Hepatitis NSW

Hepatitis B, hepatitis C, and liver health in NSW, what happens next

A report to community on outcomes from the NSW Elimination and Beyond Summit

... people should be able to get **respectful, affordable and culturally safe care,** close to where they live, without shame or fear.

Introduction

In May 2025, Hepatitis NSW brought together members of the viral hepatitis communities and sector to reflect on our progress towards elimination, and what needs to happen in the next few years to make sure we get there.

The purpose of this report is to share with the NSW community the outcomes from the Summit. It is for people living with hepatitis B, hepatitis C or liver disease, as well as families, carers, peer workers, community leaders and services.

Hepatitis B and hepatitis C are viruses that can affect the liver. Hepatitis C can now, in most cases, be cured with tablets. Hepatitis B usually needs lifelong check-ups, and some people need treatment. Both conditions can lead to serious liver problems if people do not get the care they need.

The Summit heard that many people still face barriers to testing, treatment and regular liver care. These barriers include cost, stigma, racism, lack of transport, language barriers, not having Medicare, fear about visas or work, and services that are hard to use.

The strongest message was simple: people should be able to get respectful, affordable and culturally safe care, close to where they live, without shame or fear.

This report takes the insights, suggestions and ideas from the Summit and presents the practical next steps for the best chance to achieve elimination of hepatitis B and hepatitis C in NSW by 2028.

Key messages

1. **Hepatitis B needs regular care.** Many people with hepatitis B feel well and have no symptoms. But the virus can still damage the liver over time. Regular check-ups help prevent liver cancer and serious liver disease.

2. **Hepatitis C can be cured.** Treatment is simple for most people. It is usually tablets taken for 8 or 12 weeks. People can be treated even if they have used drugs recently or are currently using drugs.

3. **Liver health matters after diagnosis and after cure.** Some people still need liver checks after hepatitis C cure, especially if they have cirrhosis or other liver risks. People with hepatitis B need lifelong monitoring.

4. **Stigma stops people getting care.** Shame, judgement and discrimination can stop people from testing, treatment and support. Services must be safe, respectful and non-judgemental.

5. **Communities know what works.** Peer workers, Aboriginal community-controlled services, multicultural workers, interpreters, community champions and lived experience leaders must be part of planning and delivering services.

6. **Care must be easier to access.** Testing and treatment should be low-cost or free, available in trusted places, and offered in ways that fit people's lives.

7. **Language matters.** Health information should be simple, translated when needed, and avoid words that create fear or shame.

What communities asked for

Community members and sector partners called for services that are easier to understand, easier to reach and safer to use. The main asks were:

- free or low-cost testing, treatment and liver checks.
- clear information in plain English and community languages.
- more peer workers and people with lived experience in services.
- better access in regional and rural areas.
- stronger support for Aboriginal and Torres Strait Islander communities.
- more culturally safe support for migrant, refugee and multicultural communities.
- care for people without Medicare.
- better support for people in prison and people leaving prison.
- less stigma in health services, prisons, workplaces and communities.
- stronger follow-up so people are not lost after a test or diagnosis.

Hepatitis B
what needs to change

Hepatitis B is a lifelong condition for many people. It can be managed well, but people need regular liver checks. Some people also need treatment. Too many people in NSW do not know they have hepatitis B or are not getting regular care.

People may not get care because they feel well, do not know hepatitis B can be serious, are worried about stigma, cannot afford appointments, do not have Medicare, or cannot find culturally safe services.

Community message: If you have hepatitis B, you deserve respectful care. Regular check-ups can help protect your liver and reduce your chance of liver cancer.

Summit participants noted that hepatitis B needs stronger attention. Without more action, NSW will not reach elimination goals for many years. Efforts to improve vaccination uptake, testing, regular care and treatment all need to be ramped up.

Hepatitis B affects many people who were born overseas. Aboriginal people are also more likely to be affected than the wider population.

More action is needed now to prevent liver cancer and deaths linked to hepatitis B.

