

Finding the "missing" in the hepatitis C response in NSW: A systemic response

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1 Executive Summary

Research question

What do key informants propose as feasible and effective strategies for NSW to test and treat the "missing"?

Methods

In a rapid qualitative assessment, we will engage a range of key informants in government health and non-government agencies to review the list of existing examples for implementation in NSW and review factors that would impact implementation at personal, practitioner and systems levels.

Interviews typically 30 minutes in duration. Key interview questions:

- Can you tell me the story of hepatitis C elimination, as you see it, over time?
- What is your view of "the missing" in HCV elimination strategies?
- What's missing in the hepatitis C elimination response?
- How do we come to know who, or what, is 'missing' in our responses?
- Thinking a little bit speculatively, are there any other ways that we might think about when considering 'the missing' as a problem?
- How would you advise NSW Health on its strategic response to "the missing"?

Analysis

Coded by key elements of frameworks (WHO building blocks; NSW Hepatitis C Strategy Pillars; WHO elimination targets; cascade of care: See Appendix 1). In addition, seeking participants views on the meanings of "elimination" and "missing" and how these meanings are or could be actioned in implementation.

In addition, thematic analysis of the interview data is summarised in section 2 of results

Results

Sample description

28 interviews were conducted. 10 were people in roles in NSW, four in roles relating to other Australian jurisdictions, five in national roles, four were academic, five people were working in the hepatitis C field in other countries. Experience in the hepatitis C sector ranged from one year to more than 20 years with the majority reporting more than five years (24/28) and 10 or more years (19/28) with 10 people having more than 20 years experience.

Recommendations (list does not indicate priority)

After presentation to and feedback from the BRISE Advisory group and the MOH Hepatitis C Implementation Committee, the following recommendations are supported:

- 1. MOH work with PHNs and pathology laboratories to understand barriers to pathology reporting of PCR/RNA to enable automated chart review in general practice
- 2. MOH is clear in communications to ensure that the goals of elimination are not lost in a "testing shorthand".
- MOH encourages LHDs and PHNs to consider the best available local information about where hepatitis C services could be strengthened – within AOD services (including private services), GP, pharmacy, services working with CALD communities, the Aboriginal community controlled sector and other relevant services important to each area, especially in relation to use of KPIs to direct activities.
- 4. MoH strongly encourages all health services and settings to work innovatively and in partnership with other groups to try new ways of working.
- 5. MOH consider how it will continue to promote elimination agenda and support programs that require time to build relationships with new communities/service partnerships etc.
- 6. MOH consider a "liver health" approach to work with GPs, especially regarding reengagement with cancer screening after COVID disruptions.
- 7. All policy and program responses should be informed by understandings of the potential impacts of stigma on these responses.
- 8. Consideration should be given to full range of testing technologies that provide acceptable modes of access for service users, and which enable testing to be delivered in sites (especially in outreach services).

However, the tables and theoretical analysis below provide a full description of the results including additional recommendations for action.

Results 1: Key findings aligned with frameworks (see appendix)

1. WHO building blocks – key findings

	Service delivery	Health workforce	Health information systems
Strengths	Some NSP/AOD have done exceptionally well to engage clients	Ability of peers to connect via trusted relationships and being in spaces/places where health workers cannot	World class research and surveillance expertise
	Some services have developed relationships of trust with their clients		
Concerns	Are all NSP/AOD equally active in the space?	Costs more per successful connection to treatment. Costs can be reduced by employing peer workers (rather than clinical workers)	Granular data is not available (unlike HIV) to understand where/how systems can intercept them – very difficult to "know your epidemic"
	Are GPs with high caseloads of CALD patients proactive?	BBV/STI remain challenging for workforce to discuss with patients	Liminal time in data systems – moving from pre-COVID energies, to COVID distruption, to focused elimination efforts. Data systems need attention
	Hepatitis C not seen as core business, esp in AOD	Planning and program workforce, not resourced/available in some high prevalence areas in LHD,	Trust in modelling data

Caro models po	stru	pact of internal LHD ructures	Lack of local level data
Care models no adapted beyond outreach, partne could be more v	l service-based ie ership models		Very different views about size/characteristics of group of people who no longer inject: potential to drive further divisions/"schisms" between
COVID and oth GP have put he burner".	er disruptions for p C on "back		services and responses – and lack of data to sufficiently characterise this group
Need another a rather than only			CALD people rarely mentioned
			KPIs provide information only on number of treatment initiations -not who/where to drive additional responses, identify gaps in local areas
			Cautionary tale re monitoring infection/reinfection – Lotus Glen
			HCV PCR is not searchable in fields of laboratory reports making audit of records very labour intensive and not accessible easily to GPs

			Reinfections not recognised in notification systems – potential sleeper pools of refinfection Know little about people who inject who use secondary mechanisms to access sterile equipment
Recommendations	Review of data re hepatitis C activity with respect to testing rates in key services	Invest in peer workforce (with a diverse peer workforce to match aims of engagement)	Linkage between notifications to PHU and LHD and primary care
	Consider KPIs to drive attention to hep C	Support workforce to work flexibly, responsibly, embrace trial and error	Qualitative research to examine specific barriers
	Testing initiatives – self; peer facilitated with remote nurse	Champions to promote and educate clinical peers	Consultation with sector and community to build trust in data systems, shared understandings (esp about people not connected to NSP/AOD) and develop agreed upon priorities and pathways
	Permission to trial innovations – culture of flexibility incl deimplementation of		priorities and patriways

	services/approaches that are no onger fit for purpose	Review of workforce and gaps – re location of prescribers, training, knowledge	Permission to go with "on the ground gut feelings" for initiatives: evidence enough
N O	Support ACCHOs to engage with NSP and to open up discussions of HCV care within community controlled sector	Educate, raise awareness with groups not typically within HCV care	Use of AI to mine data sets to find people with risk
F	For GPs, package HCV within	Continue GP education in HCV,	Liver cancer death review panel
fa d n	fliver cirrhosis" finding program – fasting growing cause of cancer death, can do something about most causes. Based on routine	perhaps rolled into liver health approach	Liver disease registry
	iver function tests	Educate workforces that are likely to be in contact with people who could be tested eg	Reinfection registry
	Outreach from liver clinics to GPs, eg fibroscan, educate clinicans	migrant resource/welfare centres – and follow-up with testing campaigns	Transplant data review
L	_iver Toolkit program		Data from private labs
			Local data to drive local responses
			Data on Aboriginal people is missing

	Country of birth data is missing
	Minimum data set was useful in the past to provide information about who/where testing and treatment was occurring
	Data linkage with SES measures
	Participatory modelling with community and wider sector
	How to reduce stigma?
	Lobby laboratories to change reporting of HCV PCR to enable search Need data on drug markets to look for coming surges in potential infections/reinfections

	Access to essential medicines	Financing	Leadership and Governance
Strengths	DAAs powered elimination agenda and targets.	Financing not fit for elimination agenda re sustained programs to 2030 and ability to act flexibility	Well-regarded NSW KPIs have driven focus
	Australia in front of the world re open access, incl re- access		
Concerns	Medicare ineligible people	Additional investments required	KPIs too rigid and specific
		How to keep invest up for elimination action	No energy during COVID
		What is interest in small numbers of the "missing" in	Treatment numbers dwindle, looks like no action happening
		elimination in "big scheme" of health care priorities?	Rules/structures that make it difficult for people to engage with services
Recommendations	Follow developments of long-acting DAAs	Security of funding for elimination period	Strengthen governance (re implementation committees)

Set understanding of what is needed to achieve elimination	Leadership from CHO on action and understanding elimination patterns
Invest in ongoing project after pilot period,	KPIs for all priority services (esp AOD). Promotion of HCV as core business for AOD
understanding need to build trust through ongoing programs	shape policies based on equity, inclusion health models, human rights
	recognising criminalisation as barrier to hep C prevention and care, and as major effect on health and rights of ppl who use drugs
	Bold policy on NSP in prison
	The story/narrative of elimination told by leadership will be important to develop and galvanise action eg:
	Focus beyond testing – prevent transmission and disease progression

	Avoid shorthand of "testing"
	Communications – capitalise on miraculous advance of science that can't afford to miss
	Recognise and promote that status quo activities will not achieve elimination
	Reframe "the missing" to "missing responses" that result in "people missing out" (to remove pejorative)
	Potential for political legacy of elimination in a relatively uncrowded space
	Policy platforms eg BBVSS, MACBBVS are very important to keep focus on elimination giving falling numbers
	Ministry connect with GPs via quarterly letter re BBV/STI policy agenda and including data, recognising business imperative of GPs re highlighting opportunities for fee generating engagement with patients, esp via practice manager engagement

2. NSW targets – key findings

	Prevent	Test
Strengths	Strength of existing primary prevention and achievements to date	Evolution of treatment technology – DBS, POC
		STIPU as a state-wide resource
Concerns	Reinfection infrequently raised	Prevalence is too low for GPs to invest in clinical audit/case finding
	Prisons as major source of reinfection	Is birth cohort screening useful?
		Add into routine health checks? Eg liver health check alongside cholesterol test
		Who's job is it? Train testers, or do outreach?

