ARCSHS World Hepatitis Day 2022 podcast

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# Speakers

Renae Fomiatti, Sean Mulcahy, Dion Kagan, Kate Seear, Adrian Farrugia, Emily Lenton, Carrie Fowlie

## Kate Seear 00:00

This podcast is being recorded on the lands of the Wurundjeri and Ngunnawal peoples. We acknowledge that Aboriginal and Torres Strait Islander people remain strong in their enduring connections to land, water and culture and pay our respects to elders past and present.

So hello, everybody and welcome to this special podcast to mark World Hepatitis Day 2022. My name is Kate Seear. I'm an Associate Professor and an Australian Research Council Future Fellow based in the Australian Research Centre for Sex, Health and Society or 'ARCSHS', which is based at La Trobe University. I'm also the leader of the Gender Law and Drugs (GLaD) program based at ARCSHS. In this podcast, I'm going to be joined by a number of researchers from our centre to showcase some important findings from major projects we've conducted recently. And we're also delighted to be joined by the CEO of Hepatitis Australia, Carrie Fowlie, who's going to offer us her perspectives and reflections as well.

So the theme of this year's World Hepatitis Day is 'hepatitis can't wait'. This theme is designed to draw our attention to the urgency of efforts to eliminate hepatitis across the world. But as you'll hear in this podcast today, our efforts to eliminate hepatitis by for example, rolling out new treatments that can cure the virus, can't be separated out from other challenges with which the virus is entangled. And that includes things such as stigma, and discrimination. To kick things off, I want to now invite Dr. Dion Kagan and Carrie Fowlie to join the discussion. Dion is a Project Officer in the Gender Law and Drugs Program at ARCSHS, and he's going to guide you through our discussion today. And as I've already mentioned, Carrie Fowlie is the CEO of Hepatitis Australia, which is Australia's peak community organisation, for representing and addressing issues of importance for people who are affected by hepatitis B and C. So welcome, Dion and Carrie.

## Carrie Fowlie 02:11

Oh, hello, lovely to be here.

## Dion Kagan 02:14

Likewise, thanks so much, Kate. So Carrie, thank you, again, for joining us today. I wanted to start off just by asking you about the theme of this year's World Hepatitis Day. So this year's theme is 'hepatitis can't wait'. And I wondered what this means to you, and to Hepatitis Australia. And second to that, if you could tell us a little bit about some of the big issues currently facing Hepatitis Australia and other people and organisations in the sector.

## Carrie Fowlie 02:47

Oh, thank you, I'm so happy to be here, and to speak to a World Hepatitis Day. So it's 2022. And we're about eight years from 2030. And so that's a pretty big day, because that's when Australia is committed to achieve elimination of hepatitis B and hep C. But guess what, we're not on track to meet those targets. So we've got about 335,000 people in Australia living with hepatitis B, or C, and many more thousands who have lived experience, for example, of hepatitis C, who may have been cured of hepatitis C, but continue to experience some of the risks that go with it, for example, risk of ongoing liver disease or cancer. So the hepatitis C, are there, the 'hep can't wait' theme is a real call to action about how can we accelerate our elimination efforts. And it kind of causes us as well to reflect on some of the challenges that have emerged through COVID. So for example, we know that about 200,000, fewer people have received screening for hepatitis since COVID started in Australia. And so we already were not quite on track on some of our things, and then COVID's impacting and we're falling further behind. So that's kind of one component to it, I guess, kind of intersections that are happening. But another big part of it relates to social justice and equity, and the lack of action and focus, that we need to have to be able to achieve the goals and it's really hard to talk about 'hep can't wait' and elimination without taking head on issues about racism, issues about classism, and how those underpin some of the inaction that we've had to date. Because I guess we see quite an unequal distribution of outcomes related to hepatitis C across the community. And this inequity, we see across multiple fronts: it might be socio-economic, it might be geographic, it might be through a whole range of factors. So that's I guess one critical kind of thing is to think about what kind of systems and structures we might need to change in order to achieve our goals. And so one of the questions you asked was like, what are the kind of big issues and stuff. So one of the things that were that's really important, in particular, in terms of hepatitis C is to talk about prisons as a setting. And so we've got this terrible situation in Australia with the hyper-incarceration of Aboriginal and Torres Strait Islander people. And prisons are becoming \*the\* primary setting for transmission of hepatitis C in Australia. And so we've got two kind of key things here: one about ensuring people regardless of setting and where they are, have access to care; but also needing to take on the challenge of communities that are hyper incarcerated and preventing people from going into prisons in the first place. So that's part of it. And we can't achieve elimination without dealing with these structural issues. So there's a big part of that, I guess, for us, that's really important to talk about about equity, because one of the whole parts about the elimination goals and the UNSDGs is about leaving nobody behind. And so we're really encouraging people to think about, I guess, when we say 'elimination', maybe to start from there: who's currently being left behind? And how might we restructure our responses to start from that point?

