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.

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

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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.*

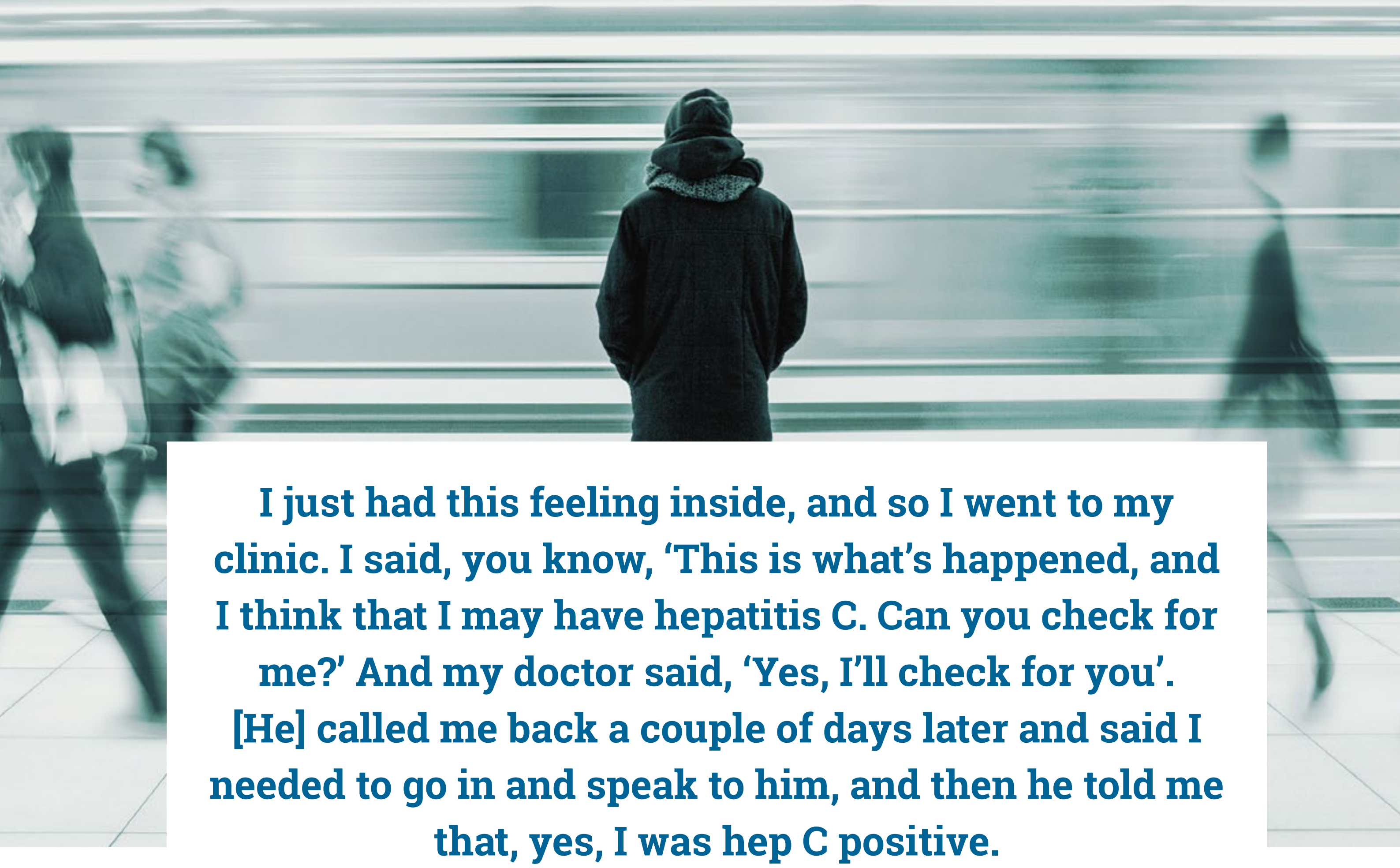
Some people had been tested at the request of others in their lives, such as intimate partners. Gracie (female, 65, experience with DAA treatment), for example, found out she had hepatitis C after a new partner asked her to have a test for HIV. She recalled thinking it was just a formality and being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

