

The ‘missing’ in the ‘endgame’ of hepatitis C elimination: A qualitative study in New South Wales, Australia

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Abstract

Introduction: After a promising start in Australia, elimination efforts for hepatitis C are not on track. Following the global campaign to ‘find the missing’ in hepatitis C response, this qualitative study explores stakeholder perspectives on the ‘missing’ in the ‘endgame’ of hepatitis elimination in the state of New South Wales, Australia.

Method: Twenty-eight key informants working in New South Wales, elsewhere in Australia and internationally in high income countries participated in a semi-structured qualitative interview. Analysis examined key informant accounts of the ‘missing’ in efforts to eliminate hepatitis C.

Results: Participants’ accounts framed the missing in relation to epidemiological knowledge, making-up four population categories ‘missing’ or ‘missed’ in hepatitis C response. In turn, accounts situated the missing in relation to where and how individuals were presumed to connect, or not, with existing health-care infrastructures. This gave rise to concerns about the capacity of health services to be made available for those at risk or in need, with systems said to create opportunities for people to ‘miss out’ on hepatitis C services.

Discussion and Conclusions: The ‘missing’ in the ‘endgame’ of hepatitis C elimination effort is not simply a function of who—populations missed—but of where and how, that is, situation and context. Our findings encourage a focus on how services, systems and contexts may create situations in which people become missed or are ‘made missing’ from care. We therefore advocate for a systemic, and not only population-based, approach in the final push towards hepatitis C’s elimination.

KEYWORDS

elimination, health services, hepatitis C, populations, strategy

Key Points

- To address significant gaps in testing for hepatitis C virus (HCV) we need a better understanding of who and what is missing from elimination efforts.
- Previously relied upon descriptions of ‘who’ was missing are insufficient. We also need to understand the ‘where’ and ‘what’ of service design and delivery.

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- Eliminating hepatitis C is a challenge of social and structural change to ensure that services and systems do not miss the needs of the people they seek to serve.
- Achieving HCV elimination will require multiple constructions of HCV that are informed by knowledge that is locally connected to context.

1 | INTRODUCTION

Hepatitis C virus (HCV) is a blood-borne virus that can result in significant morbidity and mortality: 16% of people living with chronic HCV and without treatment are estimated to progress to cirrhosis at 20 years post infection, and 40% at 30 years [1]. Highly curative direct acting antiviral medications were made available to all people living with chronic HCV infection in Australia in 2016 [2]. Since then, a global effort was established to eliminate HCV [3, 4], including cascade of care consensus [5], analyses of investments and phasing of efforts [6, 7] and establishment of global targets [8].

New South Wales (NSW) Australia is considered a 'world leader in the prevention, testing and treatment' of HCV [9]. The most recent HCV strategy (published 2022) recasts the global targets, including escalating the target year for elimination to 2028. The NSW 2022–2025 targets include incidence (60% reduction), harm reduction (20% or less reported receptive syringe sharing among people who inject drugs; 10% increase in distribution of needles and syringes), testing (10% increase in antibody tests; 20% increase in RNA tests), treatment (65%) and mortality (50% reduction). Importantly, targets have been included for the first time for reduction in stigma and discrimination foregrounding the importance of social and structural contexts for delivering HCV elimination (75% reduction in the reported experience of stigma and discrimination among people affected by HCV and among people who inject drugs; 75% reduction in the reported incidence of stigma and discrimination towards people who inject drugs by health-care workers).

The impetus generated by these targets has centred scientific and policy attention on particular affected populations. People who inject drugs figure prominently in the epidemiology of HCV in Australia. Epidemiological data from a number of sources was used at the beginning of the century to characterise the Australian HCV epidemic as comprising 90% of incident infections and 80% of prevalent infections experienced among people who inject drugs [10, 11]. The current NSW Hepatitis C Strategy lists the following as priority populations: people who currently inject drugs, people with a history of injecting drugs, Aboriginal people, people living with hepatitis C, people in custodial settings or with a history of incarceration, and people from culturally

and linguistically diverse backgrounds. The selection of these is based on 'groups with a higher prevalence of hepatitis C, higher risk behaviours or who experience greater barriers to accessing services. People belonging to several priority populations are especially vulnerable' [9, p. 9].