## Dion Kagan 06:47

Cool. Thank you so much, Carrie. And we're going to call on you again towards the end for some more thoughts. But now, I wanted to next introduce my colleague, Adrian Farrugia, who's a Research Fellow in the Drugs, Gender and Sexuality program at ARCSHS, and a researcher in people's experiences of hepatitis C and treatment, among other things. Hi, Adrian. [Hi Dion] Adrian, you've been part of a major project funded by the Australian Research Council, which focuses on people's experiences of hepatitis C and treatment. The project has a website too as one of its outputs, which our listeners can access. It's called VitalVoicesonHepC.org. And yeah, I was just wondering if you could tell us a bit about the findings from that project, and also a little bit about how they informed the experiences that are collected on the Vital Voices website.

## Adrian Farrugia 07:47

Yeah, sure. Thanks. Thanks so much, Dion. I might just start briefly with the website. So Vital Voices comes out of this project, as was mentioned, where we interviewed 50 people affected by hepatitis C living in Victoria and New South Wales. And so what we did is we collected these stories and put them together on this website, which consists of two main sections. So the first is detailed individual personal narratives from each participant where they describe their particular experience of hep C. So this might, you know, be maybe the moment of diagnosis, life with hep C, treatment and for many of people that we interviewed cure, and life after hep C as well. And then the second sort of substantive part of the website is a series of sections that are that are based around a specific topic, that was a concern for a lot of people and research. So for example, there's a topic on the perspectives on these new treatments for hep C, or there's a topic on making the decision to have treatment, the kinds of things that come together to make those decisions. And so the idea behind having these two sections is to allow visitors to kind of explore people's individual stories in detail and really get a sense of that person's full story and how it relates to the other parts of their life, and see how it kind of played out for them. As well as getting a sort of a sense of the broader issues and being able to see the kind of the range of issues and concerns that many of the people in the research shed. So the idea is you get the very specific personal accounts, as well as the broader kind of issues that a lot of people kind of share and talk about in the interviews that we that we did. And yeah, so these these stories, as I mentioned, come from this, this broader project, which had a range of sort of findings and outcomes separate to the website, and as you said that the findings are then kind of we'll use to inform the website. So just briefly, I guess would say that, you know, overall, the research really an idea sort of emphasises the diversity and complexity of experiences and hepatitis C in Australia. For example, for some people being diagnosed with hepatitis C provoked feelings of suprise and uncertainty about the future. But for other people, it was actually not such a major concern, at least at that time. And they thought about it something that they'll have to deal with later down the track - perhaps they have other things going on that just met this diagnosis wasn't such a pivotal event at that moment. You know, our participants also really emphasise the importance of family relationships and other close kind of social networks in in in sort of shaping how they make decisions about treatment, as well as about the variety of responses to disclosure to sort of talking to other people about having hep C or having had it in the past. And these really varied from helpful and supportive responses also to negative and sometimes stigmatising ones. Yeah, and, you know, I think it's important to really emphasise as well, that a lot of the people that we spoke to had had experience of the new treatments that are available and many of them describe them positively often using words like 'gentle' or 'fantastic' to kind of describe their experience. However, some of the people we interviewed also described wanting more detailed information about hepatitis C from the professionals managing their treatment. So while they may have had a positive experience, overall, they spoke about, you know, it would have been great to just have a little bit more information, maybe a bit more information about life after hep C - if there's any health concerns they need to be aware of, and that kind of thing. So I guess, overall, what the websites doing and what this research has done to is kind of emphasising that this health-related decisions for the people that we spoke to him, you know, and hepatitis C related decisions, they really make sense within when understood within the context of these individuals whole lives, and seeing that the range of kind of issues and concerns that people have that shape their experiences of hep C and health often reflect the issues and concerns that people just have outside of this kind of concern, or this particular issue.