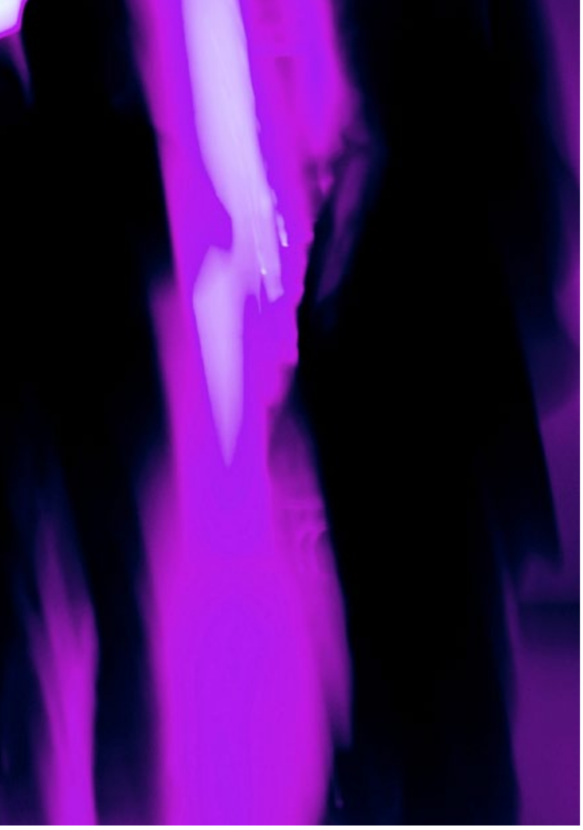
Many participants discussed the connection between hepatitis C and injecting drug consumption. Some of those who did not acquire hepatitis C through injecting said that it was important to them to explain this to others.

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

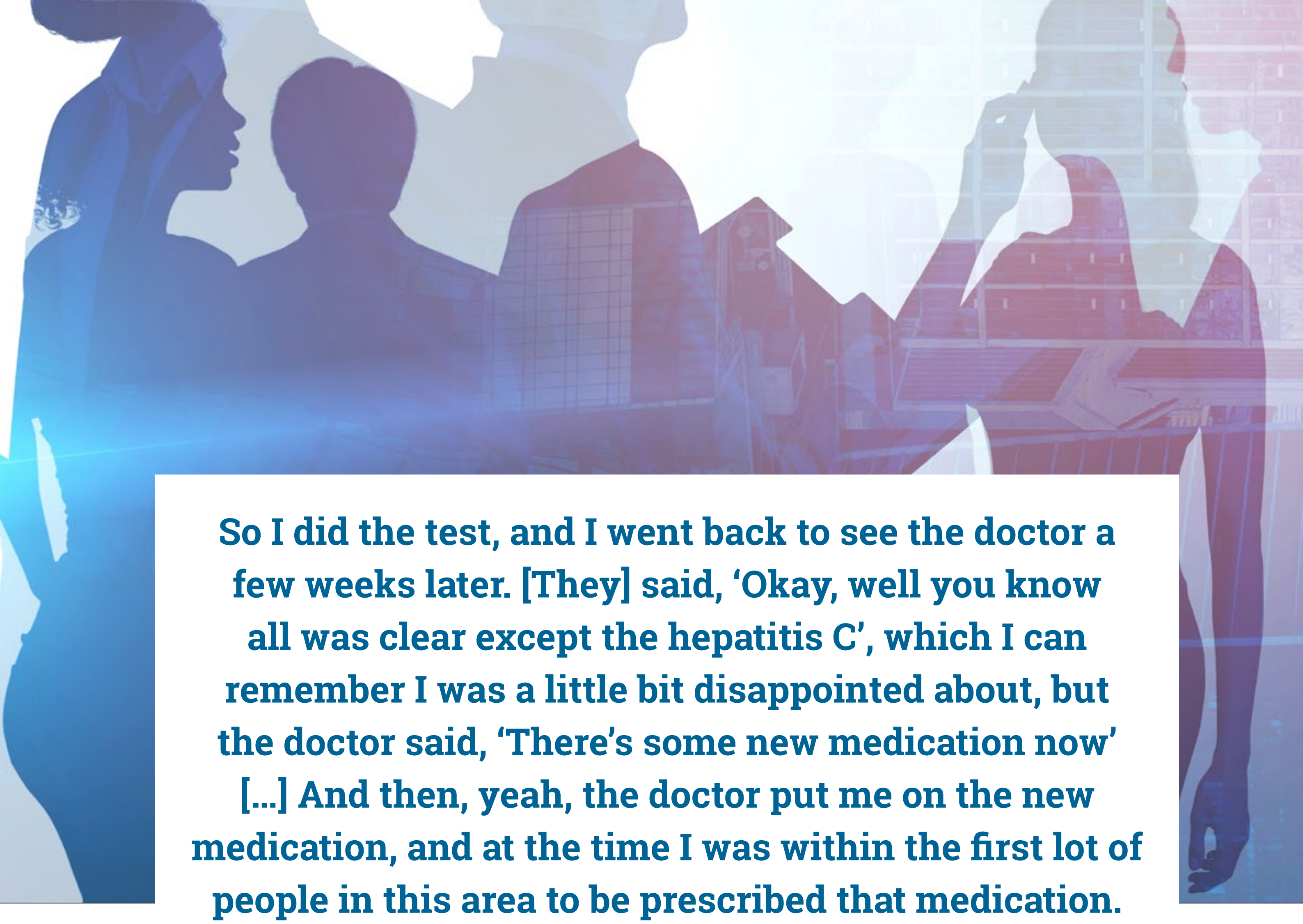
The people who participated in this research described receiving different kinds of advice from health professionals at the time of their diagnosis. For some participants, the advice was helpful, while others said they would have preferred to receive more information or different kinds of information.