In 2018, Australia was described as having laid the groundwork to be on 'on track' for elimination through the provision of high levels of screening and diagnosis, unrestricted access to direct-acting antiviral therapy, prescribing authorisation for all registered medical practitioners, authorisation of re-treatment, a diverse range of models of care, high coverage of harm reduction strategies [2, 12] and funded civil society organisations to promote awareness among community and health professionals [13]. In the most recent surveillance reporting, the proportion of attendees at needle and syringe programs who have HCV antibodies and have received HCV treatment increased to approximately 62% (from 11% in 2015) and prevalence of HCV RNA (marker of current infection) declined from 51% in 2015 to 16% in 2021 [14]. However, a mathematical modelling study published in 2020 called for vastly greater efforts: 'If current trends in testing and treatment continue ... it is projected that by 2030 only 72% of infected people would be treated ... The incidence of HCV in 2030 would be 59% lower than in 2015, well short of the WHO [World Health Organization] target of an 80% reduction. The identification and testing of people exposed to HCV must be increased by at least 50% for Australia to reach the WHO elimination targets' [15].

To address the significant gaps in testing numbers shown in modelling studies we need a deeper understanding than can be provided by broad epidemiological categories of exposure, some of which are historic, to direct action. Epidemiological science, as well as campaigns to promote elimination goals, use conceptual logics that construct 'the missing' in specific ways, largely with a focus on 'at risk' populations yet to have been reached. These logics generate specific ways of understanding and of doing elimination, and thus also, of evidencing if and when elimination has been achieved [16–19]. Yet the logics of missing population may not be the only way to frame the 'endgame' of HCV elimination, and thus, it is important to explore alternative frameworks to inform action.

We undertook qualitative interview research to explore stakeholder interpretations of the ‘missing’ in the ‘endgame’ of elimination. Importantly, we consider not only ‘who’ is missing, but also ‘what’ is ‘missing’. This reconfigures the ‘problem’ of ‘the missing’ as not only relating to epidemiologically derived categories of ‘affected population’ but also as a matter of missed connections, missing services and infrastructures, missing knowledge, and indeed missing ways of conceptualising HCV elimination futures and how they might be brought about.

2 | METHOD

Key informants were identified as those working in the HCV field including direct clinical care, research, program design, advocacy (including in community-based organisations) and governance. To ensure that we captured a range of perspectives of HCV elimination, we looked to experts working within NSW, other Australian states/territories and internationally in high income settings. Sampling was undertaken in line with the concept of ‘information power’: that is, the more information the sample holds, relevant for the actual study, the lower the number of participants required [20]. A list of potential participants was generated by the study authors. Other participants were identified via hand searching of programs of recent national and international HCV conferences. Interviews were conducted via video conference between July and September 2022.

The interview schedule asked key informants to comment on: ‘who’ is missing in elimination efforts; ‘what else’ might be missing, including in relation to workforce, infrastructure, data, resources and policy; and how we come to know what is missing in the elimination response. In this semi-structured interview, we also invited key informants to think speculatively about HCV elimination, including to inform the provision of strategic advice to NSW Ministry of Health to shape the next 6 years of action to achieve the local 2028 HCV elimination goals.

After informed consent, audio-recorded interviews were conducted by the lead author (Carla Treloar) and lasted 30 min to improve study feasibility. Approval was provided by the University of New South Wales Human Research Ethics Committee (HC220290). Participants were not reimbursed.

Interviews were transcribed verbatim and checked for accuracy against audio recordings. Analysis for this paper was guided by iterative categorisation methods [21] and centred on participants’ discussion of the notion of ‘missing’, particularly in relation to ‘who’ (population

groups), ‘how’ these groups were missing out and ‘what else’ was needed for HCV elimination. We attribute quoted extracts to participant numbers only to minimise risks of deductive disclosure. Our analysis of data are informed by critical social science scholarship that positions HCV as ‘under construction’ [22]. Here, HCV is understood as an ‘emergent phenomena, constantly being made and remade by social forces’ (p. 5), including how ‘conventions and values and social practices such as health policy and stigma make the disease as much as microbes do’ (p. 11). HCV elimination can thus be seen as a ‘gathering’ of multiple social and material forces that come together in space and time [23]. This emphasises HCV elimination as an evolving process of ‘evidence-making’ in which a variety of actors and forms of expertise are involved [24, 25]. HCV elimination targets play a crucial role in the evidence-making of viral elimination, as do epidemiological measures and mathematical models that relate to these [17, 26]. A key matter of concern is how measures and understandings of viral elimination relate to the social and material contexts in which viral elimination efforts take place.