## Dion Kagan 12:00

And I guess with the website you really get a sense of how those things are embedded, and sort of inform one another. Thanks so much for sharing those findings, Adrian. I just wanted to ask you a final question about that, which is just to sort of explain a little bit further the decision that your team made to develop those research findings into a website. Why? Yeah, what motivated that?

## Adrian Farrugia 12:28

Yeah, I mean, I guess there's a range of things that were kind of on the research teams' mind. I mean, one of the things kind of goes back to what Carrie was saying before - we're in a really important time for hepatitis C in Australia. So we have these elimination goals, but there's also a whole range of thing's shaping the uptake of treatment that make those goals, while ambitious and important, they can make them difficult to achieve. So, really wanted to, we saw this as a very important time to sort of conduct this research. And it's, you know, having the Vital Voices specifically, I mean, it's just, it's quite rare to have these kinds of public resources made available to just you know, anyone, especially, you know, healthcare providers, or people with personal experiences of hep C, or people who know other people with hep C, and to be able to encounter findings, research findings in this way. [Yeah] And we wanted to just make it as available as possible. So, you know, the visitors to the website, VitalVoicesonHepC.org we really want them to get a kind of nuanced and in-depth understanding of the participant of the sort of the perspectives of the people that we interviewed. And we hope it could be useful for people thinking about treatment themselves, or maybe just interested in the issue more broadly.

## Dion Kagan 13:45

Great. Thank you so much, Adrian. And if people listening to this conversation want to check out your team's website, its URL is all one word, 'VitalVoicesonHepC.org'. So next I want to introduce my colleague Dr. Rene Fomiatti, who is a Research Fellow in the School of Humanities and Social Sciences at Deakin University, and also an Adjunct Research fellow at ARCSHS. Hi, Renae. [Hi, Dion. Nice to see you!]. Yeah, likewise. Renae, the past couple of years, you know, we've been living through extraordinary times with the COVID-19 pandemic. And one thing that's unfolded is that the nature and delivery of healthcare has really, really dramatically and rapidly transformed, including through the advent of telehealth, which a lot of people listening, you know, might have experienced themselves. You recently worked on a project funded by the Department of the Australian Department of Health, looking at telehealth but in the context of delivering care for hepatitis C. I was just wondering, can you tell us a little bit about what you found in that project?

## Renae Fomiatti 15:05

I can. That project was led by Professor Suzanne Fraser. And a lot of the work was done by Dr. Frances Shaw, whose taken up another role now, but I just wanted to acknowledge her work in this project. But what we did during, I think 2021 - the years all kind of blur, have blurred together now with COVID. But I had to double check and I think it was during 2021. We conducted qualitative interviews or qualitative study investigating patients and healthcare practitioners experiences of telehealth for hepatitis C care during the COVID-19 pandemic. So, we conducted um, semi semi-structured interviews with about 20 I think it was 25 healthcare practitioners and 15 patients or people who access hepatitis C care during this period. And one of them was fundamental, and I suppose it's a bit unsurprising, but still important thing I think that we found is that most people found telehealth for hepatitis C treatment very convenient. You know, perhaps unsurprising, but still good to have, you know, to have written down because it wasn't available before unless you're in a rural setting. So people did find it really convenient. But while people were really positive about their experiences, they did describe needing to manage telehealth appointments among other responsibilities and across different settings, like at homes where family and children might be present or in the workplace when they were working. And that sometimes resulted in challenges with managing privacy and confidentiality. Another thing we found is that while hepatitis C was seen as straightforward enough to be well-suited to telehealth, some participants preferred in person care for more complex health issues. I think people were concerned about the ability of healthcare practitioners to provide examination or diagnosis when necessarily when, when necessary. Obviously, it's a bit harder when you're speaking through a computer screen, as we are now. [Yeah] But overall, I'd say we found that while telehealth was really accessible and convenient, it could really shape the quality of the practitioner patient relationship. So for example, both patients and healthcare providers describe shorter consultations with fewer, I suppose you'd call them social niceties, or there was also less room for addressing other health issues during telehealth and everyone. So healthcare practitioners and patients both tended to agree that relationships were easier to develop and maintain if they were already, to some degree, established by a previous in-person interaction or relationship. So that's a kind of brief summary of some of the things that we've been.