		Research projects with incentives create expectations that services can't match
		Focus on prison re testing as critical. Unsure about private prisons and HCV testing
		COVID disruption to testing programs
		Is there equitable testing of women?
Recommendations	Maintain focus on primary prevention	Testing available wherever people may intercept the health or social system with skilled staff for fewer barries, less stigma
	Expand primary prevention esp prison NSP, access to drug treatment	Provide choice of
		testing site/technology
	Expand focus on reinfection as a priority	
	NSP as safe injection sites	Outreach
		Self-test especially in relation to stigma concerns

Amend peer distribution legislation, to better engage with and understand newer/younger people who inject drugs	Pharmacy, including nurse practitioners in pharmacy and self-test, as well as pharmacist initiated
	Incentives, and to bring a friend
	GP incentives including easy to access education with CME points
	Targeted GP programs re high caseload CALD areas
	Provider coordination
	Multi component interventions
	Peers test, with remote nursing support for prescription
	Benchmarking services re testing rates
	Partnerships with NACCHO, RACGP, PHNs, AMA, ASHM for profile raising, skills development, linkages

	Promote GP role in liver disease and viral hepatitis within that
	Opt out hospital ED testing (note important ethical issues for this approach)
	Mental health
	Deadly Liver Mob
	Use COVID (everyone had less cancer screening) to reinvigorate promotion of testing re liver cancer
	Screening targeted to lower SES areas
	Consider role of STIPU in HCV
	Antenatal

	Probation and parole

	Treatment	Stigma
Strengths	Nurse practitioners who can write scripts	Research infrastructure
	AMS model of care, service delivery and support (replicated in other settings)	Awareness that stigma undermines all efforts
Concerns	Stigma is a barrier to treatment access	Often a taken for granted issue
	Barriers to GP access (availability, cost, stigma)	Need to design every new system with stigma in mind
	Same day test and treat will be a rush for some people, need time for some with complex issues	Limited investment in research in this area – fewer solutions
	doctors are still unwilling to connect people to care whilst they're still using drugs	Epi-based messaging and service delivery can entrench stigma

	models of care still built on interferon days (have to come to my services)	
	Continuity of care for people in prison (incl those entering, exiting, transferring, and in private prisons)	
Recommendations	Pharmacists initiate	Investment in stigma reduction research
	Co-payments for medication covered	Normalise testing as per any other condition
	Incentives for patients for treatment ie to avoid loss to follow-up	
	Need support for people to remain on treatment	
	Enhanced focus on post-treatment experiences	
	Focus on productivity gains and reduction in extrahepatic symptoms	

3. WHO targets - key findings

- 90% reduction in incidence

- Most discussion focused here;
- Few mentions of reinfection prisons a primary focus for reinfection

- 65% reduction in mortality

- Mortality hardly mentioned
- Focus on liver cancer prevention
- Focus on productivity issues of chronic infection

4. Cascade of care main findings – key findings (not covered by #2)

	Living with hep C	Diagnosed with hep C	RNA confirmed	Received treatment	Cured
Strengths	Achieved treatment of many ppl				
Concerns	Who and where are they?				
	How to craft messages for people not engaged with HCV/NSP/AOD				
Recommendations	Bring communications to places where people talk eg butcher, hairdresser		Reflex testing		
			Antibody notifications from public health units followed up by nurses		

Targeted social media communications for different groups		
Need to ongoing repetition of messages to achieve impact		
Shift narrative away from hep C risk factors to reach broader audience		
Promote liver cancer awareness		
Need multiple narratives – maintain focus on AOD/NSP aligned people, and reach others		

Results 2: Thematic Results (see full detail, Appendix 2)

What is elimination?

Participants focused on "finding people" for testing. Far less discussion was placed on connecting people to treatment, liver care post treatment and stigma.

Recommendation: That MoH is clear in communications to ensure that the goals of elimination are not lost in a "testing shorthand".

Defining the "missing"

There were differences of opinion on who was "missing out" on hepatitis C services. As NSW awaits further granularity in understanding data, it is possible that these differences in opinion could cause division within the sector. Also, it is possible that the response in key services (such as alcohol and other drug services) is "patchy", and work remains to be done in AOD services in some geographical areas.

Recommendation: That MOH encourages LHDs and PHNs to consider the best available local information about where hepatitis C services could be strengthened – within AOD services (including private services), GP, pharmacy, services working with CALD communities, the Aboriginal community controlled sector and other relevant services important to each area.

Approaches to elimination

Participants strongly endorsed the need for innovation; that continuing with current approaches would not achieve elimination.

Recommendation: That MoH strongly encourages all health services and settings to work innovatively and in partnership with other groups to try new ways of working.

Sustainability of elimination

There was concern among participants that investment in elimination efforts could be withdrawn. This was against the backdrop of the higher costs of engaging people not yet reached.

Recommendation: That MOH consider how it will continue to promote elimination agenda and support programs that require time to build relationships with new communities/service partnerships etc.

References

- 1. Madden, A., et al., *Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia.* Harm Reduction Journal, 2018. **15**(1): p. 42.
- 2. Seear, K., et al., *Beyond a 'post-cure' world: Sketches for a new futurology of hepatitis C.* Int J Drug Policy, 2021. **94**: p. 103042.

Appendix 1: Frameworks

1. WHO Health System Building Blocks

https://apps.who.int/iris/bitstream/handle/10665/258734/9789241564052-eng.pdf

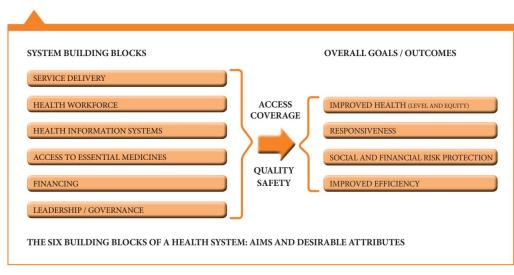


Figure 1. The WHO Health Systems Framework

Source: (3)

2. NSW Hepatitis C Strategy 2022-2025 targets

https://www.health.nsw.gov.au/hepatitis/Publications/hepatitisc-strategy-2022-25.PDF

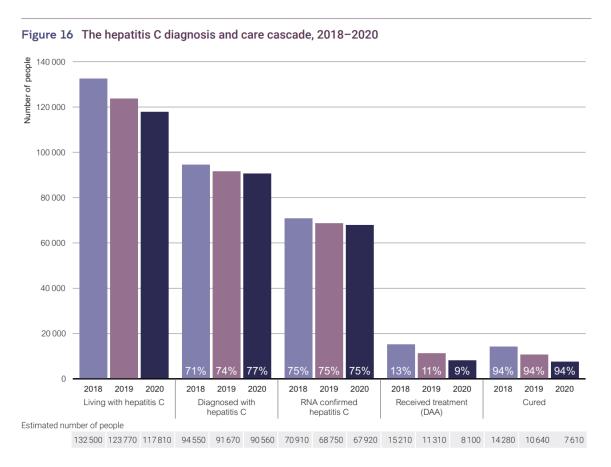
Goals:	SW where hepatitis C transmission is prevente 1. Prevent	2. Test	3. Treat	4. Stigma and Discrimination
	I. Prevent Prevent new infections through harm reduction, education and health promotion.	2. Test Increase access and testing for people at risk of infection.	J. Ireat Link newly acquired and existing infections into treatment and care.	 Stigma and Discrimination Reduce stigma and discrimination as a barrier to prevention, testing and treatment.
argets:	 i) 60% reduction in the number of new hepatitis C infections ii) 20% or lower reported receptive svringe sharing among people who 	 i) 10% increase in the number of hepatitis C antibody tests ii) 20% increase in the number of hepatitis C RNA tests 	 i) 65% cumulative proportion of people living with chronic hepatitis C who have initiated direct-acting antiviral treatment 	 i) 75% reduction in the reported experience of stigma and discrimination among people affected by hepatitis C
	inject drugs iii) 10% increase in the distribution of sterile needles and syringes for people who inject drugs	With a focus on services within: - Alcohol and Other Drug Health - Justice Health - Mental Health	ii) 50% reduction in hepatitis C attributable mortality	 ii) 75% reduction in the reported experience of stigma and discrimination among people who inject drugs iii) 75% reduction in the reported
				incidence of stigma and discrimination towards people wh inject drugs by healthcare workers
ction	1.1 Needle and Syringe Program	2.1 Alcohol and Other Drug services	3.1 Models of Care	4.1 Barriers to accessing care
eas:	1.2 Partnership with Aboriginal		4.2 Data, research and surveillance	
거고	communities			4.3 Communication and education
П	1.3 Peer workforce	2.3 Embed testing in key settings	3.3 Post-cure management	
	1.4 Custodial settings	2.4 Primary Care	3.4 Data, research and surveillance	
		2.5 Communication and education		

3. WHO elimination targets

The strategy proposed the elimination of viral hepatitis as a public health threat by 2030 (defined as a 90% reduction in new chronic infections and a 65% reduction in mortality, compared with the 2015 baseline).

4. Hepatitis diagnosis and care cascade

https://kirby.unsw.edu.au/sites/default/files/kirby/report/Annual-Surveillance-Report-2021_HCV.pdf



Appendix 2: Thematic analysis – full details

What is elimination?

Most of the discussion of how to do elimination was focused on testing (with the assumption that treatment would follow). This misses the other elimination targets (from WHO and NSW) regarding liver disease mortality and stigma.

Some participants reflected on the potential of "confusion" between what each target requires, and also the focus on transmission goals at the expense of other outcomes (notably reducing mortality).

you shouldn't confuse the two jobs [eliminate transmission, stop people dying of hepatitis C unnecessarily] because that's where I think people get very confused in their minds about what the task is and what the purpose of a particular moment is ... but I think we have to be really clear in our heads about how we think we're going to do the task required for those groups -7

They're less likely to transmit hepatitis C. I think their life is of no lesser value. - 13

it's definitely about problem definition and how problems are described and defined. - 23

What else can elimination bring/achieve/have potential for?