Recommendations for hepatitis B

1. **Make hepatitis B testing easier and more normal.** Offer testing in GP clinics, community health services, Aboriginal Medical Services, multicultural health services, prisons, antenatal services, community events and outreach settings.

2. **Support lifelong care.** Use reminder systems, peer workers, interpreters and community workers to help people return for regular monitoring.

3. **Remove cost barriers.** People should be able to get hepatitis B testing, monitoring and treatment even if they cannot pay or do not have Medicare.

4. S**trengthen vaccination.** Keep infant vaccination strong and offer catch-up vaccination for adults who missed out.

5. **Use trusted community voices.** Work with community leaders, Aboriginal Health Workers, multicultural workers, interpreters and people with lived experience to share accurate information.

6. **Train health workers.** All staff should understand hepatitis B, stigma, racism, trauma and culturally safe care.

7. **Give clear messages.** Explain that hepatitis B is not spread by sharing food, hugging, coughing or casual contact. Explain that care can prevent serious liver disease.

If you have hepatitis B, **you deserve respectful care**. Regular check-ups can help protect your liver and reduce your chance of liver cancer.

Possible next steps for hepatitis B

- Create plain-language community resources in key languages.
- Set up community-led testing and liver health days in areas with higher hepatitis B rates.
- Build reminder and recall systems so people are contacted when their liver checks are due.
- Support GPs and nurses with simple care pathways and quick access to specialist advice.
- Fund peer and community navigator roles to help people move from diagnosis to ongoing care.

Hepatitis C
what needs to change

NSW has made strong progress on hepatitis C. Many people have been cured. But hepatitis C has not disappeared. Some people do not know they have it. Some people are diagnosed but not treated. People can still get hepatitis C again after cure.

Hepatitis C is passed on when blood from a person with hepatitis C gets into another person's bloodstream. In Australia, this can happen through sharing injecting equipment, unsterile tattooing or body piercing, some medical or cosmetic procedures, and other blood-to-blood contact.

Strong leadership has helped NSW make progress on hepatitis C elimination. Continued leadership is needed to finish the job.

Community message: Hepatitis C can be cured. Testing is the first step. Treatment works well and people should not be judged for needing it.

Summit participants said NSW must keep prevention, testing and treatment strong. If services slow down, hepatitis C could increase again.

Recommendations for hepatitis C

1. **Keep prevention strong.** People need easy access to sterile injecting equipment, opioid treatment, harm reduction information and safe, non-judgemental services.

2. **Make testing available in more places.** Testing should be offered through prisons, needle and syringe programs, Aboriginal Medical Services, drug and alcohol services, community organisations, outreach teams, pharmacies and events.

3. **Make treatment fast and simple.** People should be linked to treatment quickly after a positive test. Treatment should be available through trusted services, telehealth, outreach and community-based care.

4. **Support people in prison and after release.** People should be able to test, start treatment and continue treatment after leaving custody without interruption.

5. **Expand peer support.** Peer workers help people feel safe, understand their options and take the next step toward testing and cure.

6. **End stigma in services.** Health and justice staff need training in hepatitis C, harm reduction, trauma-informed care and respectful language.

Hepatitis C can be cured. Testing is the first step. Treatment works well and people **should not be judged** for needing it.

Possible next steps for hepatitis C

- Run local testing campaigns in places communities can get to easily and feel comfortable.
- Offer same-day or rapid links from testing to treatment wherever possible.
- Fund peer workers in hospitals, prisons, outreach services and regional areas.
- Improve release planning so people leaving prison can continue treatment and get housing, income and health support.
- Use data to find places where people are still missing out on testing or cure.

Liver health
what needs to change

Liver health is about keeping the liver as healthy as possible and finding serious liver disease early. This matters for people with hepatitis B, people who have hepatitis C now, and some people who have been cured of hepatitis C.

Many liver problems can be prevented if found earlier. Regular liver checks can help find liver cancer when it is easier to treat. People should not have to wait until they feel sick, because liver disease can be silent for a long time.