## Dion Kagan 17:38

Yeah, and I'm sure like with all of these projects we're talking about today, there's so much more detail. And I mean, that's, that's really interesting. And obviously, telehealth, among other things that we've experienced over the past couple of unusual years are here to stay. So I'm wondering, based on what you found, in that research project, did the project make any specific recommendations for the future of hep C? In telehealth.

## Renae Fomiatti 18:05

made several recommendations and I checked, we made 15, in fact, so hopefully anyone listening might have a look at the report we produced, which I think is available through the La Trobe University or ARCSHS website. But one of the key recommendations is that the temporary MBS telehealth items made available to health care professional professionals during the early peak of the COVID-19 pandemic should be made permanent to enhance access to hepatitis C treatment. And I know that's an ongoing arrangements this year, but I don't know if they have actually been made permanent beyond this year. But that was one of the key recommendations. You know, patients really benefit from ongoing access to telehealth, and so we also recommended that the option of video consultation should be provided where possible, because a lot of telehealth does or you know happens over a quick phone call. We also recommended that a telehealth care model for hepatitis C treatment should be embedded wherever possible in pre-existing healthcare relationships to support trust, communication and a really positive experience of healthcare for patients. And in the absence of a pre-existing relationship or an initial face-to-face appointment. And we recommended that MBS telephone items should support longer consultation times to improve patient's comfort and engagement and understanding treatment. I don't know if anyone else has experienced telehealth appointments, I'm sure we all have now that they can just kind of happen in a, you know, in an instant. So I think having those like longer times for kind of more complex issue or treatment trajectory like hepatitis C and hepatitis C care is important. But I might leave it there because there are 15 recommendations, as I said, but yeah, I really encourage anyone listening to read the full list or to have to check out the report.

## Dion Kagan 19:45

Yeah, it's a really fascinating project. And I think, you know, having, you know many of us experience telehealth now we can sort of relate to the potential complexities of it. So, thank you so much, Renae. I now want to introduce another colleague of mine Emily Lenton, who's a Project Officer at ARCSHS. Hi, Emily [Hi Dion]. Emily, you've been working across a number of projects on hepatitis C, at the moment and over the years, including another major Australian Research Council funded project that explores people's lives after treatment. And I should say that actually, we work together on this project. So this is my question for you: Since we now have access to much more tolerable and effective treatment for hepatitis C, there's understandably been a lot of attention paid to diagnosing and treating people. But what about care for people after treatment? And that's, that's what the project's been investigating. So I know there's a lot to say here. But what are some of the things the project has found out about people's post-cure lives and needs?

## Emily Lenton 20:58

Yeah, no, thanks, Dion. And I should say that we've only just concluded the interviews with people who have cleared hepatitis C, with the direct-acting antivirals across Victoria and New South Wales and Queensland, and we spoke to 30 people. But really, one of the things that really stands out is that they told us they can just been an immense lifting of the psychological burden, as well as physical and health benefits. So for example, as we know it, often people with hepatitis C live with a persistent concern that they might infect others, including their partners, children, family members, or co-workers. So upon clearing the virus, they really can experience it in a more enormous relief from the worry of being infectious. Another thing that really stood out among the the interviews and the stories that we've heard so far is that many people report feeling extremely grateful and lucky that the Australian government has invested in and taking these bold steps in making the direct-acting antivirals universally available. And so many people with hepatitis C, as Carrie's also already mentioned, have already experienced poor and inadequate access to some of the most basic forms of health care and experience, and the experience to access to these government subsidised curative treatments can be really gamechanging for individuals, and can spark shifts in their lives that enable them to do a range of other beneficial things for their health, their wellbeing and social connectedness. One of the other things that's really stood out in the data is that the shift from treating people in tertiary settings to community and primary primary health settings has meant that obviously much people have gotten much wider access to treatment. And people are being cured in settings that they trust and having existing relationships with. We also have interviewed 30 people across Australiap who work with people who were affected by hepatitis C in community, service, policy, and advocacy roles, including people that lived and living experience. Both groups told us about their post-cure life can be more complicated for people who remain at ongoing risk of infection, especially for those who have experienced imprisonment.

## Dion Kagan 23:29

And just on on the theme of those ongoing complexities, are there ways in which people who have been through successful treatments, that have cleared their hep C are, you know, still affected by having had hep C in the past?