3 | RESULTS

Interviews were conducted with 28 key informants: 10 in roles in NSW, 4 in roles relating to other Australian jurisdictions, 9 in national roles and 5 were working in other countries. Experience in the HCV sector ranged from 1 year to more than 20 years, with the majority reporting more than 5 years (24/28) and 10 or more years (19/28) with 10 having more than 20 years’ experience.

3.1 | Who is missing?

Participants tended to make sense of ‘the missing’ in relation to epidemiological categories of ‘at risk’ population, focusing on: (i) people who use drugs currently connected to or targeted by health services (primarily needle and syringe programs [NSP], opioid dependency treatment [ODT] services) or who are in prison; (ii) people who injected drugs in the past but were no longer connected to drug-related services or networks; (iii) people from migrant communities; and (iv) Aboriginal and Torres Strait Islander peoples. Although some overlaps between these four primary groups were flagged, the main distinction emphasised in participants’ descriptions of these population categories was point of access to the health system; that is, those connected to services for people who use drugs, as distinct from

those who are 'out there in GP [general practice] land'. The 'who' of 'missing' was therefore largely configured as a function of where and how people said to be at risk connected to existing health care infrastructures.

In relation to the population of people who inject drugs, some participants felt that drug-related services had been saturated with HCV testing efforts and that therefore little was to be gained in maintaining status quo. This was not a consensus view, however, with others concerned drug-related service provision was patchy or inconsistent, driven by perceptions that HCV was not 'core business' of drug-related services (participant 10). Here, there was said to be a need for specific targets to create accountability to help galvanise action:

'[drug-related] services and NSPs have KPIs [key performance indicators] on this. They need to have clear targets as well. ... some sort of target or accountability and something for them to work on to contribute to [the] hep C elimination strategy. When we did some in-service at drug health, some clinicians still think that like hep C is not their sort of target'. (participant 2)

The second epidemiological category used to narrate 'who' was 'missing' in HCV elimination efforts, people who previously used drugs, occupied much of the discussion, and were considered by some to be 'big chunks of the missing' (participant 13). This population category was considered particularly 'hard to reach' through current HCV testing because of the focus of these in drug-related services, lack of general community awareness about HCV (especially for those with historic use of drugs), the long latency of HCV symptoms and the stigma attached to drug use. Even if people were aware of HCV, asking their regular general practitioner for a HCV test might be unacceptable to these imagined 'family people' who 'dabbled back in the old days [with injecting drug use] and don't identify with that anymore' (participant 1). Here, HCV elimination was imagined not to have currency as a matter of identity or concern for past users of drugs.

'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'. (participant 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. ... 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 this 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'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"'. (participant 12)

Yet the size of this group imagined to be missing was highly variable. Participant 12 above, using their own recalculations of existing published data, specifies this second group as '50 + %' of people remaining with chronic HCV. Other participants who felt that this segment had been over-estimated drew on their own clinical experience ('I haven't actually had a lot of them', participant 7) and on trial data and clinical audits in general practice showing 'relatively few people that they could find through this larger GP network that hadn't been treated' to suggest that the size of this group has been 'overplayed' with potential to 'side track' HCV testing and elimination efforts (participant 4).

The importance of 'GP land' was emphasised in discussion of the third epidemiological category narrated as 'missing' from HCV elimination: people from migrant communities. Here, especially, we see the inextricable, yet often obscured, links in participants' invocation of a specific epidemiological category ('who' is 'missing') with 'where' and 'what' is missing in the HCV response. The consensus among participants was that not much has been done in these communities ('It's like no one is talking about it', participant 2), for HCV efforts had been mostly directed to engaging people in NSP and ODT settings. The need for a focus on people from culturally and linguistically diverse backgrounds was driven by the perception that 'we know the epidemiology' (participant 8), including the geographical patterns of settlement of

migrant communities ('look at the bloody map. It's not even hard', participant 7). The missing 'who' therefore also relate to 'where' the missing might be found.

