

Barriers and enablers to liver cancer screening among people with inject drugs

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ECA 2: PEOPLE AT RISK OF LIVER CANCER RESEARCH WORKING GROUP

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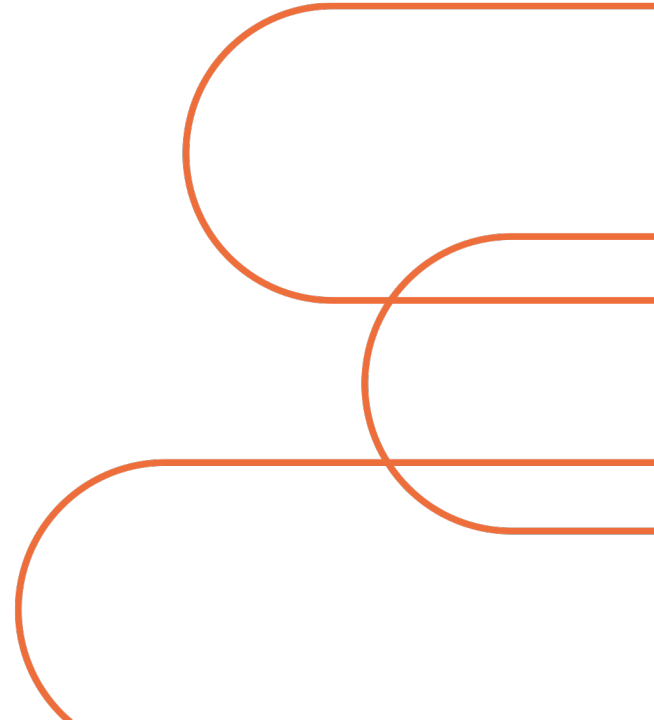
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reach for the many



Disclosures

I have the following disclosures to report for 2025-2026:

- AbbVie – payment received for education presentations, membership of an advisory committee.
- Gilead – payment received for education presentations, travel support to attend international conference in 2025 and 2026.





At Burnet Institute, we proudly acknowledge the Boon Wurrung people of the Kulin Nation 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.

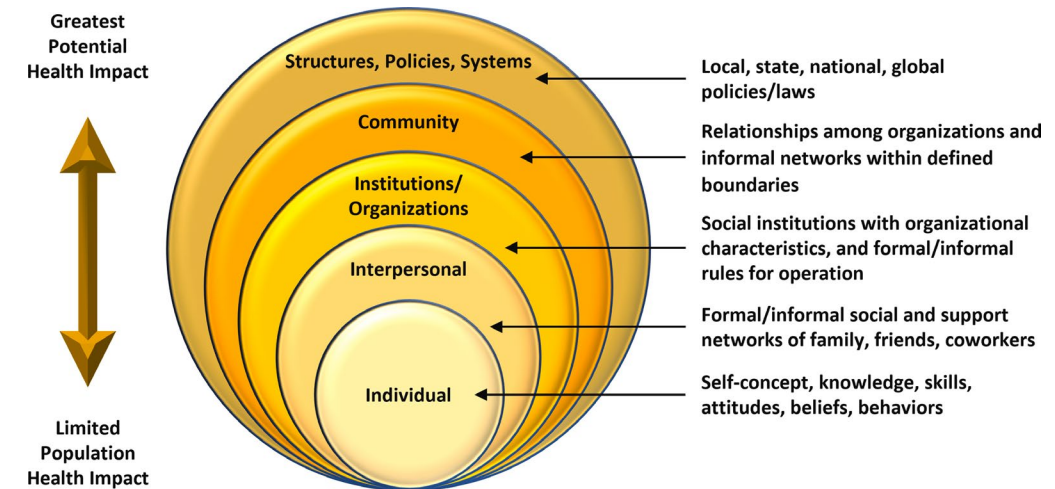
Image: Stacey Edwards (Taungurung/Boon Wurrung/Bunurong)
'Bunjil The Creator' 2021, acrylic on canvas

This artwork was created through The Torch, a not-for-profit organisation that provides art, cultural and arts industry support to First Nations people currently in, or recently released, from Victorian prisons.