## Emily Lenton 23:45

You there has been a number of different issues that have come up. And I think you know, that, that given the highest incidence of people with hepatitis C are people who have experienced injecting drugs, there remains a significant stigma and disapproval of drug injecting in the community more widely. And while DAA treatments can cure the hepatitis C but on their own, they can't cure the stigma associated with the virus. So for people with past or present experience of drug injecting everyday experiences of stigma and discrimination, including inadequate access to basic healthcare and welfare needs, may be ongoing after cure. And discrimination against people who have injected drugs can happen in employment settings, legal settings, in education and beyond. However, medical and healthcare setting remain the most commonly reported places this occurs. [Yeah, yeah]. And what our particular problem that has come up again and again in the interviews is the presence and ongoing recording of people's past hepatitis C status in medical records. And our interviews have found that this can affect the quality of care for people in their post-cure lives. And an example of this is in access to proper and adequate pain medication for people who may have had past hepatitis C status on their medical records. And a final example I'd like to share and to talk about is just a very specific example of where hepatitis C can continue to affect people post-cure is in medical and pathology settings where the presence of hepatitis C antibodies comes up in the blood test. So although new treatments can cure hepatitis C, the hepatitis C antibodies remain detectable in the blood of people who have had who have had the virus and often the presence is misunderstood or it's misinterpreted, and can mean that people are often incorrectly informed that they have hepatitis C when they in fact they don't, as well as continue to experience hepatitis C-related stigma and discrimination.

## Dion Kagan 25:53

Mmm. Thanks. Thanks so much for sharing those insights from that work on post-cure life, Emily. I think, much like Adrian's project, people's experiences are incredibly diverse, so you know, but it's great to draw out some of the common themes and think about some of the ways that they might get addressed. So on the same project, I wanted to introduce another co-researcher, my colleague Dr. Sean Mulcahy, who is a Research Officer at ARCSHS in the Gender Law and Drugs program and has also been working on the post-cure lives research project, but with a focus on legal aspects. Hello, Shaun. [Hi Dion] Hi, thanks for tuning in from the UK for this conversation. Sean, I wanted to ask you this question about how the law might shape people's lives post-cure. You've been you've been looking into this and I was just wondering if you could share with people listening some of the things that we found around how law might continue to impact people affected by hepatitis C, even after treatment.

## Sean Mulcahy 27:14

Thanks, Dion. So what we've found from our research is that the law does continue to impact people with a history of hepatitis C in several different ways. So this shift to treatment and onto cure has meant that people with hepatitis C are now much less likely to be granted access to the Disability Support Pension, but are simultaneously more likely to be deported if they've overstayed their visa, though this very much depends on the availability of treatment in their home country. Despite the advent of curative treatment, people with a history of hepatitis C are still required to disclose this in insurance applications and may face increased premiums or wait times as a result. In terms of the criminal law, we're seeing it play out in a variety of different ways. So in terms of sentencing, during COVID-19, there was more limited access to treatment options. So this may have resulted in a reduced term of imprisonment. But simultaneously, it is regarded as an aggravating factor in sentencing, the possible transmission of hepatitis C. For victims of crime, if there is a chance of hepatitis C transmission, that often can lead to increased compensation. Even just the fear of hepatitis C transmission, not the actual transmission itself, can result in a greater award. And finally, in the areas of criminal offending, transmission of hepatitis C is still regarded as a serious injury under criminal law. So therefore, there's a higher criminal penalty attached to it, even since the advent of curative treatment. So what we've found is that medical cure doesn't necessarily cure the discrimination and stigma that's attached to hepatitis C. Yet, perversely, it may be more difficult for people that have been cured of hepatitis C to access the protections of discrimination law, due to different definitions of disability under federal, state and territory law. So what we concluded from our research is that for the law to play a meaningful role in post-cure life, there needs to be a really thorough audit of these laws that impact people with hepatitis C. And from that reforms - reforms that reflect the advent of new treatments and tackle the stigma and discrimination that still lingers for people even post-cure.

## Dion Kagan 30:02

Thank you so much, Sean. And I know that there are some early reports and some forthcoming articles coming out of that research into the legal circumstances of people who have cured their hep C. And, if people are interested, interested, they are on the Gender Law and Drugs website. I'm going to turn back to Adrian now just for a follow-up question for you, Adrian about access to treatments. In your work, one of the things that you've been documenting and investigating is the barriers to treatment that people with hepatitis C continue to encounter. And you recently published a paper on that topic. I was, you know, I know, again, this is this is a big question, but I was hoping that you could tell us about some of those barriers and what you think this might mean for the race to eliminate hepatitis C by 2030.

