Absence, presence, and engagement in the endgame of hepatitis C elimination

MOBILISING CARE FOR PEOPLE WHO INJECT DRUGS THROUGH A PEER- AND NURSE-DRIVEN VAN

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AT BURNET INSTITUTE, WE PROUDLY ACKNOWLEDGE THE BOON WURRUNG PEOPLE OF THE KULIN NATIONS AS THE TRADITIONAL CUSTODIANS OF THE LAND ON WHICH OUR OFFICE IS LOCATED AND RECOGNISE THEIR CONTINUING CONNECTION TO LAND, WATERS AND COMMUNITY. WE ACKNOWLEDGE ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES AS AUSTRALIA'S FIRST PEOPLES AND ACKNOWLEDGE THAT SOVEREIGNTY WAS NEVER CEDED. WE PAY OUR RESPECT TO ELDERS PAST AND PRESENT, AND EXTEND THAT RESPECT TO ALL FIRST NATIONS PEOPLE.

Disclosure of interests

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- SS, TD, MS, KL have no competing interests to declare in relation to this work.
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Eliminating hepatitis C by 2030?

2016 Global Health Sector Strategy: We have what we need to eliminate hepatitis C as a major public health threat.

Australia's early success: offering universal access to DAAs since 2016, accompanied by simplified care and decentralisation.

Race to elimination is now a quest for innovation: ~68,000 people in Australia still not linked into hepatitis C care in 2025.

There is an **urgent need** for new approaches to reach the 'missing' …

…or else we might miss the target.

Current work will identify **new models of care** for HCV that are **effective**, **acceptable**, **cost-effective** and **sustainable**, and therefore easily **scaled up** to increase HCV testing and treatment in key populations.

Slowing down to expand: ethnography in the elimination era

How are innovative interventions *'put to use and made to work'* in their respective environments?

How can we move towards thinking about *caring for and sustaining elimination* in the longer term?

Approach:

Ethnographic case study design

Case 1: The “Community Corrections” case

Data collection: June 2024 – July 2025

- Field observations
- In-depth interviews
- Project meeting minutes

Rhodes & Lancaster 2019; Lancaster & Rhodes 2023

"It doesn't stick out like a sore thumb" (CNM03)

*It looks like a clinic, **it looks like a real clinic**, yeah, it looks like, you know, one of those orthodontics, it looks like that.*

Oh yeah, because of that chair?

Yeah. It looks real, it's real, it actually does.

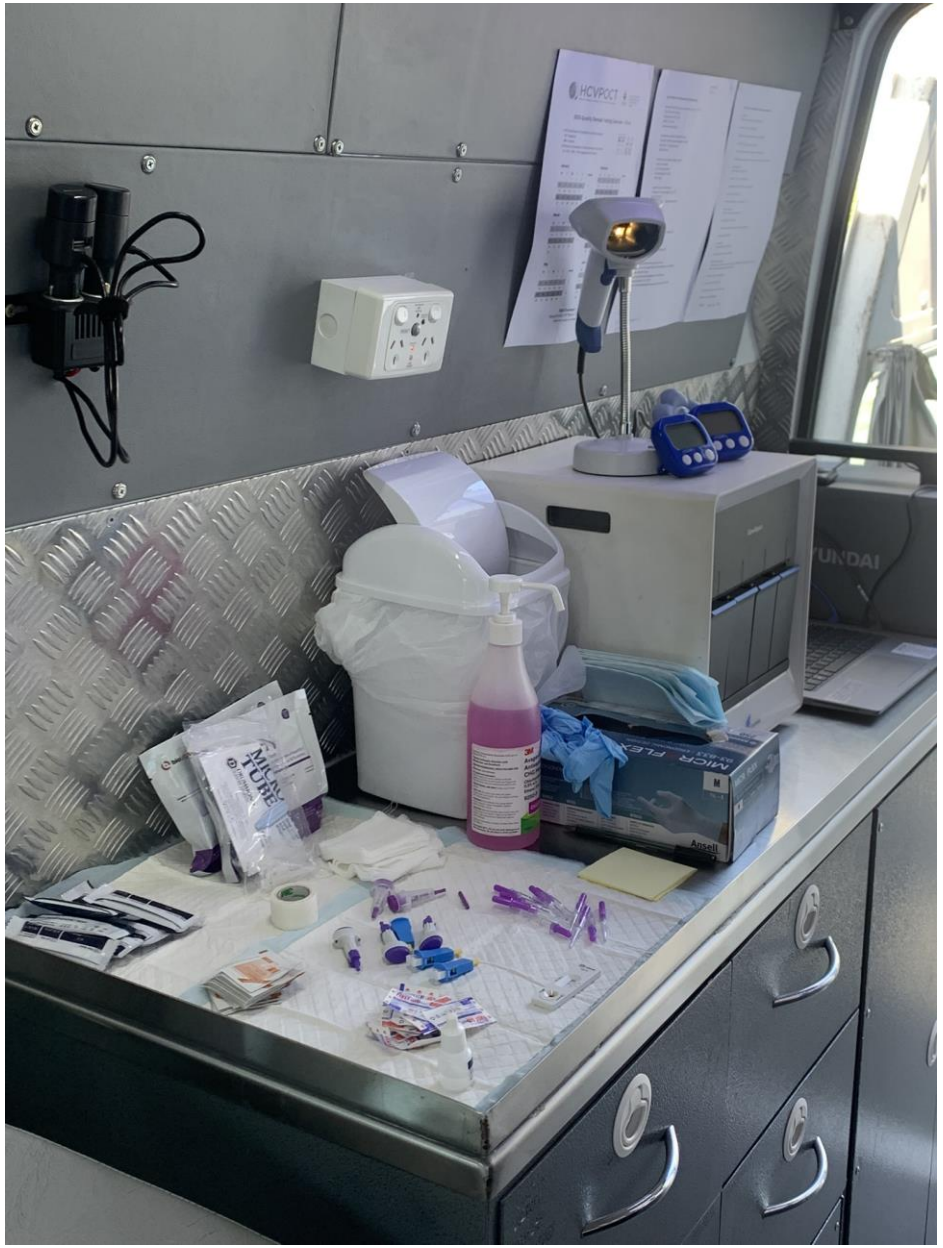
Mm. And does it feel like a clinic as well?

