiring management. While treatment was significant for many people we interviewed, it does not address all the issues and concerns experienced by people affected by hepatitis C.



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TERENCE (MALE, 34, EXPERIENCE WITH DAA TREATMENT)

Reflections on life after hepatitis C

Concerns about the future

Many of those we interviewed described the ways their experiences with hepatitis C and treatment shaped their thoughts about the future. As noted, several participants explained that while they had been cured of hepatitis C, they had ongoing concerns about their health. Offering a different perspective, some people interviewed said that hepatitis C was not an ongoing concern and that they rarely thought about it any more.

While being cured of hepatitis C was a positive experience for many, for some participants, such as Regina (female, 69, experience with DAA treatment), the long-term health effects of hepatitis C remained a concern.

> *Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't dying but, of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something. There's always that slight worry, but I try not to worry […] I think I've got cirrhosis, if I remember, a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink. Not that I was a big drinker, but I've not had a drink of alcohol since.*

Others worried that cure was only temporary or incomplete, and that hepatitis C might affect them again. Some said that they worried the virus might re-emerge in their bodies or 'come back' spontaneously, while others thought about reinfection because they injected drugs.

According to Chris (male, 60, experience with DAA treatment), since finishing treatment he had been more 'careful' in how he managed his injecting, to minimise the risk of reinfection and to look after his health.

> *So, I think when you are in your twenties, when you're young, you think you are invincible. You have lots of energy, nothing is going to be a problem, you just take risks. You don't even know. But with the training I have had from my job and the life experience, I am going to be much more careful, and I don't want [my injecting] to be [a] compuls[ion] or an anxiety, but I do want it to be a safe practice. [I want to maintain] clean living and clean health and clean practices around risky things like taking drugs.*

For some participants, the experience of undergoing treatment for hepatitis C produced uncertainty and concern about the virus returning, and about ongoing health effects. For others, it meant hepatitis C was no longer an issue or part of their lives.

Conclusion and recommendations

The experiences and perspectives reported here suggest that while hepatitis C cure is important, a range of issues and support needs persist and must be addressed to allow for improvements in life in general after treatment.

Our data indicate that many participants still actively engage with the legacy of hepatitis C by managing their health, diet and wellbeing, and for some, by adjusting injecting and hygiene practices to minimise the risk of reinfection. While most participants did not report ongoing liver or health problems following cure, some did have concerns and support needs that were not adequately addressed by health professionals.

For some of our participants, treatment was not considered significant or life-changing but was nonetheless associated with positive changes in health, employment and social relationships. For others, especially those who had lived with the virus for a longer period, concerns lingered about its impact on their health or its potential to return in the future.

Key recommendations based on these findings

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

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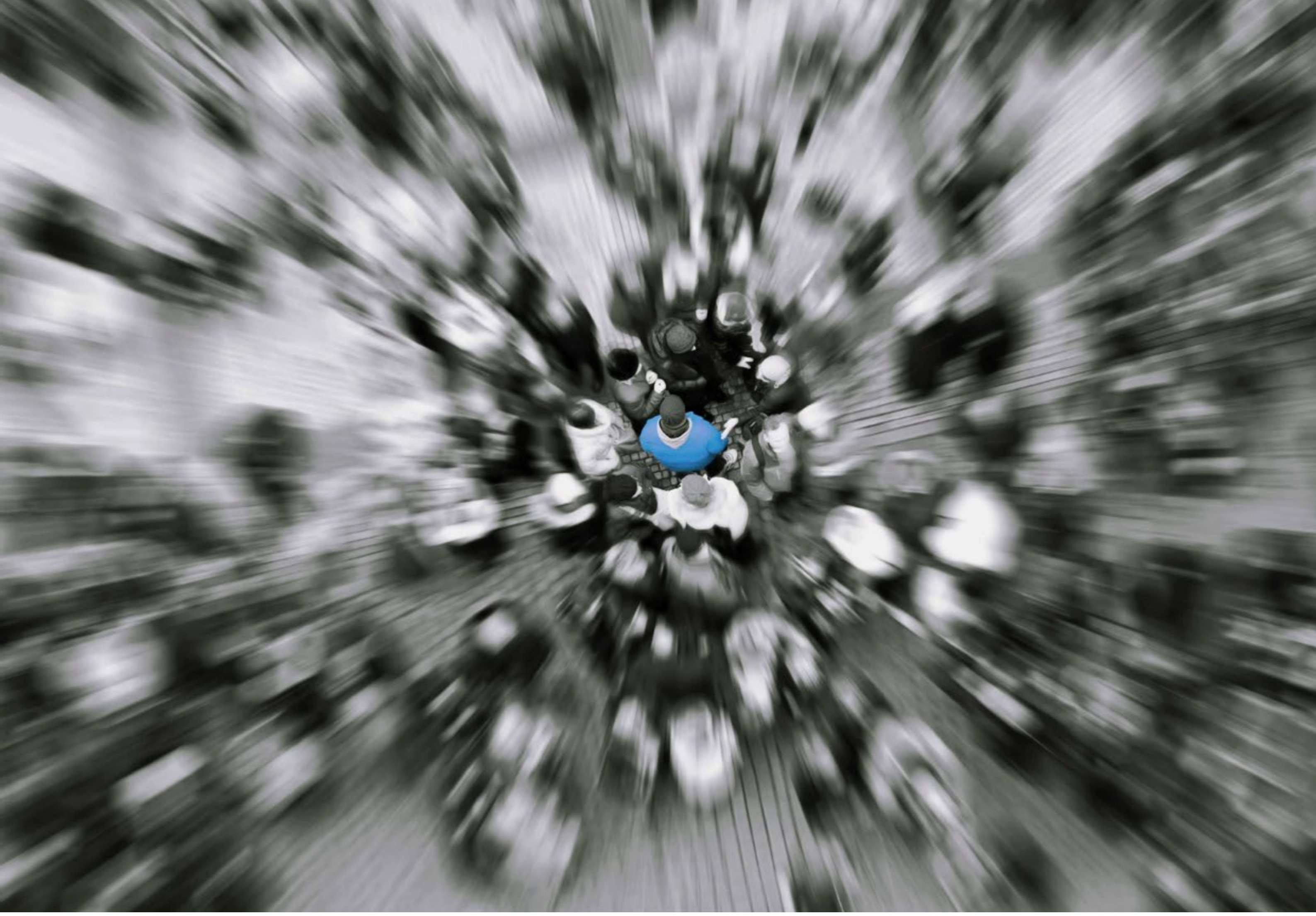
Appendix 1:
Participants

Participant information	Number
Gender	
Men	27
Women	21
Trans women	1
Non-binary	1
State	
Victoria	27
New South Wales	23
Age	
30-39	10
40-49	21
50-59	9
60-69	8
70-79	2
Type of treatment	
DAA treatment	19
Interferon-based treatment	9
Both DAA and interferon-based treatments	9
No treatment experience	13
Employment status	
Working or studying	15
Not working or studying	31
Retired	4

Participant information	Number
Education level	
Incomplete secondary	22
Complete secondary	12
Post-secondary	6
Tertiary	10
Cultural and ethnic background*	
Australian	32
Aboriginal Australian	5
New Zealander	2
North African and Middle Eastern	1
North American	1
North-West European	2
Southern and Eastern European	6
Southern and Central Asian	1
Sexuality	
Heterosexual	41
LGBQ+	9

* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.



Appendix 2:
Articles in press and under review

Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness.* https://doi.org/10.1111/1467-9566.13467

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.

La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the 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 and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world’s largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to ‘gamagoen yarrbat’ – to soar.

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