## Adrian Farrugia 31:02

Yeah, thanks. Thanks, Dion. Yeah, we did document a series of barriers to hepatitis C treatment in Australia, even in a period in which there's kind of this focus on universal access. But as a number of us have been talking about today, that doesn't immediately mean that, you know, there's perfect uptake and access to treatment - its shaped by a range of, you know, dynamics in Australia. I mean, for us, some of the things that we came across in the research was, you know, barriers related to healthcare and other relevant social services. So, simple things, well, I mean, I guess you could think of them as simple but things like, you know, the lack of lack of information about the new hep C treatments within healthcare and other other services that might provide services to people for whom hep C treatment could be relevant. And as well as limitations related to services and regional areas, specifically, exacerbating some of these things. A lack of follow up support and access to appropriate diagnostic and testing equipment was was one of these issues. And these sort of also impacted treatment decisions. Outside of those specific kinds of settings, there's a range of broader issues. So our research indicates that seeking and completing treatment for hep C are also you know, is really shaped by things beyond or outside of individual control and outside of the individual decision making. So broader issues such as insecure housing, stigma and discrimination, as Emily and we've all mentioned today, and mental illness or experiences of mental illness can act as barriers to treatment. And these all need to be addressed in efforts to improve treatment uptake, even though they could be or some people might, or they might otherwise be thought of as separate issues. But they kind of intertwine with with hepatitis C in Australia and on the treatments specifically, while the new treatments aren't associated with significant side effects, and generally people have a have a fairly good experience using them, our research indicates that the negative reputation of past treatments can can still linger and discourage some people from seeking treatment at the moment, or that or people might delay treatment because hepatitis C can not express many symptoms for a period of time. So, one final barrier I'll just mention as well - it relates to the criminal justice system, which we heard about at the beginning of our discussion today - and basically, that experiences in the criminal justice system often disrupt efforts to access hepatitis C treatment, or even just look after health and general wellbeing more more broadly. And, you know, when thinking about all these different findings together, and these barriers, and I just think I think sort of emphasise some of the things that Carrie was saying at the beginning of our discussion, which is that even in a context shaped by these highly effective treatments, and this work towards universal availability, these barriers continue to impact the lives and treatment experiences of people affected by hepatitis C. And where these issues continue to shape the fabric of everyday life for people living with with hep C, the focus on elimination needs to be broadened. So in this sense, the elimination project isn't just about treatment and cure specifically or, or even institutional healthcare arrangements, but also about addressing the social position of people living with hep C and that includes social distinctions and understandings about life and health and lives worth living that often register those affected by hep C as somehow deficient. And so this kind of speaks to the issue of stigma and discrimination that we've already touched on a few times. So for us, you know, we need more interventions and for these kinds of understandings, and we think that Vital Voices, the website, VitalVoicesonHepC.org is kind of one, one contribution to this. And we see it as kind of a de-stigmatizing public resource, trying to interrupt some of these marginalising attitudes affecting people who've lived with hep C and reducing our ability to reach these elimination goals more broadly.

## Dion Kagan 35:39

And it seems like that's something that's come out of all three of the projects that we've talked about, which is the sort of, you know, the complexities of people's lives and the diversity of people's experiences is so central to how they grapple with living with hepatitis C getting, you know, accessing treatment and life after treatment. And so really, all of these questions are about so many of those complexities beyond just the instrumentalities of you know, how to how to make treatment access happened, and so forth. Thank you so much, Adrian. And thank you, Renae, Emily, and Sean also, for sharing some of the findings of all these fascinating and really important research projects. It was great to hear you talking about them. I will hand back over to you Kate.

## Kate Seear 36:35

Great, yeah, thanks so much, Dion. And special thanks to all of you, but also Adrian for so beautifully, sort of summarising some of the key themes across all of the projects there at the end, and, and all the issues as you say that needs to be addressed alongside medical treatment and cure. Carrie Fowlie, I want to come back to you to wrap up. I want to ask you for some of your thoughts about those recent research findings that we've been showcasing today and what they might mean for people affected by hepatitis C and for those who work in the sector. And I know that's a big question, but reflecting on some of those findings, what does it mean for the next lot of national hepatitis strategies, which are on the horizon and due to come out for consultation soon, but also for the elimination agenda and those 2030 targets more broadly?