Overview

- Background
- Methodology
- Results
 - People who inject drugs with self-reported hepatitis C and cirrhosis hepatitis C data presenting using the Socio Ecological model
 - Individual level
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- Summary



Background



- Primary liver cancer is estimated to be 7th most common cancer worldwide
 - In Australia, 90% of liver cancers are Hepatocellular Carcinoma (HCC) - start in the hepatocyte (liver cell)
 - 80% of people diagnosed with HCC have liver cirrhosis
- Six-monthly surveillance improves early detection and survival; however, access to and sustained engagement in HCC surveillance remains challenging (Hui et al. 2023).
- HOMER 2 describes all consecutive new cases of HCC in greater Melbourne diagnosed between 2018 and 2021 (Flores et al. 2026)
 - 348 (34%) of 1013 incident HCC cases were due to hepatitis C infection
 - 8% had been treated for hepatitis C but not diagnosed with cirrhosis
 - 26% who had been treated were not enrolled in HCC surveillance

Cancer Australia. 2025. Liver Cancer. Accessed on 14/07/26 from: <https://www.canceraustralia.gov.au/cancer-types/liver-cancer>

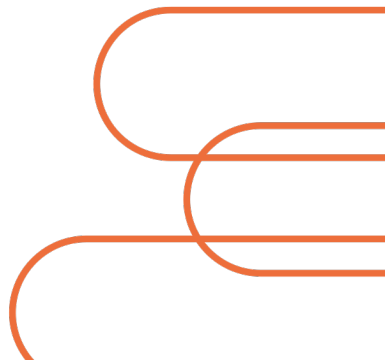
Hui S, Bell S, Le S, Dev A. Hepatocellular carcinoma surveillance in Australia: current and future perspectives. Med J Aust. 2023 Nov 6;219(9):432-438. doi: 10.5694/mja2.52124

Flores JE, et al. Remaining chronic hepatitis C treatment gaps impact on the care cascade of HCV related hepatocellular carcinoma. J Hepatology 2026 Vol84, S433-434.

Methodology



- Semi-structured interviews were conducted with:
 - People who inject drugs with self-reported hepatitis C and cirrhosis recruited through harm reduction organisations in New South Wales, Queensland and Western Australia
 - Health workers from the same harm reduction organisations
- Client interviews explored personal, social and structural enablers influencing engagement in HCC surveillance
- Health worker interviews explored perceived barriers, facilitators and potential system improvements.
- Interviews were analysed using reflexive thematic analysis and are presented using a Socioecological Model



Results



- Face-to-face interviews were conducted between October 2025 and April 2026
- Nine participants identified as currently injecting drugs and self-reported hepatitis C and cirrhosis
 - Seven males and two females, aged 39-70 years
- 13 health workers
 - Harm Reduction workers (n=3)
 - Medical Practitioner (n=2)
 - Nurse (n=2)
 - Nurse Practitioner (n=3)
 - Peer case worker (n=2)
 - Counsellor (n=1)

Socioecological model: Individual level

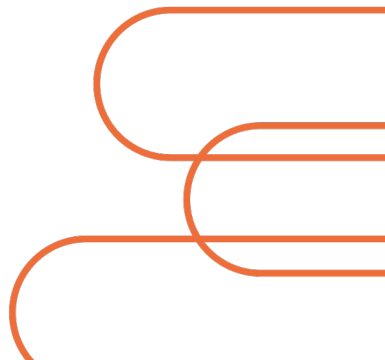


- Liver health was perceived as a low priority compared with competing health and social needs
- Asymptomatic nature of liver disease reduced the perceived urgency

“[My liver is] not giving me any problems ... I wouldn't see the liver clinic at the moment, I've got issues with my arm, I broke it ... so, to me like the liver doesn't seem to give me any problems, [my arm's] more important at the moment” (Participant 2).

- Fear of receiving a cancer diagnosis or "bad news" was common
- Participants had limited liver health literacy

“I had ultrasounds and [the nurse] found out I had scarring on my liver - two lesions: a 5mm and a 7mm, and she said that's cirrhosis ... I said to her ... so I've got liver cancer you're saying, she said yes that's what cirrhosis is” (Participant 1).