A broader agenda beyond the current elimination targets was canvassed by some participants; that is, regarding drug law reform, stigma reduction and human rights. In one case this was put forward as a transactional relationship (what else we need to do to achieve elimination). In a second case, hepatitis C elimination efforts were described as a launch pad opportunity for a broader reform agenda in drug user health and human rights.

So, if we fast forward to 2030 and say that we're all, you know, cracking out a frothy and celebrating the achievement of the elimination of hepatitis C and we say, "God! Look back over the last, you know, 10 years, 15 years. How did we get here?" I think we would identify things like obviously the unrestricted availability of DAAs, but we might celebrate other, you know, sort of pivotal moments or pivotal achievements as well. So, if we're eliminating hep C by 2030, we've done something pretty significant about stigma, discrimination. You know, I think it's a massive barrier for people. You know, stigma and discrimination, I think people can think about those things and think, oh yes, people are mean or, you know, people don't have a nice time discussing this, but it is, you know, a so much more significant barrier than that, and I think in and around our space where significant progress has been made in destigmatizing and confronting and removing discrimination, I think law reform has been an important component of that process and I'm thinking here about removal of, you know, the criminalization of same-sex sexual behaviour and, you know, the broad support and then legislated availability of same-sex marriage. You know, I think they were pretty important processes that lead or, yeah, they lead, you know, further destignatizing and removal of discrimination for affected populations, and I think in hepatitis C, you know, we need absolutely some strong steps in that direction and if we're looking

back from 2030, we would probably say, "God! How important was drug law reform! Oh my God! I can't believe we didn't do that earlier." - 13

I just think there's so much to be gained beyond just eliminating a virus that would cause severe disease, you know, among already affected people, even though that's an important endeavour to prevent end-stage liver disease and liver-related deaths, of course, that's a primary objective, but if you're going to put so much effort into this overall endeavour. I think there's sort of almost an obligation to bring other stuff forward with it, so to speak, and not just focus on, okay, we'll get incidence down to a certain level that we're going to reduce liver-related deaths, you know, by X percentage - - that's if the only focus you have is on the epidemiological targets themselves as, you know, the missing piece to achieve those targets, and I think, as I said, we've got the opportunity to really do so much more than just get the hep C incidence down to 2 per 100 person years in people who inject drugs and get the population levels down under 5 per 100,000, etc., etc. So, that's what I'm about, I suppose, and look, I always like to sort of be someone that keeps pushing things forward rather than saying, okay, you know, we do this pretty well, we've just got to tinker with this and do it a little bit better.... "Okay, what are the key issues for drug user health and human rights going forward?" and they're like pulling people from these different sort of areas and almost coming up with a strategic plan around that. So, we've got a hep C strategic plan, but you could almost ... and I'm sure there's some drug and alcohol sort of strategic plan, it's something that pulled elements together to say how could we sort of take forward some of the key issues around drug user health and human rights 4

Why should we eliminate? Other imperatives to consider?

Elimination discussion focused on testing and treatment. Very infrequent mention specifically of "cure". Most discussion focused on the notion of treatment as an end in itself. Very infrequent mentions of sequalae of long term infection (eg specifically liver disease mortality, reinfection).

Testing/treatment was used as a shorthand for all other effects of elimination efforts. While this is an easy shorthand, it risks obscuring the wider effects and consequences of engaging in elimination efforts, such as liver disease mortality, impacts on QOL [1] and individual's hopes/plans for their futures (which are not uncomplicated [2]).

Another aspect of hepatitis C clinical manifestation raised by only two participants was extra-hepatitic impacts of hepatitis C and the effect of these on productivity. Participant 8 indicated that productivity issues could be another driver of government focus – that is, not only on focusing on mortality as an economic and social gain, but focusing on decline in productivity of people living with chronic infection.

why we need to find them and why we need to diagnose and intervene and it's about a few things. I mean obviously ongoing transmission, but in terms of burden

of disease, it's the liver disease per se and it's an important co-factor for liver disease and for complications, but the extrahepatic stuff as well, the linkage with potentially mood disorders, work productivity and all of that. So, from an economic point of view and a burden of disease, you know, having hepatitis C being undiagnosed, having chronic lethargy and poor work performance and all the things that goes with that, that's obviously got economic impacts. From the government response point of view, I think it's important to be diagnosing and treating everybody and there's clear evidence that the earlier you treat people, the more advanced disease that you prevent. ... Well, again, if you're making arguments to government about why we need to do this, it's not all [inaudible 22:54]. You know, many of those people won't have liver disease for years and if they're putting 20-year timelines on stuff they won't ... looking at that timeline if they're in the 20s now, unless they've got comorbidities, but they still could have significant other impacts, you know.- 8

talk about productivity lost right or lives lost or you know family members, family members who have died, so I think, yeah, that will be interesting to kind of keep playing on that. -19

Approaches to elimination

What to do depends on problem definition

Overwhelmingly, discussion focused on how to "find people" ostensibly for testing and treatment (though the focus of discussion was on testing, with treatment an assumed or presumed outcome of testing). The mechanisms of achieving linking to treatment were not frequently unpacked. Where to "find people" was a key element of discussion. Once found, participants infrequently considered what might happen next (that is, there was limited discussion about what type of testing to offer, by whom – though some issues were raised including importance of peer workforce, trust in services etc)

Far less attention was paid to (in relation to cascade of care and targets):

- o Reinfection
- o Post treatment issues including liver disease mortality
- o Stigma

Trial and error needed, system has to change: "we've got to get off-piste" - 13

The participants recognised that, generally, continuing with only the current approaches would produce not produce sufficient gains for elimination.

getting at the pointy end - sort of feeling like we're reaching saturation to get people on to treatment and now it just feels like it's uphill [laughs], it's going uphill again trying to find some hidden, you know, population and trying to get to reach out to those that have been living with hep C, but they haven't come to the services 2 we go around the same networks, you know, looking for people with hepatitis C, if we continue to test and retest the same populations over and over and over again, we're going to wear out or extinguish, you know, available cases, cure available cases. ... we can't eliminate hepatitis C by just doing more treatment in prisons and more treatment in NSPs and more treatment in opioid treatment services.- 13

Participants were calling for innovation and permission for services to trial new approaches. While other arguments put forward by participants included the call for additional investment, this section refers to factors that "money can't buy" (6) including a culture of flexibility (including deimplementation of activities no longer bringing returns), activating influence, and positioning champions in key networks.

we've treated everybody who wanted to be treated, and now now this is where the hard work, I think, really, really begins and it's requiring us to, I think, really change, we have to change in order for this next phase of elimination. ... to shake it up a bit. I think there are things that have been funded for a very long time because they've just always been funded. I think we've got to start looking at these other ways of doing things, perhaps not looking so much at the numbers, but listening to the words of people with hep C or people at risk, people who represent people who are at risk and really hearing about what it is they are telling us, and then, yeah, I think having the courage to actually say, well, that doesn't meet our needs anymore -6

everybody has got their own spheres of influence right, so the more people we get on board and you know you have seen the people who are kind of the champions in those spheres right, you have certain politicians who have kind of taken it on, so whatever it takes to like convert more people, like that's kind of what we need. – 19

These calls to "shake it up" sat alongside the clear call to remain focused on primary prevention as a necessary continuing activity of elimination.

it's not a one or the other. There's a ... we need to invest and maintain our investment in people who inject drugs proper and that needs to be protected and it needs to be resourced. Like all the gains that we're getting will disappear in five seconds if that infrastructure is not supported and maintained. So that's like a non-negotiable, no matter what happens, but that is not sufficient to do what we're talking about when we talk about the whole population. So, it becomes about saying, "if we want to do more, well, we have to invest more". Like you can't just shift resources and it's really ... so it's really critical to invest back into ... like hold the investment there, where we've got it - 23

This aspect of the findings draws tension in relation to "evidence enough" issues. Participants called for a range of additional/nuanced data (see below) but also commented on the need for courage/permission to go with "on-the-ground gut feelings" (6) when that data wasn't available or would take too long. To continue with same pace and same strategies, participants characterised elimination as an ongoing project that wouldn't meet goals

that if we work slowly and even if it's consistently, if you're only finding and treating at a slow rate, you're always going to have transmission, you're always going to have new cases, and you're going to always be doing this, - 9

MISSING

"They're missing out" (21): Intercepting person wherever they might connect with health system

When asked to discuss "the missing", some participants focused on people with hepatitis C were missing out on interventions. Participant 7 rejected the use of people as missing as pejorative and responsibilising, and dismissive of structure barriers to access.