*Yeah, no, it's more comfortable, **more comfortable than a clinic,** you know, like it's **not as daunting**, like yeah, like you don't feel scared, like **you don't feel cold and scary**, you know, it's not cold and scary. Yeah. (CNM 13)*

The van in Melbourne metro site

Looks real – feels better

C no more staff practising fingerstick testing on a researcher



Clinic tools

Creating opportunities with presence

"Hey fellas, I'm from Harm Reduction Victoria. Want to do a finger prick test for hep C? $40 bucks." (Fieldnote extract)

I'm not sure how to explain that, because **as soon as I had a phone call and I knew the van was there I was straight down there** *like, but* **every other day I tell meself "I've got to get a blood test, I've got to get a blood test" but I don't go get it.**

> *You don't think about it as such a big deal because It's like you going to a van rather than you going to get a blood test?*

Um… **How do I say it? I thought I was getting the blood test**, *you know what I mean? I still flew down there, yeah. .. Then it was just a fingerprick. (CNM 05)*

Parking: critical to mobile care

A network of relations sustains engagement

11 positives in [study location] this month already. The last 2 months have been the busiest they've ever been. **"Nearly all these people have been in the too hard basket"** Mark says. (Fieldnote extract)

We often email each other or call each other very regularly about minor details about people because ***unless you keep a strong thread knowing where people are*** *and what they're doing and what they want and what they don't want,* ***they can't achieve the result that they want****. (CNM08)*

Nurse Bridget attempting contact

Care beyond cure

Yeah, he's a gentleman, **he's always, you know, looking out for me, and making sure I go to my appointments,** *I mean he goes out of his way. He doesn't have to, but he does, yeah. …*

Well, **if it wasn't for him and Bridget, I probably would never have done this**, *and then when I finally, eventually did do it, you know, blood tests or something, it might have been a bit too late, you know? I mean my liver would have been too far gone. …*

But **if you're too far gone, it's just bad luck, you know?** *Because there's only one thing and it's a transplant, and at my age, and my lifestyle, I wouldn't have a hope, you know,* **I'm a smoker, I'm a drinker, a junkie, you think the doctors are going to put me on the list,** *I don't think so. (CNM09)*

An awning protects against elements

Absent presence

They said they had vouchers and I was hungry. (CNM13)

….

Screening/doing the consent Bridget asks about his address. Sparks a conversation: Housing struggles are massive. **He lost his house, Centrelink during covid lost all his info, he didn't complain then but now he's fucked. It's a "computer says no" type scenario**. His address is a caravan park, they just think he's on holiday**. He is clearly worn out, cries...** Bridget can't do much more than give him numbers, for acute services, all in Melbourne.

