

From lived experience to cure: Activating hepatitis C notifications

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I HAVE NOTHING TO DISCLOSE



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

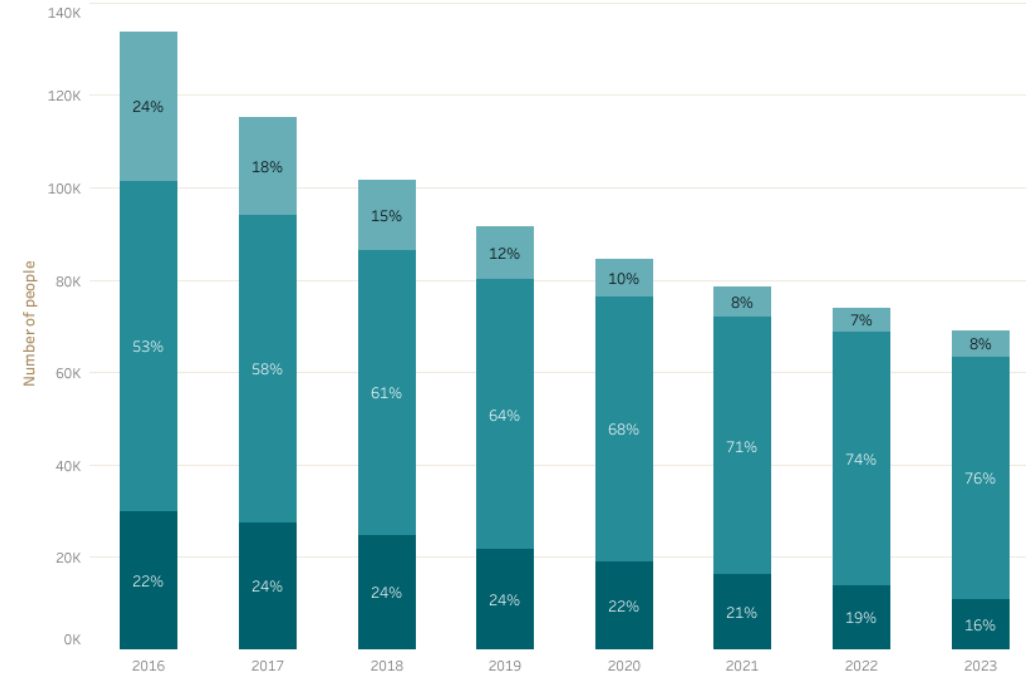
This artwork was created through The Torch, a not-for-profit organisation that provides art, cultural and arts industry support to First Nations people currently in, or recently released, from Victorian prisons.

Hepatitis C and the gap we still need to close

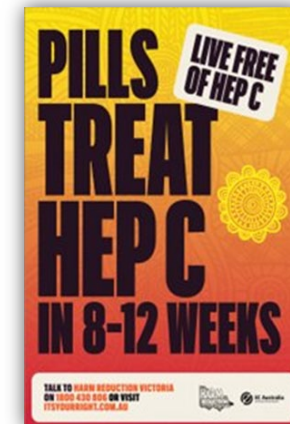
- Hepatitis C is a blood-borne viral infection that can lead to serious liver disease if left untreated.
- Since 2016, direct-acting antivirals have achieved cure rates above through short of oral treatment.
- Australia is on now on a pathway toward elimination.
- Despite these advances, many people diagnosed with hepatitis C are still not progressing to treatment.
- Notifications data provides a powerful underused opportunity to identify and support people into care
- Strengthening follow-up and data use could improve linkage to care, increase treatment uptake, and support elimination efforts.

Hepatitis C diagnosis and care cascade gaps

Undiagnosed (beginning of year), Diagnosed but not treated (beginning of year), Treated (DAA) during year



Source: Kirby Institute Annual Surveillance report 2025



Connect C: Activating hepatitis C notifications to link people to care



What is Connect C

- Connect C is an NHMRC funded national hepatitis C research program (2023–2026)
- Working across multiple jurisdictions in Australia, the program supports national hepatitis C elimination efforts
- Strengthening hepatitis C notifications systems and their use to improve linkage to care and treatment uptake

What Connect C is doing

- Exploring community-informed changes to surveillance, follow-up and care pathways.
- Using notifications data more actively to support treatment linkage and engagement.
- Co-designing practical solutions with people with lived experience, providers and policymakers.

Goal: Turn notification data into active follow-up and improved treatment engagement

Bringing everyone together.

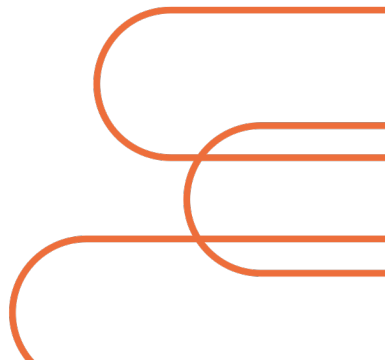
Between 2024- 2026, we convened co-design workshops in the Northern Territory and Queensland

Who was involved:

- Individuals with lived experience
- Healthcare providers
- Policymakers
- Community organisations
- Justice Health
- Public Health Units

What we explored:

- Current use of notifications data across surveillance, follow up and care pathways
- Barriers and opportunities for linking people from diagnosis to treatment
- Improving how data supports follow up and engagement
- Strengthening linkage between systems, services and people
- Co-design practical, system level improvements with stakeholders



Key Insights: Shared Voices, Shared Vision

Notification follow-up to link people to care was acceptable to community members

There was broad **support** for using notifications data to link people into care, when the data was used securely and responsibly.