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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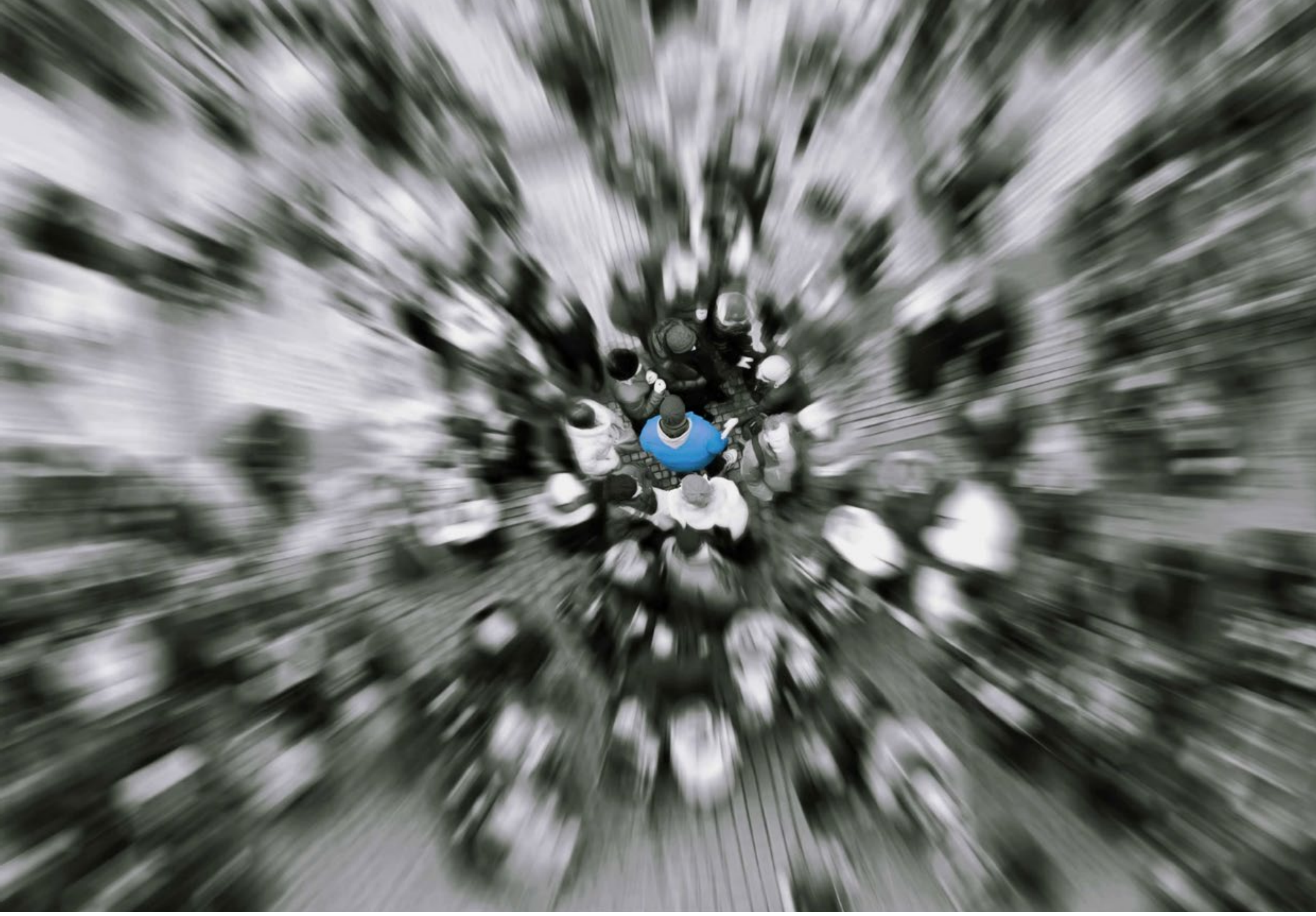
Appendix 1: Participants

Participant information	Number
Gender	
Men	27
Women	21
Trans women	1
Non-binary	1
State	
Victoria	31
New South Wales	29
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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