I actually find this notion of missing is really pejorative, to be perfectly honest, like somebody's missing. They're not missing. I mean we kind of, on a certain level, know who people are. So, they're not missing in a way we're missing. I've always been a little bit of the view that they're not missing, we're missing them or we're missing. ... I think it's just really important for us to understand and be careful about that because I think it can create this sort of sense that it's somebody else's fault, like the person with the disease as opposed to actually ... I think I am truly of the belief that most of our problems are created by social, structural health ... like say in healthcare are historical structural issues, funding and misunderstandings of things as opposed to the individual-.... So, people aren't missing, we're just not where they are.7

Following this, hepatitis C interventions were described as needing to be available wherever people intercept/intersect with the health system (and community services) and further that these interventions should be multiply available to provide people with hepatitis C choice of what best fits their needs. This requires "clinical commitment" to provide those interventions in put the interventions in place.

robust toolbox of how to make these interventions available ... to tailor your intervention where it meets the patient where they are ... these the hard-to-reach populations, but they're actually going through the system all the time. They're in an emergency department, they're in a jail, they're in a prison, they're having babies, you know, in the case of women. There's multiple opportunities. They're at a syringe exchange program. There are multiple opportunities to engage them, so I think the missing are they're really just missing out. They're missing out on interventions that could be made available to them if the right clinical commitment and program was put in place. I don't think they're dodging the intervention. I really don't think even the homeless are that hard to find. So, I think it's really not so much missing but that

they're just missing out because we're not putting the right program in place to reach them. - 21.

we know that there's not going to be one initiative that is going to be able to find everybody and people have different, you know, check-in points and touch points with health services and community services. So, we can't expect to find everyone and treat with one single initiative. ... I think there's a place for everything and everyone and it really then gives people, individuals, the opportunity to intersect with whatever service fits them the best. ... it just gives people choice on where to find information, where to seek support, seek treatment if that's what they want - 18

taking testing and treatment to where people are works. It reduces barriers. If handled properly, staffed appropriately and educated, trained skilled staff or workers can make it a less stigmatizing, less discriminating and less barrier-filled experience and that's a good thing. So, I think we need to continue to go down that path. The challenge I would note there, though, is who are these people and where do they go? - 12

To put these services in place requires multi-faceted understanding of the communities that the programs are trying to reach, to "paint a picture" of people who could access services and then design services to address these issues.

we really need to have that granularity of understanding, that very nuanced understanding about who are these communities, who are these people, you know. Who are they? Where do we find them? What are their lives like? How can we best intercept with this? What is going to make this something they want to be doing? What are the myths and misconceptions that they labour under that we can work with? What's the stigma? But we really don't know very much, and again, I go back to, you know, if you think of the absolute investment in data that is, you know, that underpins the HIV response, there's a very specific reason why they've been able to achieve what they've been able to achieve in, you know, significantly reducing and being well on the way to ending transmission, and that's data because it doesn't just paint a picture of the now, it also gives them a really good indication of the before and after. So, you know, they've been able to really clearly demonstrate that the things that they put in place actually had an impact down the line.- 11

A number of key resources were described as facilitating individuals taking up the offer of hepatitis C services when they were available – trust, in particular.

We've got to go to the mental health nurses and the drug and alcohol nurses because they've got the trusted relationships with the people that we want to be able to test or offer testing to, and then potentially link into care, but we can't do that without them ... So, looking at it that they're not missing, we just haven't found them yet. We haven't set up shop in a place where they might feel comfortable - 6

I think Deadly Liver Mob is a good model, you know. I think the way that we're working with people is a good model. You know, even blitzes work to some extent but I think like there's another side to the blitz story that we have to, you know. ETHOS, like all of them are good models. I think though we need multiple ones and one of the ones we need is like that. You know, the person that can really infiltrate, that might not be the right word, but really get into those communities and talk to people and gain trust and gain them access. - 14

Who is missing? (or missing out)

Most conversation focused on people <u>not accessing NSP/AOD services</u>. This group was characterised as:

the people that may dabble back in the old days and they don't identify with that anymore - They're family people. -1

everybody else who contracted hepatitis C either through injecting drug use, sharing equipment way back when, '70s, '80s, '90s, 2000s, but no longer inject and certainly do not see themselves as part of any drug using or injecting community. They are naturally older people living out in the broader community who are not accessing drug health services because they have no need to. -5

What we now are grappling with are the remaining 50+% of people that are not necessarily focused on their health, are not necessarily aware of the latest treatments for whatever reason. They may know that they have been exposed to hep C or have hep C but are not necessarily conscious of the impact that it's having on their health. There may have been a decline over time, a level of tiredness, aches and pains that they have attributed to other issues, ageing generally or other lifestyle factors. So, they're not committed or not connected to the most up-to-date information around it and then, of course, there are people that have been potentially exposed, don't know that they have it anyway. So, they just don't focus on it. I think that group is now the hard group. They're the ones that need to be reached and it's going to take some different approaches because where those people access health services, how they access services, and how they identify is not necessarily attached to the injecting drug user community. It may be through other identities, whatever they may be. It may be through their cultural identity. It may be through their gender identity. It may be through any other number of things, but it's not necessarily a homogeneous, cohesive and focused group where you can tap them on the shoulder and say, "Hey, you hep C crowd, come on in." - 12

There were differences of opinions of where to find this group – with primary care/general practices featuring mostly.

but they're hard to reach for their hepatitis C. You know, they're not disengaged from care, but they're disengaged from care for their hepatitis C. So, you know, the never found and the need to find again, I think, are big chunks of the missing.- 13

GPs are the only health service who those people in group 3 access on a regular basis. If they have something wrong with them, they go to a GP - 5

However, some participants felt that this segment had been over-estimated and that there were few people who were totally disconnected from previous networks.

conservative, middle-class, in my late 50s, you know, so somebody this, who are they, where are they, where is that person? I've had this discussion with a lot of people. [Another clinical specialist] has one patient who he can describe looks just like that, you know, and I think I might have had one once, you know, I'm not sure, but I haven't actually had a lot of them, but they've seen me ... We don't see a lot who are not actually in some way connected back to people who they knew in the past ... my belief is there's not that many of them, but there is this group that they all hung out once together and did that, but they all still know each other, and if we could get into their networks, because that's where trust comes from, we would pick up a lot of that group of people, but I don't think that they're these isolated lady with pearls, don't talk to anybody, because I ask patients this as well, this is one of the benefits of still seeing patients and talking to people a lot, and I do, is I've literally purposefully gone and asked people these questions like, "Do you keep in touch with your old crew?" You know, people at work as well who I know, you know, used to do stuff once upon a time, they kind of know where the old crew is and try every now and then to convince-7

but then there was this notion that there was this huge population out there in, you know, suburbia sitting down watching Gogglebox and not addressing their hep C, and we had to just go out and find them, and look, there was some stuff from Hepatitis Australia that perpetuated that myth, and I think it is a bit of a myth. .. but they're not sitting in sort of average GP land; some are, of course, but they're not huge numbers. .. we did a randomized trial of the sort of intervention among GPs that I was involved in this other group and it was really quite interesting in terms of the relatively few people that they could find through this larger GP network that hadn't been treated. So, I just think we've overplayed that, that we've overplayed that, whereby hep C is still, for me at least, an issue of largely marginalized populations, always has been, continues to be, and that is where the focus needs to be. So, yeah, I think we sort of lost some ground there for a while. I think we got side-tracked – 4

The perception that there is not a high number of people living with hepatitis C who could be found in general practice (and nowhere else) was drawn, by some participants, from clinical audits in general practice compared with positivity rates in services providing support for people who inject drugs

I look at the evidence that we have in general practice where clinical audits have been conducted and the numbers that people are finding, they are small. So, it's funny, isn't it? I don't know if I think there are people who are missing. QUIHN has continued to test all this year and has continued to have a 15% RNA positivity, but there are people out there who still haven't been tested, who are still coming forward and they're positive. Then in other places, they're testing and they're testing and they're testing and everybody is negative. - 6

People from culturally and linguistically diverse backgrounds

Not much discussion of CALD communities. Consensus was that not much has been done in these communities as priority has been on people engaged with NSP/AOD. The need for a focus on people from CALD backgrounds was driven by the perception that "we know the epidemiology" (8).

multicultural communities, I haven't seen anything much, you know, being done really. We know that some communities have higher prevalence, like even they are priority population as well. Like, for example, Egyptian community or some communities, but I haven't seen much work being done in that space. It's like no one talking about it. -2

culturally and linguistically diverse communities, and to me, I look at that as being really simple, but we're not allowed to talk about it obviously, it's like with hepatitis B, where it's the one time when racial profiling and us being racist might be useful, but hepatitis B, as I say, if somebody is yellow, brown or black, I actually want to know why you haven't done a hepatitis B test on them because that's where we know that there are countries that didn't have the vaccination program. It's so simple to me. I just look at it and go, look at the bloody map. It's not even hard. You can pick up most. You'll miss some, but you'll pick up most, and similarly for hepatitis C, how hard is it to know that if somebody came from a country at a certain time where the health system might not be flash, but we should at least have a conversation if their liver function tests are deranged, but I don't ... because I suspect whole screening is just not going to get us there. It's never worked anywhere. It's never worked for anything, but there are ways to be more sophisticated about it. -7

I've still got concerns, I guess, that some of them are in the migrant populations and some of the GPs in that space are quite proactive, but others aren't .. I do work in multicultural type settings and patients do get referred and we get a lot of hep B referrals but not that many hep Cs, but I know they're out there as well because, you know, we know the epidemiology, - 8

GPs with high caseloads of CALD, you know, CALD clients, whatever those CALD clients are. So, not necessarily CALD GPs, just GPs with high caseloads, ... This is the moment. It's not going to happen anywhere else. It's going to happen in GP land. So, we just need to get really good at working very, very closely with these GPs and, you know, providing them with the tools and the narrative and the whatever else that actually engenders a response that isn't, "Oh my God! I'm freaking out. I don't want to know. I'm leaving" ... we've already hit the second generation of GPs, you know, carried with them their misconceptions and stigma and their particular way of working. We're already hitting the second generation of GPs who might be from a particular

background, but have grown up here or have been at least partially educated here. You know, that's actually a real bonus. It's a different mindset.- 11

Is the job done for people in AOD services?