Later in the car I ask about this – Mark says those services don't really help, the whole team agrees housing is a big issue and **those conversations are really hard because you need a housing worker to help but there just aren't enough houses.** (Fieldnote extract)

The waiting / survey room

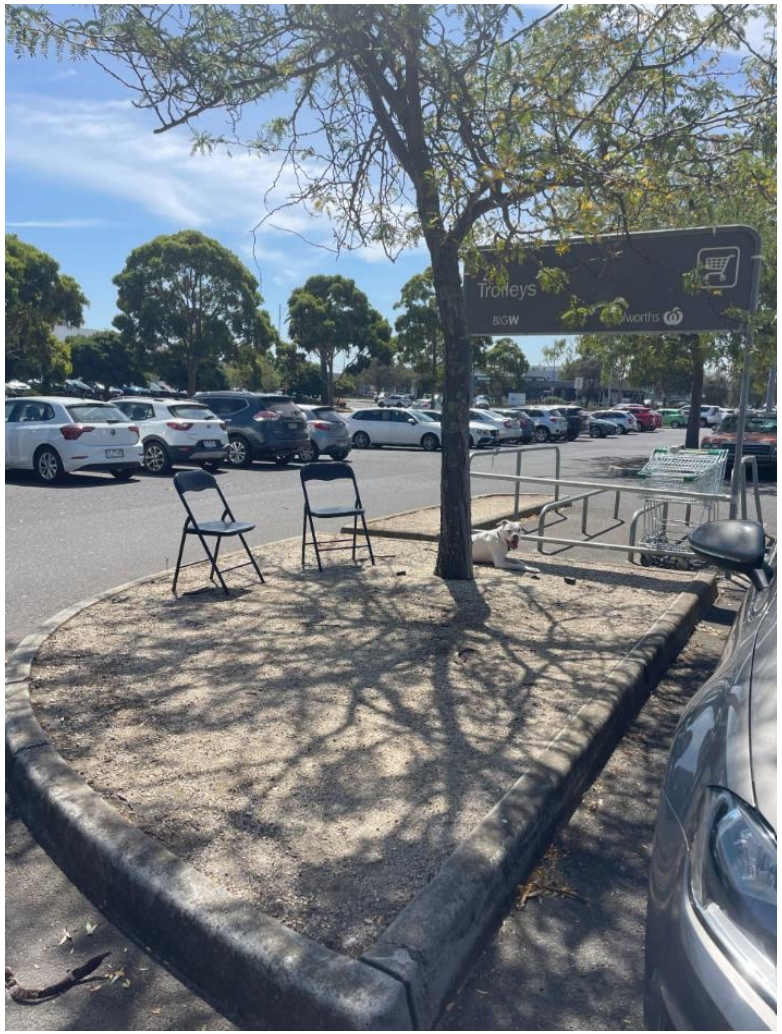
Is Hep C work patch-work?

Care looks different every time.

Cure is co-produced by a network of relations beyond the visible elements of the clinic.

C no more mobilises care that responds to what's present for the individual.

The model 'treats' hepatitis C by *caring for instability*.



The waiting room:
same location, different day

Takeaways and Actions

1. Meeting people ‘where they’re at’ creates opportunities for engaging and sustaining people in care
   - *What does that look like in your respective implementation settings?*

2. Going ‘above and beyond’ to take people out of the ‘too hard basket’ helps to see them through to cure
   - *Can ‘above and beyond’ become standard practice?*

3. Establishing a flexible, relational network creates the tapestries from which patchwork is made
   - *Who/what else exists in your setting that could be mobilised? (secondary contacts, dispensing models/supports, incentives)*

Sustainability: demand beyond 2030

We'd love, if [the van] can be around we would continue to engage clients with it. I think it's fantastic. ***So it's sustainable from a point of view I think there will always be interest in it and demand in [Melbourne suburb] if it continues to be delivered the way it is*** *- and I would continue accessing the service. (CNM 08)*

The van at CBD study site

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References

Hellard, M., Schroeder, S. E., Pedrana, A., Doyle, J., & Aitken, C. (2019). The Elimination of Hepatitis C as a Public Health Threat. Cold Spring Harbor Perspectives in Medicine.

Schroeder, S. E., Pedrana, A., Scott, N., Wilson, D., Kuschel, C., Aufegger, L., . . . Howell, J. (2019). Innovative strategies for the elimination of viral hepatitis at a national level: A country case series. *Liver International*

Rhodes, T., & Lancaster, K. (2019). Evidence-making interventions in health: A conceptual framing. *Social Science & Medicine*

Lancaster K; Rhodes T, 2023, 'Problematising the emergence of outbreak science in the governance of global health: making time for slow dis-ease', *Critical Public Health*

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Thank you!

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