## Carrie Fowlie 37:29

Thanks, Kate. First, I just want to extend a huge congratulations to the ARCSHS team, what a fantastic body of work. And really, really timely given that the national strategies are due for consultation soon, hopefully, they'll drop any day now for a consultation. And some of the findings and insights, I guess, from the work that's been discussed today will be really critical. And a lot of stuff coming from community is advocacy about really thinking about the whole person and their whole life course, and the context in which they're in. And I think a lot of the research that you've been doing about seeking to elevate the voices of different communities, where they're at, their experiences, but the different contexts they're in is really critical to that. Another, I guess, is about elevating the space of the law as well. One of the goals of the national strategies at the moment speaks to legal issues, but then it kind of peters off a little bit. And we don't quite have the oomph, I guess, in the strategies to help us do, I guess, some of those recommendations that you're speaking to Sean about really being able to do some reform work. Another part of the strategies as well that we really need to get some behind as well relates to human rights. And so that's kind of a core principle of the national strategies. And it's great that it's in there, but we then also really need to tie that into tangible actions, and I guess, going to, you know, the beginning of this conversation, which has just been so fantastic, is to I guess, really think about people who are incarcerated, and 1) preventing people from being incarcerated in the first place. But then, after that, ensuring we have equivalence of care to that which is in the community. And that's a key thing in terms of the hepatitis C response that we don't have. So we're calling for a really clear statement in the national strategies about implementing harm reduction and needle and syringe programs in prisons, and that this is a direct violation of human rights as they stand for people in prison at the moment. So we really, really need to get behind this because if we don't do this, it will undermine all the efforts that we've been able to do to date, and all the work that communities have done to date. It also causes me to reflect on I guess, the agility and, you know, talking about telehealth and different technologies that are coming into place about how are policies going forward need to be responsive to communities and really forward looking and, you know, thinking about how can we have things like self testing in communities and what type of things like innovation might that mean, for people, but also, I think, the critical role of the community workforce working alongside other components of the response. And it's so great, I guess, this body of work, also highlighting that, because people have experienced hepatitis C treatment doesn't mean that we forget about them, you know, they still matter, and they still count, and we still stand with them. And that's such a critical part, particularly since this space was so driven by epi [epidemiology] and how do we kind of broaden this space. And from our perspective, we're, we're with you in lockstep of not leaving them behind. Although we still want people of course to access the cure as much as possible. And it's really great as well to have I guess, more nuanced and more detailed pieces of work as we talk about stigma and discrimination as well. Yeah, so I would just like to, again, say congratulations for that great body of work. I think there's some really good things we can input into the national policy context, but also in terms of implementation. And these are just the type of conversations we need to be having for World Hepatitis Day. So thank you for the invitation, and we wish you all the best.

## Kate Seear 41:55

Oh thanks, Carrie. Absolutely wonderful to have you join us, and thank you for those reflections. And, you know, of course, also for highlighting some areas of special focus, such as the issues that are going on in prison, that, as you say, are likely to, to potentially get worse over the coming years, and that really do need to be a focus for us, including from a from a human rights perspective, I fully agree with you on all of that. I want to just wrap up and thank everybody and mention our websites, again, there's a few of them, but you can find all of our work there. So let me remind you of the websites that we've mentioned, where you can find our research and our reports, blog posts about these issues, other podcasts that we've put together on issues that that will be of interest to our listeners. So VitalVoicesOnHepC.org, which Adrian spoke about. The Gender Law and Drugs program has its own website, which is genderlawanddrugs.org. We also have a website for the Drugs Gender and Sexuality program at ARCSHS that's drugsgenderandsexuality.org. ARCSHS, of course has its own website. So the Australian Research Centre in Sex, Health and Society, you can find us at La Trobe and Carrie of course from Hepatitis C, Australia, all the excellent work you're doing there, you can find out more about that on HepatitisCAustralia.com. Thanks to Dion Kagan, for guiding us through the discussion so beautifully Dion, thanks to Emily Lenton, Adrian Farrugia, Sean Mulcahy and Renae Fomiatti. And of course, again, Carrie Fowlie, for joining us. And thank you all for sharing your insights this World Hepatitis Day, it's been a pleasure to talk.