Alongside the perception that AOD has been saturated with hep C testing, was a concern that the efforts had been patchy or inconsistent in AOD services and driven by perceptions that hepatitis C was not "core business" of AOD services.

like AOD services and NSPs have KPI on this. They need to have clear targets as well.- some sort of target or, you know, accountability and, yeah, something for them to work on to contribute to, yeah, to target part of hep C elimination strategy - when we did some in-service at drug health, some clinicians still think that, you know, like hep C is not, you know, their sort of target.- 2

drug and alcohol don't see it as core business and I think that's fucked .. I think the Ministry needs to give drug and alcohol KPIs around treatment numbers.- 10

Missing workforces/Systems

- WHO building blocks

I think there's some limitations sometimes and it starts at the top with do you have the right policy in place. Do you have the right financing to support the implementation of that policy? Is the policy appropriate for the epidemiology of your population? Then, have you trained the right providers of that service, ... systemic facilitators of delivering testing and treatment. The interaction between the community and the clinical setting, sometimes hard to put in place but, you know, what's the role of community care or community service providers and how they interact with the clinical care providers - 21

- Pharma support

industry activity around clinical auditing projects. AbbVie have got a project that they're working on at the moment and they've got some nurses who are doing some in-practice work as well whereas Beyond the C is completely virtual - 18

- Prison

really, really critical is prisons obviously, and I think that the more that we can invest in prison-based treatment is really important in testing. I think that both Justice Health and Forensic Mental Health have been doing that, but I think there's still a lot of work around integrating testing, both dry blood spot testing and point-of-care testing into the prison setting because if we're going to achieve elimination and again the question is where the missing are going to be, but it's definitely going to require a maintained focus on prisons, drug treatments, needle syringe programs and other places where people who inject drugs are attending - 17

- Provider coordination

very site specific and often, you know, practitioner specific activity, but I feel that there's maybe been a bit more of a coordinated approach to that overseas, - 18

actually have provider coordinators that has been explored in other countries. So, a coordinator where their sole job is to get the providers act together and help them to sort of figure out how they would set up programs for treating, and it's maybe a bit like the Beyond the C project for that. - 17

- Multicomponent interventions

point-of-care testing, dry blood spot, patient navigation, peer support. Those all have really strong evidence around linking people to testing and treatment, ... first thing is around simplifying the diagnosis pathway. So, that includes things like onsite testing to get, you know, multiple visits to see a provider, to at least remove the need of referring people offsite for phlebotomies. Reflex testing. - 17

- <u>SES</u>

do something based on socioeconomic status or local health districts or ... not local health districts, sorry, post codes which are more socially marginalized. So, do you pick those as having higher proportions of people who may inject or may have injected in the past and do some concerted efforts around more population-based screening – 17 (and ? 4)

- Private drug treatment

, what's the prevalence of hep C among private drug treatment clinics where hep C might not be a priority? ... it's a very simple solution, you know. The Ministry of Health knows who the largest OAT prescribers are and has a list of those individuals and, you know, all you would need to do is take the top 30 private OAT prescribers in New South Wales and, you know, deliver either testing campaigns or do a medical record chart review to get a handle on what is the treatment uptake, what is the prevalence of current hep C infection and treatment uptake in those clinics- 17

- <u>Al</u>

people who may have been diagnosed a long time ago and have sort of fell off the radar as it were. So, there's work kind of looking into the primary care datasets and different datasets to try and work out whether those people are there and also kind of thinking about different algorithms that could be used with big data and GP surgeries and those sorts of things to try and identify people who might be at risk, so someone who's got kind of an injecting history recorded or drug history recorded on their primary care record, but there's no record of them ever having been tested for hepatitis – 16

artificial intelligence that they're launching in the UK - 22

- Consultation with affected communities

what I see happen is that bureaucrats in health make decisions and impact people who use drugs without consulting them adequately. So, I see a lot of tokenistic consultation but not people sort of at the table when the higher level decisions are made.- 15

- NSPs as safe injecting sites

We can't underestimate the value of medically supervised injecting centres on the public health response to hep C. There's been one in Kings Cross for the last 20 years. We know that it works, but yet there's significant resistance around, you know, having more sites across the state and quite frankly, I think that to have a significant response, you know, just about every NSP should be equipped to, you know, provide that type of support or service. -15

- Knowing what workforces know

type of workforce analysis, and I'm not talking about peer workforce analysis, but looking at like literacy of harm reduction among AOD and other healthcare workers in metros versus regional areas. – 15

- Private prisons

The caveat I would place on it is around the private prisons where there is perhaps not as much of a focus or a commitment to going down that path. - 12

- Harnessing community

very good at engaging and harnessing the community organization, the communities themselves. - 11

- Coordination of efforts

there is the potential for duplication. Maybe in some cases, it's already there and by duplication, but then there's the converse which is, you know, enormous gaps in the response because everyone's focusing here and no one's looking over there and then, you know, and so really kind of having a better coordination of the current resources, I think, you know, is a very smart approach because there just aren't a lot of resources again compared, you know, it is the poor cousin of HIV and then hep B is the poorest cousin - 11

System navigation for CALD

system navigation for people from CALD backgrounds. So, you know, I mean obviously we have a wonderful medical system, you know, health system and we do compared to other countries. It's not with its complexities, and so it's not immediately obvious how you would enter it and what your pathway is. So, you know, I do think that there are some real opportunities for some improved system navigation that, you know, it's a little bit about

resourcing, it's a little bit about, you know, changing the pathways themselves, it's a little bit about, you know, greater access to in-language materials.- 11

you can have patient navigators that are peers but the whole point is to help people get to appointments, get their paperwork completed, all the stuff that people put off so that they can get treated. Patient education, there's some data around that, - 17

- <u>Peers</u>

I would say investment, committed long-term investment integrated into community settings which involves peers - 20

I think peers should be taught to be doing point-of-care testing and DBS testing and I know that's starting, but if there's no funds or, as far as I know, limited funds that go to LHDs for peers and, you know, we've got one service across the state apart from Hep New South Wales, sorry, but for injecting drug users, it's providing peers that are completely stretched and I think, you know, if the LHDs actually worked closer with peers and used peers in all of their work, I think we would have a much better chance of getting people treated. ... It's the ones that are not engaging with us that we need to treat, and I think the peers have more chance of finding and engaging with those people than what we do by sitting in a building and, you know, handing out a few syringes or whatever.

- 10

lack of emphasis around peer support or intervention ... that was kind of with the establishment of the NSPs and all the rest of it, and I think that what often gets overlooked is the value of a peer workforce because we know that it all started with peers, the value of a peer workforce integrated in alcohol and other drug treatment settings- 15

making a significant investment in NUAA and looking to kind of expand that organization statewide rather than concentrating it in metropolitan areas – 15

peer model, I suppose, basically is the concept that people with lived experience are often better placed to educate the other people who are at risk, you know, using that kind of common experience, common life ... community peers are embedded in the NHS in the local NHS team, you know. So, they work alongside, they go to the MDT. They work alongside the consultant, they work alongside the nurses. So, there is a kind of, you know, it's a collaborative integrated team. It's not that there's a kind of separate set of peers who do a different kind of piece of work to everyone else.- 16

- <u>Co-design</u>

very little co-design around at the moment, I believe. So, you know, having direct client input into the interventions and the resources that are provided would be good. -10

co-design, with community engagement, with recognizing that, you know, there are different approaches to health and well-being and, you know, chronic disease that aren't lesser than because they're not ours, it's just different, but if we can manage to harness and incorporate that in our messaging - 11

- <u>GP, PHN</u>

Yeah. Yeah. Because the problem is the Ministry doesn't have the lever over the private [GP] practices. So, it's how can the Ministry better partner with private practices to get a handle on what's happening outside of the public sector? - 17

I guess, the missing link ... so that's why we wanted to get GPs to do more, but then yet, you know, PHN sort of for us, it just needs some work. We need commitment and, yeah, priorities with PHN - 2

GPs with high caseloads of CALD, you know, CALD clients, whatever those CALD clients are. So, not necessarily CALD GPs, just GPs with high caseloads, ... This is the moment. It's not going to happen anywhere else. It's going to happen in GP land. So, we just need to get really good at working very, very closely with these GPs and, you know, providing them with the tools and the narrative and the whatever else that actually engenders a response that isn't, "Oh my God! I'm freaking out. I don't want to know. I'm leaving" ... we've already hit the second generation of GPs, you know, carried with them their misconceptions and stigma and their particular way of working. We're already hitting the second generation of GPs who might be from a particular background, but have grown up here or have been at least partially educated here. You know, that's actually a real bonus. It's a different mindset.- 11

ethno-specific medical organizations - 11

- Disparities in workforce/resources across geographies

funding distributions, okay, whereas for my district where we had a high burden of hep C and hep B and everything and, you know, the work performed in terms of like hep C report

card, but yet, we have relatively smaller workforce and funding allocated whereas like inner city, they have an army of staff. -2

- ACCHOs

AMS in our district, they've been in receivership a few times. - 2

- <u>STIPU</u>

Could NSW STI Program Unit (STIPU) also take on hepatitis C work as an integrated approach? They have a statewide role, an army of staff, infrastructure and website to do some good work on hepatitis C. - 2

- Pharmacists

multidisciplinary care, pharmacists are missing and they shouldn't be. pharmacists are one of the only providers that are left out on any kind of referral systems. So, when we refer a patient, it's got to be a phone call or an email or a sheet of paper whereas, you know, we know that there are electronic referral systems that we could be a part of where that could go straight to a patient's GP or a care team- 3

pharmacy-based roles coming through to really try and get the newer, you know, the more at-risk people who aren't engaged with drug treatment into testing and treatment, - 16

- Who should be there (workforce)