There was little discussion by participants of HCV elimination relating to services for Aboriginal and Torres Strait Islander communities except to note some overlap with the first and second categories and that there is limited data presented about First Nations people in key reports relied on to characterise the geographical patterns of HCV in Australia. That led to needing to 'making the best of what's available but at the same time advocating for better data sources' to understand barriers within systems to best meet needs of First Nations people (participant 1). Such relative lack of targeted attention to the needs or concerns of First Nation peoples may speak to a broader structuration in who and what is made 'missing' in elimination efforts.

3.2 | 'Missing out' on services

Participants' accounts of 'who' was missing bring together notions of epidemiological risk with perceptions of service access and engagement. Here, narratives entangle the 'who' with the 'where' and 'what' to focus on how populations 'miss out' on service provision. The narrative of 'missing out' begins to shift the focus of attention to the failures and missing limits of services rather than locating the problem of missing as a characteristic of 'hard to reach' or 'at risk' populations per se. Participant 7, for example, felt the framing of people as 'missing' in the HCV response was pejorative, individually responsabilising, and dismissive of structural barriers to access. The shift from the 'who' of epidemiological categorisation, to a concern with 'where' and 'what', reconfigured the problem of 'the missing' and the locus of response.

'they're not missing. In a way we're missing ... we're missing them. ... 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 ... like say historical structural issues [in health care], funding and misunderstandings of things as opposed to the individual ... So, people aren't missing, we're just not where they are'. (participant 7)

The problem of missing is here re-located from the imagined unreachable 'out there' to the limitations of services 'in here'. HCV interventions were accordingly described as needing to be available wherever people intercept or intersect with the health system (and community services) and further that these interventions

should be multiply available to provide people with HCV choice of what best fits their needs. The 'clinical commitment' to provide those interventions in a range of settings requires an entangling of the missing 'who' and 'what'.

'[we need a] robust toolbox of how to make these interventions available ... to tailor your intervention where it meets the patient where they are ... these "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 in the case of women. ... 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'. (participant 21)

Designing services or infrastructures (the 'what') that are effective for HCV elimination necessitates an understanding of the missing beyond broad epidemiological categories of 'at risk' or 'unreached' population. There is a need for context-based and 'nuanced understanding' to 'paint a picture' of how and why people do not access services in order to re-design services to foster engagement built on trust (participants 6 and 14).

'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?'. (participant 11)

In discussing how to achieve health services that provide points of trusted intersection with individual's lives, participants drew on recent experiences designing COVID-19 responses which eschewed large scale epidemiological data to focus on building 'capacity of

organisations to capture information' (participant 6) to enable nuanced, contextualised and local data that could inform local responses. This required building capacity of organisations to capture data that could contribute to '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' (participant 11).

4 | DISCUSSION

As we enter the seeming 'endgame' of HCV elimination, our analysis indicates that understandings of this virus and how to respond to it, remain a work in progress [26]. Discussions of HCV elimination in this study highlight the making and remaking of categories of risk, identity and service need in relation to epidemiological knowledge that entangles with practice-based knowledge of various kinds. We see configurations of 'missing' articulated as a problem of 'who', drawing largely on circulating epidemiological ideas of 'at risk' and 'unreached' populations, combining with the 'where' and 'what' of missing based largely on accounts of social and material limits in service provision. Our study emphasises the need to see the 'endgame' of elimination not simply as a population-based problem of reaching the unreached but as a challenge of social and structural change to ensure that services and systems do not miss the needs of the people they seek to serve.

The conceptual logics and epidemiological constructions of HCV from 20 years ago—that 80% of prevalent infections and 90% of incident infections are among people who inject drugs—are not adequate to guide HCV elimination efforts now. Key informant participants pointed to numerous, sometimes overlapping, categories of people affected by HCV. But more than this, their accounts emphasise the ways that health systems are made up to engage, or miss, opportunities to provide HCV care. This resonates with previous scholarship [27], which suggests that diseases do not only impact on society, but are constituted by social forces including the ways in which health services themselves are constructed and delivered. In this case, the legacy of those long held epidemiological logics and the operations of the health system were seen by key informant participants to both make up HCV and to under-serve people in each of the four categories identified.