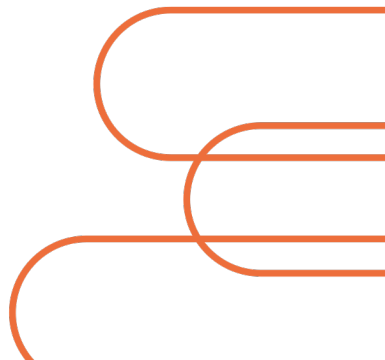


Socioecological model: Interpersonal level



- Interpersonal relationships emerged as central enablers of engagement
- Trusting, respectful relationships with liver clinic nurses and drug user health service staff (peers and nurses) fostered feelings of safety and ongoing participation in surveillance.

“[The liver clinic nurse] knows me really well and she knows I've got a bad memory. That's why she reminds me of the tests. She goes; I'm calling you on Thursday for testing again” (Participant 9).



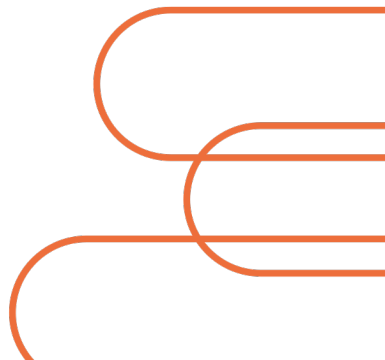
Socioecological model: Interpersonal level



- Support from family, friends and peers
 - Family support motivated some participants to “stay well” and attend regular appointments.
 - Peer networks played dual roles - they were sources of shared lived experience about liver disease, and potential conduits for harm reduction education and encouragement of screening.

“The only time I talk about [cirrhosis], is with people that I’ve known had hep C and I say to them, have you got cirrhosis from it? I try to educate them a bit – I say you should find out - you have an ultrasound, and just see if you have it” (Participant 1).

“I tell [my street family] to go and get tested and ... I even go take them up there [to the harm reduction health service]” (Participant 7).

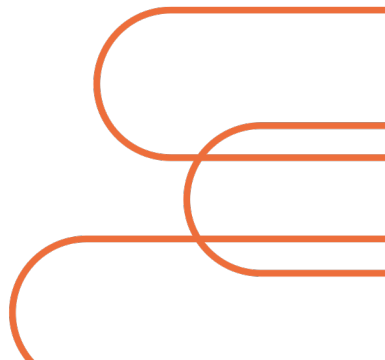


Results – Organisational level



- Hospital-based specialist services were difficult to access without support
 - Limited transport to get to the hospital appointments
 - Inflexible appointment systems for specialist appointments and liver ultrasounds
 - Lack of coordination of appointments

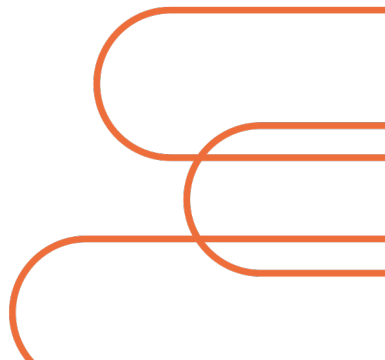
“I’m getting a little bit sick and tired of going to hospitals ... I was there Monday for the physio for this ... broken thumb, and this new doctor sent me to the [hospital name] to have an x-ray ...I don't know if they've got a liver clinic [at that place]...” (Participant 2).



Results – Organisational level



- Fragmented healthcare pathways and poor coordination between primary care, specialist services and correctional health
 - Participant 9 first injected drugs and was diagnosed with hepatitis C in prison:
“If I knew [about hep C and the risk of cancer] before going to jail I would not have used needles. Would never have put a needle in me in jail”
 - Participant 9 goes on to describe inadequate education and poor post-prison release referral pathways for liver care.
“They gave me their pamphlets ... on the pills ... there’s a long arse waiting list ... so I’m still waiting for the jail system ... they didn’t give me the right information ... like which people to go see”.



Results – Organisational level

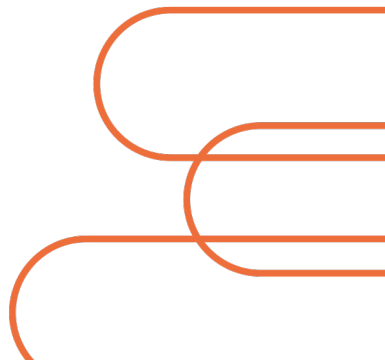


- Conversely, co-location of specialist services facilitated attendance
- Participant 8 preferred hospital-based care describing convenience and established rapport with staff as key enablers:

“Just the fact that you know them [at the hospital], you've got that relationship ... You don't have to repeat your story ... it's good, because it's just caring as well and there's everything there too” (Participant 8).