We mostly as soon as possible should get rid of expensive specialists from this thing. We should be literally the pointy end, and the structure and the system should always be somewhere else - 7

- <u>Too much regulation (what's missing is stripping away procedural barriers)</u>

do the really simple things and get rid of a whole lot of the rules that are not costing us anything, but holding us up, and the more we can have governments advocate appropriately to get rid of unnecessary rules so that people ... so, as I say, they're not missing, we have structures in place that make it hard for them to engage. - 7

- Antenatal

antenatal sector is pretty well covered and, you know, pretty much the College of Obstetrics and Gynaecology now does recommend routine screening so we can identify them, but there is a potential for loss within that system while we're not treating them while they're pregnant. So, loss of both the mother to treat and the baby to be tested. There's opportunities obviously to make sure that we don't miss them and lose them, but you know, that's a difficult time, particularly if we can't link them to treatment yet while they're pregnant. ... Transmission to babies, is the other one, it might only be 5%, but it's real and I've certainly seen 20 adults with end-stage liver disease from vertically acquired hepatitis C. So, I've seen quite a number of those, including transplant itself- 8

antenatal is for everyone. You know, so we already test for HIV and hepatitis B in antenatal. So, they're adding in hep C. That's kind of a tricky one in terms of it doesn't meet the screening criteria, but they're managing to pilot it. And I think, yeah, in some hospitals, when they're taking blood anyway, they're basically saying we're going to check for hep C. - 16

- Probation and parole

MOU with Probation and Parole to be doing some clinics with them - 9

Evidence/data - A liminal period for knowing how to progress with hep C elimination

We don't know who is missing vs are the numbers real? Data is gold vs the number is freaking us out

we're still having the conversation of that do we know for sure and is that what we're actually seeing and how many. We don't know. These are all unknown. So, it's very hard to argue, you know, when you are sitting in those decision-making spaces, it's very hard to argue with great conviction when you don't have the numbers behind you. We all know that, you know, data is gold.– 11

there's like too much weight put on numbers, that we need to dial back from, so stuff like the prevalence number. I think we just need to take a breath on that, because it's putting pressure on a whole bunch of systems and responses to somehow respond to this number as if one it's real ... there's too much power in this number. It's freaking the whole response out, like it's just it's too full on - 23

The politics of modelling: its not just maths - 13

and I don't think population estimate adjustments, you know, that place us back on track are seemly really. I think, yeah, I think it's unfair to assume that changes made to modelling are just numbers, you know, that those are not deeply political. . - 13

Kirby is prosecuting a case currently for a further downward revision of the population estimate of another 30,000 people and, you know, that puts us back on track. So, that's 70,000 people removed from the baseline with a calculator compared with 90,000 removed from the baseline through 12 weeks of direct-acting antiviral treatment and a billion dollars of taxpayers' money over 5 years. And, you know, without making an argument about the mathematics involved in that modelling, that's the scale of it. That is deeply political. You know, what the implications are, you know ... That's not just maths. - ... an enormous amount of trust that is required, you know, to support and accept those re-estimates without question. Yeah. That's a big expectation 13

it actually causes tension in the sector around this because changes to the numbers of people living with hepatitis C actually have an impact in terms of where hepatitis C fits on the list in accordance with other disease. So, if the burden of disease goes down, it actually de-emphasizes the importance of hepatitis C relative to other diseases. So, as I said, it's very fascinating watching this unfold and how do you work collaboratively with all of the stakeholders to also provide confidence in the estimates that are generated because then it ends up becoming concerns about, well, was this modelling wrong, why wasn't it done correctly. Well, that's not the case. The case is that you just have to adapt as new data comes in to get closer to the truth and I think people sometimes struggle with this because they want a concrete number that doesn't change over time and so it creates a question in the estimates, but that shouldn't be the case. People should keep an open mind and as new data comes in, we improve our assumptions about the modelling and until we continue, and that's when we go back to testing. So, I think until we test in a range of settings, we need to be testing in drug treatment clinics, needle syringe programs, homelessness settings, mental health, primary care, private drug treatment clinics.- 17

I think it's all about whether or not we've got the numbers right in the first place. We are relying on the modelling largely from the Kirby, and we have to ... I guess, we trust that, that that estimate is correct, but it is an estimate and I don't know that it's correct. It's obviously been revised or revised down because it was a bigger number before, but it could be wrong, but it's all we've got at the moment, and while it gets revised all the time, they're still pretty big numbers. I don't know if they're right or not. -8

Timeline of knowledge and evidence

- Elimination is mostly perceived to have commenced with DAAs, 2016
 - Some awareness that big uptake of treatment would peter out
 - o 2019, people starting to try new things eg outreach vans
- 2020-2022 COVID
 - No energy in hep C elimination response

- couple of years during COVID, we had like absolutely no energy in the response - 14
- 2022/23 what to do now? How to reinvigorate the response? Feeling paralysis because don't know enough about target groups and size of the problem, and where to find people – risks doing more of the same, without leadership for change/experimentation/deimplementation
 - there's like there's conceptual stuff here that hasn't been quite kind of unpicked yet and it's ... the change has happened in like 3 years... ... the different arguments are bumping into each other and it's quite hard. – 23
- Currently waiting on or wishing there was data on (in no order):
 - Liver cancer death review panel
 - Liver disease registry
 - o Transplant data
 - Reinfection registry
 - Consultation
 - With sector
 - I mean we've been down this road since 2016. We're 6 years down the road. I don't think there's ever been any consultation. ... I think now's the time for everyone to get together and, you know, really evaluate what's happened. As you say, what's the missing and how are we going to get there next? Because otherwise we're just going to continue on for another 8 years and the next thing you know, it'll be 2030 and, you know, we're still missing 50%.- 10
 - With community
 - the missing voice, of course, is the people, obviously with hepatitis
 C, those people who haven't come forward for treatment 6
 - •
 - Testing results to give prevalence data to
 - Drive local responses
 - Update estimates/modelling
 - as we start to test more and more people, I wonder if that's the only way that we're going to get a true handle on how many people are left. So, I think as we start broad-scale testing in a range of different settings, we'll get a better handle on how much hep C is still around.- 17
 - o Data linkage
 - Linked with admin data re other indications of social marginalisation (SES – geographical area; social security; housing)
 - Qualitative data
 - What are barriers to staff offering testing
 - Private drug treatment services
 - Better data from private labs
 - You know, we can't get the private labs to provide us with certain really simple data. No cost to them. We're prepared to pay for it, but there's all sorts of rules, whereas they suddenly were able to with COVID. So, we know these things are possible. It's not that they're not possible. - 7

- o "cobbled together" local data
 - Testing results from local initiatives/responses
 - Community feedback
 - build capacity of organizations to capture information. So, they could turn around and say we've tested these number of people and this proportion was positive. I think that is really useful because it tells you what you should be doing more of and what you should be doing less of. So, it's got to be sort of nuanced, though, to the context. It's got to be contextualized because the numbers are going down and the complexity is going up. So, you know, people are spending more time with fewer people 6
 - I guess what we see is a real lag between the epi data, and then what's kind of happening in the community and the importance of elevating multiple community real time experiences and that this is a legitimate form of evidence and then multiple kinds of evidence and knowledge needs to come together to say, "right, kind of what's going on? And how do we assess this?" 23
- Data on Aboriginal people
- Data from individual clinics via chart review/audit for QI processes
 - why is provider A doing a great job and provider B is doing a less good job and how you can help provider B overcome some issues that they may be having in that particular setting, so that value of almost real-time data so you could really take some action for quality improvement. - 21
- Country of birth
- Minimum data set
 - minimum dataset that we used to report on to the Ministry of Health, and all LHDs had to do that. That got stopped not long after the DAAs came in. ... used it as an internal document because it was really good to show, you know, what populations we were targeting, you know. How many homeless people, for example. So, it just gave you a bit more of an idea about the trends in your LHD and therefore gave you places to target,- 10
- What to do to reduce stigma?
- Participatory modelling
- o Pilot projects to drive new initiatives
 - some little demonstration projects internally first, to get some evidence that that work has the opportunity to work and then we base sort of pilots on that work. - 24

Stigma

The effects of stigma associated with injecting drug use and by extension hepatitis C was commented as important to a number of different aspects of elimination.