The four categories of unreached population described by participants draw on established epidemiological characterisations which frame the public health problem of HCV elimination. What was contested was the relative emphasis to be given to each. Accounts, for instance, revealed an uneasiness and lack of consensus

regarding the relative size of two categories at this point in elimination (people who currently and people who previously injected drugs) and the extent to which sufficient efforts had been extended to engage with them. Very little discussion involved categories of cultural and linguistic diversity and of Aboriginal and Torres Strait identity. These characterisations go beyond the need for 'discrete population' definitions as required for micro-elimination efforts [28]. These accounts suggest that typical descriptions of population categories are not fit for purpose to guide elimination efforts in HCV endgame and that different knowledge and logics are required, particularly those that bring sharper analysis of how health services are designed and delivered.

Participants identified that the usual, previously relied upon descriptions of 'who' was missing was insufficient: 'the missing' was described as being made up of the entanglement of a more nuanced understanding of 'who' along with the 'where' and 'what' of service design and delivery. This embellished construction of HCV elimination challenges both the programmatic view and the science of HCV elimination. Experts wanted greater granularity to aid their efforts, and to understand how HCV is made up for these groups: 'what are their lives like?'. This asks designers of health systems to think deeply about their approaches, to understand that their operations are part of how HCV is made for individuals and communities (especially in relation to how HCV is managed in the other aspects of their lives), to embrace different forms of local knowledge and to hold uncertainty as a key operational element of ongoing HCV elimination programs.

Key informants challenged the health system to acknowledge the impact of power in its HCV elimination efforts. Rather than framing characterisations of people as 'missing' (the who) to shift focus to the what: that is, the role of the health system in constructing the opportunities for people to 'miss out'. This led to discussion of providing HCV care in other areas of health and social service delivery, such as in emergency departments. Close analyses of people who inject drugs who have so far 'missed out' on HCV treatment show lives of complex, longstanding inequities and HCV treatment as unpredictable to attain when opportunities for treatment are reliant on a web of fragile connections [23, 29]. The reconfiguring of missing to 'missing out' does some of the work of lifting responsibilities off those with least power to achieve HCV elimination [30].

However, expanding access to HCV care in other settings for the purposes of elimination needs firstly to genuinely address the ongoing impact of stigma associated with injecting drug use [31]. Most work on expanding access to HCV treatment extends only so far as to engage

services that already serve people with a history or current experience of drug use and other experiences of social marginalisation—drug-related services, general practitioners who prescribe or pharmacies that dispense ODT, NSPs or other harm reduction services, prisons and homelessness services [32]. Some work has been done in opt-out screening and linkage to care programs in hospital emergency departments in Australia and elsewhere which meet standards for cost-effectiveness [33, 34]. Although these programs report that this approach was acceptable for participants, other analysis has shown the complex legal and ethical implications of projects [35]. There is very limited guidance on implementation of HCV treatment in mainstream settings, especially in general practice and especially targeting the categories of people who no longer or never did inject drugs, and for people from culturally and linguistically diverse backgrounds for whom the makeup of HCV may be informed by social, cultural and legal norms of countries of origin. The makeup of HCV for Aboriginal and Torres Strait Islander people is different again, and informed by centuries of colonisation and institutional racism [36, 37].

There is still much to understand and get done in HCV elimination; even with a short time frame to 2030 (or 2028 in the case of NSW). Eliminating HCV is much more than a technical and biological challenge: to provide prevention technologies at sufficient coverage and to get therapeutic doses of biomedicine into bodies carrying chronic infection. HCV elimination is inseparable from diverse social phenomena that make it up. Accounts of key informants direct us to think about the inherent two-way ties between how we have made up HCV in the past with epidemiological logics, stigma and power relations, and how health services themselves have been constructed to respond. While we are ‘doing’ HCV elimination right now, these findings help us to remain alert to the ways in which HCV and HCV elimination is being made up by social forces, and what might still be revealed when established constructions of HCV are transformed or reconfigured [26]. To achieve HCV elimination will require the undoing of commitments to universal approaches in favour of pursuing multiple constructions of HCV that are informed by knowledge that is locally connected to context, bodies and socio-political worlds: to understand the entangling of the ‘who’ and the ‘what’.

AUTHOR CONTRIBUTIONS

Carla Treloar: Conceptualisation; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Roles/Writing—original draft; and Writing—review and editing. Kari Lancaster: Conceptualisation; Formal analysis; Roles/Writing—original draft; and Writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

Carla Treloar has received speaker fees from Gilead. Lise Lafferty has received speaker fees from AbbVie.

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