Direct follow-up with the client

It was considered appropriate to directly contact people notified with HCV when they were not engaged in care, or they required additional support, or when the notifying clinician was unreachable.

Person focused models

A **nurse and peer-led model** was identified as optimal to support sustainable, person-centred linkage to care after notification.



Barriers to accessing care

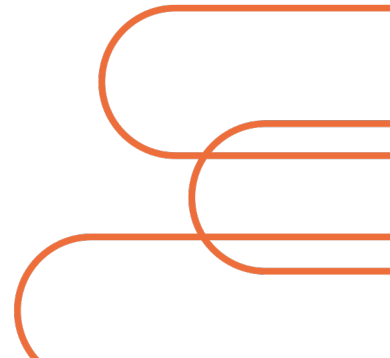
Barriers to accessing HCV care included lack of awareness of treatment, stigma, insufficient social support, and poor access to healthcare.

Empowering patients

People need to be aware of their diagnosis and be provided with access to information to make informed health decisions.

Data Integration

Ensuring data that supports clinical decision making is integrated into public health systems i.e. additional test results



From Agreements to Action

There was agreement that, with community partnership, barriers to better use of notifications data can be overcome.



Post Workshop Activities

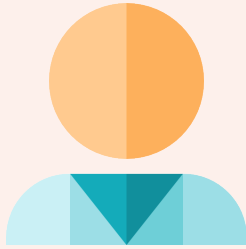
Consensus statements developed and delivered to jurisdictions to support system and regulatory changes

- Hepatitis C notifications converted from 2:2 method to fully identifiable records (embedded in practice)
- Jurisdictional access to negative PCR results to support infection status, treatment completion and reinfection identification (Health Legislation Amendment Bill 2026 introduced 4 June 2026, now has house support)

Refined nurse- and peer-led follow-up model integrated into notification and care systems

- Systems designed, implemented and linked for flow of treatment cascade

What the model looks like in practice



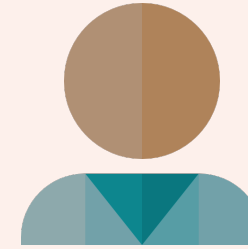
22-year-old (custodial setting)

- Ab positive in hospital (Mar 2026), no reflex RNA initially
- Hub coordinated RNA via prison health (May 26) , within days we had → positive result
- Referred for treatment work-up



57-year-old (complex medical/mental health history)

- Ab positive in hospital (Jan 2026), discharged before results
- Hub followed-up with GP enabled RNA testing → positive
- Referred to gastroenterology for treatment (likely long-standing case)



31-year-old (re-engaged after loss to follow-up)

- Previously RNA positive (2023), lost to follow-up post-release
- Hub followed up bi-monthly as couldn't contact patient.
- Re-engaged via hospital admission (Nov 2025), RNA confirmed.
- Treatment commenced; SVR achieved (Jan 2026)

Data doesn't cure, people–systems that act on it do.

Building systems that act



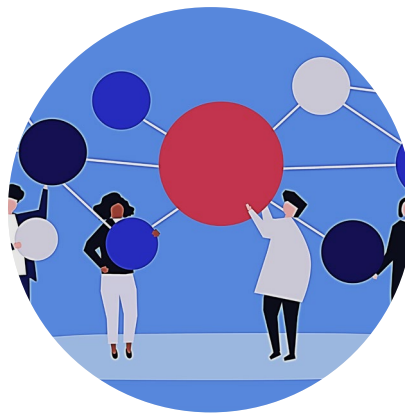
Shift in Approach

Co-design embeds lived experience in policy, regulation, and care pathways.

Moving from passive reporting to active follow-up

Embedding community health services and peer support

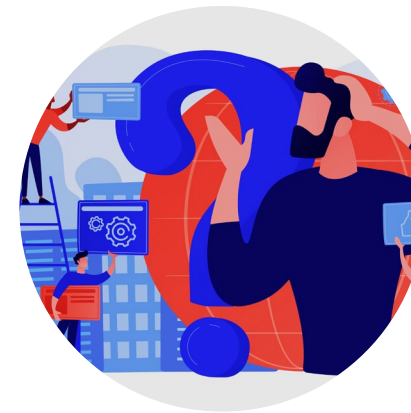
Using notifications data to support people into care



What Connect C shows

Co-designed, consensus-driven approaches can:

- Overcome barriers to notification data use
- Strengthen linkage to treatment
- Improve engagement in care and treatment



Why it matters

Enabling more effective use of notifications data

Supporting progress towards hepatitis C elimination

A framework for hepatitis C elimination efforts and other communicable diseases across Australia.

Thank you

This work would not have been possible without the collaboration of partners and communities working to improve linkage to hepatitis C care.

Special thanks to the **Northern Territory Department of Health, Queensland Health**, and people with lived experience for sharing their insights to support more person-centred care.

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