Accessing services

stigma obviously plays into a lot of that because we've got people who just aren't going to want to access care regardless of, you know, what's offered and what's available. - 18

we haven't talked about stigma and, you know, the concept of a trusted service where people can go and know they're not going to be treated poorly -6

de-stigmatizing not just hepatitis C, but injecting drug use within the Aboriginal community, I think there's still a lot of work to be done around that, especially the workforce that are coming into, you know, Aboriginal health spaces, I think, there should be some work done, you know, around they're going to come into them spaces, they need to be more culturally appropriate and really understand some of the challenges and, you know, the people that they work with -1

Tensions between epidemiological characterisations and generating stigma "ourselves"

And I think that's really interesting and so, you know, we talk a lot about stigma and breaking down stigma. Yet, we're obsessed with putting people into categories that may be stigmatized or stigmatizing as opposed to just dealing with their health issue. So, it's a bit of conundrum for me. -... start from within ourselves thinking about this, as I said, as a health issue, as you know, liver health, as something broader, then I think that we can probably go towards breaking down some of the stigma that we ourselves generate or perpetuate.11

While you're saying we got to reduce stigma around this disease, we're almost inherently stigmatising. So, I really went for this baby boomer approach to really destigmatise it, to have a more normative approach to this, that this is a community problem. This is not the other problem. This is everybody's problem - I think for a general message, I think we just should say this is a disease that's curable and it causes liver cancer and, yeah, if you have it at the moment, at that point of getting treatment, it doesn't really matter how you got it. -21

Normalising calls for hepatitis C testing, "alongside any other illness"

the EC Australia It's Your Right campaign, you know, splattering all over billboards and bus stops and all of that sort of stuff. You know, public health information about hep C testing and treatment is incredibly helpful and it goes to destigmatizing hepatitis C. You know, if you see it everywhere, then I think that the fact that drugs are ... it's better than nothing. You know, the epitome would be some decent drug law reform even if it was kind of in that decrim diversion, you know, the diversion type space in New South Wales, but in the absence of that, you know, I guess, increased funding into normalizing, when I say normalizing hep C, just recognizing hep C alongside any other illness rather than it kind of being so stigmatized. – 15

less stigma as a marker of achieving elimination

I think we'll know [we have reached elimination] when there's a hell of a lot less stigma around hepatitis C. I think we'll know when, you know, people kind of talk about getting hep C treatment as just sort of par for the course in the same way that the community of men who have sex with men talk about being on PrEP - 15

Underinvestment in stigma research, especially in comparison to other types of research:

stigma and discrimination and drug law reform related issues, but it's still an area that we've made a very modest investment in. If you think it's a really crucial central issue, we've thrown all this money at treatment, I'm not saying it's inappropriate. We've thrown a lot of money at the epidemiological research and other sort of areas of research, but there has been very limited investment in these sort of parallel and related sort of issues that need to be addressed, and maybe that's partly because the solutions seem less clear and the task seems much greater -4

Communication, health promotion

Who to target? Benefits/costs of a risk-based approach?

to understand the hep C affected population through a lens of risk and incidence alone means that we filter out the majority of the population. -13

targeting them, you know, the family person with the surfboard -1

Modalities - community, targeted social media

the hairdresser, the butcher shop, you know, that type of place in that as well, you know. How do we do health promotion campaigns or get information to that everyday Australian that are accessing them - places where people have yarns 1

It's about identifying where are the population groups that we think that are hardest to reach, men over 50 or anyone over 50 or over 40. A lot of them appear to be on Facebook, ... TikTok may work for Aboriginal communities, Instagram may work for Aboriginal communities because we do have just no evidence-based advice that those ... certainly, Instagram is a preferred source or social media mechanism for people of Aboriginal/Torres Strait Islander cultures. TikTok seems to be something more for younger and culturally diverse population groups. – 12

Pollinating different groups - not just repeating the same

need more and more people who are really engaged and who become mobilized in this right, so kind of like pollinating of different groups, and so I think lot of us unfortunately like are always at the same meetings right, so are we saying the same things to the same people and it's exciting and it's fun and there are a lot of innovations within that space but then to actually permeate within like the GP conferences – 19

the question here is how do we engage with those who are disengaged, who are lost to follow-up or whose risk factors are historic, you know, 30 years ago. How do we craft messages that can reach those people, you know. It's really tricky. I think if this was obvious, if this was doable, easily achievable, not necessarily easily achievable because the next thing I say is going to seem unfairly critical. If it was straightforward, researchers would be doing this. 13

Need to repeat, requires ongoing investments

but it wasn't sort of until they had the screensaver, the mousepad, the pen, they saw a card that it was like, "Oh, okay. Hep C," ... So, for us you've got to keep the message refreshing and coming as many times as possible, that actually just seeing it once is not often enough for people to act. They need to see it again and again and then they act ... What we found is that people need multiple messaging and multiple locations and that's the clinicians, that's the community, clients- 9

shifting narrative, "I could be part of this picture"

shifting the narrative away from hepatitis C as something that happens to injecting drug users to hepatitis C is something that happens to people ... because people will not see themselves in that missing. You need to get people to see themselves in the missing. Not just us to see the missing, the community needs to recognize, "Oh, hang on. I could be part of this picture." You know, you need to start sparking those thoughts because that then drives behaviour of "I'm going to go to the GP, I'm going to ask for this and I'm going to find out about this," you know. "Could it be me?" And I know that was a tagline from one of our campaigns, but you know, so I think that needs to happen as well, Carla. I mean I think we're just too focused on that and have been and I think it's been to the detriment. We've gone beyond missing to invisible. - 11

Other clinical benefits – cure of chronic illness, Liver cancer focus

cure for other chronic diseases, doctors would be handing it out like nothing - 1

we've tried a few different approaches in the media and how we talk about it and we actually have been doing promotion around cancer awareness and liver cancer and trying to remove that stigma associated with injecting and hep C. So, we have encouraged a hep C test if someone's never had a test in that sense of that liver cancer can be prevented if you have a test. So, we've tried that. -9

primary care doctors aligning hepatitis with is just general liver health and then considering, like we do a lot of work in metabolic disease and check people's cholesterol and the whole idea of fatty liver and kind of viral hepatitis kind of being both ways, you can promote liver health and prevent liver cancer I think is important messaging too. -19

... like what we have also tried to do is to make sure people realize there it is a social justice issue, it's health equity, it's maternal child health issue, you know it's a chronic disease prevention issue, so I think it's all these other pockets that it affects and yet it is still considered like this STI, you know drug user thing and so I feel like we have missed the opportunity or we need to keep honing in that it's so much more than that - 19

Multiple narratives, needs ongoing and new investment

there will need to be additional resources put into it because you need to continue to reinforce the health promotion messages for people who inject drugs, but you need to find ways to reach out to other groups and the groups are going to be identifying differently. So, you can't have just one strategy. - 12

This current moment in elimination story: it's the start of elimination [see timeline above and reinvigoration "after" COVID]

"This isn't the end. This is the start of elimination in Australia." You know, he said we just need to keep ramping up our efforts – 1

getting at the pointy end - sort of feeling like we're reaching saturation to get people on to treatment and now it just feels like it's uphill [laughs], it's going uphill again trying to find some hidden, you know, population and trying to get to reach out to those that have been living with hep C, but they haven't come to the services 2

Sustainability of elimination: "how long can we keep looking?"- 22

Understandings of costs of elimination

just a fact of disease elimination that the last 10% are much more difficult to find and treat than the first 10%. – 21

I talk to the nurses about a lot, is their outputs are going down. You know, they're testing and treating fewer people, but they've never been busier. So, the investment that is required is going to increase more, I think, as we get closer to elimination because we've got people that are requiring us to really work in different ways and that is, you know, nurses who I know who go and meet people on street corners and drop off drugs every week, they know they're going to be there because there's a certain food van that's there at that time, you know, and they're curing people, these people are being cured because they're motivated, they want it to happen, but they've also got somebody who is prepared to work differently and support them in their needs ... some sort of measure of marginalization to be able to ... not for general consumption, but to be able to say to funders, "Okay, I used to treat 100 people, now I treat 50, but that's because 40% of them are homeless, you know, and then 20% are this and I've got to work differently. – 6

Investment, security of funding and priority? - for government and pharma

funding, dedicated funding to do this work because having these goals within strategies and just hoping for the best and carrying on with what we're doing currently is not going to achieve elimination. So, extra effort and energy and drive is needed ... If you're serious about eliminating hepatitis C, be serious about investing in that. Otherwise, you are not going to achieve elimination.- 5

need for reliable ongoing secure funding. (eg pilot projects) ... That bought us 3 years of a nurse who has been able to go out and create relationships, create systems, create networks, and that funding runs out in March. We've got all the evidence in the world to show that the project works, that it's really treated some marginalized people that would never have had access to hep C care, and yet the funding sort of ends. So, there's a bit there, to me, about security to 2030- 6

at some point it is going to stop being a priority for government and for industry, and like what do we do then? Like what's our plan B or what's our contingency when the funding, you know, and the interest drops off because it will, you know. And actually I wonder what that threshold is? What is that threshold? So, we've got the 50,000 and everyone is still really super-invested, but if we get to say 40 or 30,000, is there still going to be the same level of interest in finding that remaining? Like what's our threshold for stopping, taking the foot off the brake? ... because we're spending a lot of money not in the scheme of things, but you know, there's still a lot of resourcing, I should say, not a lot of money because it's actually not a lot of money,

but a lot of resourcing to find 50,000. How deep are we going to go and how well resourced will we be as we get closer and closer?... (pharma) Like if we're continuing to find people and there's less and less prescriptions being written, I don't know how that all works and what their investment will be - 18

for local practices eg audit review

In the big scheme of health concerns, 50,000 is, yeah, it's not a big number. So, I think that's why with Beyond the C, even though it was small numbers, we were still really pleased because it's such a labour intensive, you know, high cost activity for practices to be involved in, that for them to find, you know, even 40 people to recall and have a few treated with a great success, because of the amount of effort required internally to find those people and, you know, even we were having some practices say, you know, "What do we say to people when we find them?" You know, there's still that concern from healthcare workers about having that conversation. - 18

Prison

big whole prison testing events which are very, I think they're quite disruptive, so it's a great kind of elimination program and I'm not sure it could be sustained over the long term for most prisons, - 16

Leadership and recognition and legacy

Australia recognised as a leader in hep C elimination

- Australia has played a really big part in this. So 20
- Australia is already ahead, but like if you could put your stamp on like having actually eliminated hepatitis ... and you are so close, you are already like ... I am so far, you have already removed so many of the barriers that so many countries are still struggling with – 19

NSW - Well-regarded, achieved much already, MOH includes people with knowledge and commitment, CHO can be very powerful in elimination effort.