“Oh, the [liver clinic staff are] lovely ... really comforting and ... knowing about the hep C, and how I was feeling and all that” (Participant 1)

- Structural accessibility therefore encompassed not only transport but also service integration.



Results - Community level

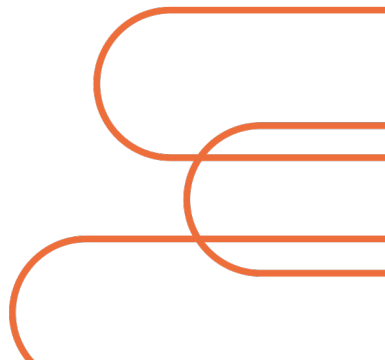


- Stigma towards people who inject drug use is a barrier to healthcare access

“I experience [stigma] ... many times ... it's not all of the medical staff ... some are good, some are bad, ...it's like lotto” (Participant 4).

- Limited community education about hepatitis C and liver cancer
- Limited availability of peer support programs to provide the support that is needed

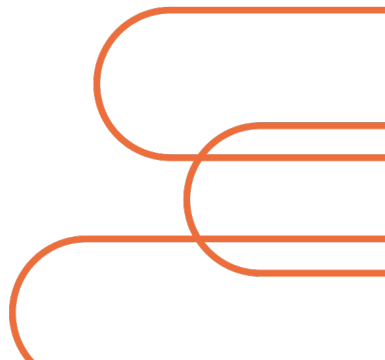
“It's quite confronting for clients, when they need to go to the hospital. It's not like just coming in here [Harm reduction organisation] to see the nurse practitioner. They actually have to go to the hospital and I think that's a barrier ... that smell, that environment... Even trying to find the front door to the place is a pain in the arse” (Peer worker).



Results - Policy / structural level



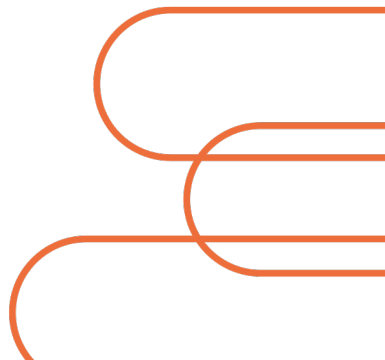
- No national liver cancer surveillance program
- Siloed healthcare system
- Inadequate funding for outreach and peer-supported models
- Limited investment in integrated care
- System-level discrimination against people who inject drugs and people who experience marginalisation.



Results: Health workers



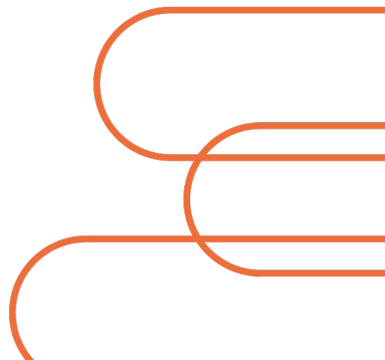
- Health workers described HCC surveillance for people who inject drugs as clinically necessary but operationally difficult.
 - People are often asymptomatic, cured of hepatitis C and yet remain at risk of cancer which can lead to confusion, fear and disengagement.
- Low-threshold, peer-navigation models were described as a critical enabler.
- Co-located services, outreach, shared-care arrangements with hepatologists, and expanded peer case manager roles (navigation, reminders, testing support) facilitated access.
 - However, these models were identified as labour-intensive and constrained by funding, siloed systems, and specialist-focused guidelines.



Summary



- Cirrhosis was not seen as urgent; asymptomatic nature of liver disease lowered its priority
- Engagement in healthcare is enabled by trusted relationships
- Access barriers are structural, e.g. transport, fragmented pathways, inflexible systems, but stigma and fear also prevent access
- Co-located/shared care models were preferred for the delivery of highly specialised HCC surveillance and liver disease care
 - Along with peer navigation for engagement with hospitals/liver clinics
- Interviews are ongoing.



Thank you

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