- New South Wales has been a leader in the development of strategy and the delivery of services globally. So, I think that should be recognized. I think it's important to note that it's actually a good news story – 17
- I think you've got some people there that are very well meaning. They understand the issues. They articulate their desire, I suppose, for some improvements on those sort of fronts, but sometimes they're just simply constrained by legislation, by other competing priorities or other agendas, you know, political and otherwise. So, I think we need to, and

I'm talking about the broader sector, we need to take the opportunity that there are really good people in the department. It's actually quite different to the Commonwealth where people change every second month. We've got some really good people there, really committed, been there for a long period of time, including Kerry as the Chief Health Officer. So, I see it as an opportunity, I think, you know, to sort of in a sense sort of sit down and say how can we take some of these sort of agendas for what they would do? What are the realistic sort of opportunities that we have over the coming years? ... New South Wales Health, I think, are probably quite well regarded and respected by many people in the community because of their genuine sort of commitment -4

What's missing from NSW response:

What's missing in the New South Wales response is <u>that acknowledgement of the other</u>. ... we can't just treat at-risk populations, test and treat at-risk populations and think that we're eliminating anything, you know. It will eliminate over time as people die with hepatitis C or die because of hepatitis C, you know, but there's a futility to focusing entirely on one component of the prevalent population at the exclusion of others- 13

so the majority really, kind of got left behind and a lot of the policy making and messaging and service provision didn't really consider that group, and then in some ways, that <u>schism</u> really consolidated over the, you know, in the ensuing years. I don't think we really have made up much ground in that space. – 11

The committees, you know, one of the things that's been disappointing is not having anyone senior at the hep implementation committees, if we're even still having them, I don't know. You know, like those have been like a very lacklustre affair over the past few years, and I think we need that drive from, you know ... well, probably Kerry to be honest. Like we need Kerry to be kicking butt, you know, taking names. You know how she is. ... I want Kerry to kick some ass – 14

KPIs

There was some support for KPIs set by NSW Health for accountability and to drive performance in areas that were considered to be underperforming, especially the AOD sector.

you look at New South Wales and think they're so far ahead of everybody else in that they've at least embedded KPIs within the structure of health services or the local health districts. So, that helps to prioritize and provide some sort of profile for elimination. I think that, and I know that's been sort of problematic, but yeah, that is one way of trying to drive some sort of change by changing the system and getting the system as an advocate -6

like AOD services and NSPs have KPI on this. They need to have clear targets as well.- some sort of target or, you know, accountability and, yeah, something for them to work on to contribute to, yeah, to target part of hep C elimination strategy - when we did some in-service at drug health, some clinicians still think that, you know, like hep C is not, you know, their sort of target.- 2

... if you can't work out how to test everybody for hepatitis C coming through a drug and alcohol service and know you have tested them and know their status and know that you need to test them actually annually, I don't understand why they get given money. You know, why are they not having a performance thing? - 7

However, some participants critiqued current framing of KPIs as "test and treat models" as overly rigid and a limited way to conceptualise elimination success, or to organise health systems to have effective impact on individual's health.

I think it's weird when you look at their obsession with LHD-based treatment uptake. I mean I just find that really odd and, you know, they've got KPIs and CEOs get a letter that they haven't met their treatment uptake target. I mean I just find that such a weird, rigid sort of format for success. So, I think it's trying to, as you described, reimagine opportunities and where we might head to find that missing link. 4

we're narrowing the hep C interventions to such a kind of test and treat kind of model that you know, the whole other, I don't know, the health and wellbeing, you know, other stuff, the harm reduction, the brief interventions, the mental health, like all the other stuff, it doesn't have a space to report on, it's not allowed to count, there's not a way to kind of do that outside of the test and treat model, and you know, a lot of this, it relates to this kind of obsession with treatment as prevention and all this ... these are all like really interesting kind of like unintended consequences of these pushes, but it's just the pushes also, are kind of working and so it's changing and so it's like, how do we recalibrate when parts of it work? And how do we frame that really positively in a space that used to only dealing with things that are broken and not working. - 23

While acknowledging the importance of KPIs to drive performance and provide profile, participant 10 also describes the limited information that is available when KPIs are the only source of information (in this case KPIs on treatment initiation devoid of context of where testing/treatment was taking place, who was receiving treatment etc)

having a KPI for all LHDs and I think the NGOs should be having them as well ... I think they drive people. The fact that we now have to report to the Ministry on those and, you know, funding can be linked to those. I think it's really important. I think if they didn't put those KPIs in, people would just be going along as normal and would not be putting as much effort into meeting those. I mean some people that are passionate would, but the majority would just be going, "Look, there's no KPI. Forget it," because in LHD land that's what drives your work, is the KPI.-... having a KPI just with an initiation number and reporting on a number is not giving us much information at all. 10

Legacy

The political opportunity for NSW (and its politicians) to claim legacy of elimination was noted. This legacy was discussed in terms of the strengths of NSW as a recognised international leader in this space, and the relatively less contested field (compared with HIV) and the processes for reporting of elimination dossiers to WHO.

compared to HIV, there are so few people in the space that they would actually be visible, yeah, and they would actually get quite a bit of attention around them and I think we need to do a better job of kind of pitching it as a legacy type thing for politicians and at least with the hep C, you know we already have the cure as there is a chance to do this in their lifetime. -19

we have guidance on what we are looking for, what WHO is looking for to validate or verify that you have eliminated it, so you know the country would submit a dossier and it will be viewed by the regional committee - 19

Learnings and cautionary tales from other infectious diseases

- COVID
 - Hyper local approach for CALD communities
 - get all those more district-based services on board as well in this picture. So, it's almost like, you know, you kind of need to make sure that your HARP units are on board and your liver clinics are on board and then you've got your PHN which represent a particular area, and so they're all working in synchronicity in the delivery of a range of very, very localised and nuanced strategies which broadly resemble each other but actually speak to the communities that are there, and that are quite different. I mean across Sydney in particular. You know, what you've got in inner Sydney is very, very different to what you've got out at Southwest or Western, you know, or beyond. - 11
- measles/polio resurgences

- o communications, expectations
- I mean WHO didn't say elimination in the same language as polio elimination. Alright? They said eliminating is a public health threat which means they actually do accept that there will be new cases, there will be people untreated and quite substantial numbers. I mean numbers like 80 and 90 sound really high until you realize that that's the overall number and it's going to be much higher in certain populations – 22
- that's really got this problem and really sort of increase the social norm of this is an unacceptable disease that is curable, eliminatable, and it's just like when we have, you know, people get upset when we have a measles outbreak or they found a polio case in New York City. We've got to get to that kind of mindset where, no, this thing was almost cleared out and now we've got this last little bit.- 21
- HIV
 - Shaping notions of elimination
 - ... I think perhaps the successes from HIV infection around treatment as prevention started to like mobilize the hepatitis C field to be looking at that. - 17
 - Medicare ineligible
 - because they don't have Medicare with them at the time. unable to provide sort of compassionate care either in terms of hep C treatments. I think it's unlike HIV treatment - 2
 - o possibilities of community advocacy
 - the unity that you have and had with HIV in terms of one particular group affected who weren't really good historically, you know, particularly coming from America in coming together, raising awareness and lobbying for change because they had already done it in the HIV field. - 20
 - o what can be achieved in social media
 - I think the work that I've seen in terms of HIV, particularly around Middle Eastern men who have sex with men who don't necessarily get identified, it appears that what's been presented to me is that it seems to work.
 - Downward comparisons from HIV to hepatitis C re quality and availability of data to "know the epidemic:
 - ... clearly a big difference from, you know, the HIV sector where you know everything about everything about everything and there's more data than you could ever work your way through in a lifetime, and this has been an issue since I ... you know, I have been part of this picture since 2004 11
 - we really need to have that granularity of understanding, that very nuanced understanding about who are these communities, who are these people, you know. Who are they? Where do we find them? What are their lives like? How can we best intercept with this? What is going to make this something they want to be doing? What are the myths and misconceptions that they labour under that we can work with? What's the stigma? But we really don't know very much, and again, I go back to, you know, if you think of the absolute investment in data that is, you know, that underpins the HIV response, there's a very specific reason why they've been able to achieve what they've been able to achieve in, you know, significantly reducing and

being well on the way to ending transmission, and that's data because it doesn't just paint a picture of the now, it also gives them a really good indication of the before and after. So, you know, they've been able to really clearly demonstrate that the things that they put in place actually had an impact down the line.- 11

- More opportunities for political legacy in HCV compared with HIV
 - compared to HIV, there are so few people in the space that they would actually be visible, yeah, and they would actually get quite a bit of attention around them and I think we need to do a better job of kind of pitching it as a legacy type thing for politicians and at least with the hep C, you know we already have the cure as there is a chance to do this in their lifetime. - 19
- o availability of resources
 - better coordination of the current resources, I think, you know, is a very smart approach because there just aren't a lot of resources again compared, you know, it is the poor cousin of HIV and then hep B is the poorest cousin - 11
- integrated screening antenatal screening, ED
 - antenatal is for everyone. You know, so we already test for HIV and hepatitis B in antenatal. So, they're adding in hep C. That's kind of a tricky one in terms of it doesn't meet the screening criteria – 16
 - in the ED testing, that is hepatitis C and HIV and hepatitis B, you know. Don't take someone's blood and only test it for one virus. It's a wasted opportunity and trying to kind of really integrate it, make it a long-term system -16
- Claims of elimination in other settings
 - $\circ \quad \text{Lotus Glen prison}$
 - prisons and I think we're always going to be chasing our tail, aren't we? I always go back to the Lotus Glen, "Oh, look at us, look at us, we've eliminated." So busy having a party, they didn't quite notice it got back in again. – 6