Community message: Looking after your liver is not just about hepatitis. Alcohol, diabetes, weight, smoking, some medicines and other health issues can also affect the liver. Support should be practical, respectful and realistic.

People at higher risk of hepatitis-related liver cancer include people living with:

- cirrhosis.
- hepatitis B (a risk factor in itself).
- hepatitis B with hepatitis D co-infection.
- hepatitis B plus other risk factors, such as heavy smoking, alcohol use, other infections, metabolic syndrome, central obesity or type 2 diabetes.
- a history of hepatitis C plus other risk factors, such as older age, longer time with hepatitis C, alcohol use, obesity or fatty liver disease.

People living in regional and rural areas may face higher risks and poorer outcomes because services can be harder to reach. Prevention should be a stronger focus in liver health care across NSW.

Recommendations for liver health

1. **Make liver checks easier.** People at higher risk should be reminded when they need blood tests, scans or other checks.
2. **Use safe language.** Avoid words that feel frightening or linked to policing, such as “surveillance”. Use words like “regular liver checks”, “monitoring” or “cancer prevention checks”.
3. **Bring services together.** Liver care should connect with diabetes care, alcohol and other drug support, dietitian support, mental health care, Aboriginal health, multicultural health and primary care.
4. **Remove costs and referral barriers.** People should not miss liver checks because they cannot afford scans, transport or appointments.
5. **Improve access outside cities.** Regional and rural communities need better access to liver nurses, scans, specialist advice and telehealth.
6. **Support healthy choices without blame.** People need affordable food, safe housing, income support, culturally safe services and practical help to look after their liver.

Looking after your liver is not just about hepatitis... Support should be practical, respectful and realistic.

Possible next steps for liver health

- Produce a plain-language liver health checklist for community members.
- Set up one-stop liver health clinics or outreach days where people can get several supports in one place.
- Fund mobile liver health services for regional and rural areas.
- Use GP and hospital systems to remind services when people need liver cancer prevention checks.
- Co-design liver health messages with affected communities before they are used.

Guidelines for community-facing action

- **Use plain language.** Keep sentences short. Explain medical words. Use examples.
- **Offer information in more than one way.** Use print, videos, audio, translated resources, community talks and peer conversations.
- **Use interpreters.** Do not rely on family members to interpret private health information.
- **Ask people what they need.** Do not assume one message will work for every community.
- **Use teach-back.** Ask people to explain what they understood, in their own words, so workers can check whether the information was clear.
- **Protect privacy.** Make testing and care confidential, especially in small communities.
- P**ay and support peer workers properly.** Lived experience work is skilled work.
- M**easure what matters to communities.** Track whether people feel safe, respected, informed and able to get care.

Call to action

To achieve elimination of hepatitis B and hepatitis C by 2028, as well as to improve liver health, reduce liver disease and cancer, we need to ramp up our efforts once more. Critical to success is making hepatitis and liver health care easier to access, easier to understand, more affordable and safer for affected communities.

Summit participants told us the following as the key factors that will see us achieve our goal.

Hepatitis B

1. **Treat hepatitis B as urgent.** NSW needs clear leadership, funding and responsibility so more people can be diagnosed, treated and supported.
2. **Make testing easier.** People should be offered hepatitis B testing in more places, including community settings, health services, pregnancy care, prisons and GP clinics.
3. **Help people stay in care.** Services should remind people when liver checks are due and help them return for care in a respectful and culturally safe way.
4. R**emove cost and Medicare barriers.** People should be able to get hepatitis B testing, check-ups and treatment even if they cannot pay or do not have Medicare.
5. **Make treatment easier to get.** More GPs, nurses and community services should be supported to help people access hepatitis B treatment and specialist advice.
6. **Work with communities to reduce stigma.** Community leaders, Aboriginal Health Workers, multicultural workers, interpreters and people with lived experience should help shape messages and services.

Hepatitis C

1. **Keep hepatitis C elimination on track.** NSW must continue prevention, testing and treatment so hepatitis C does not increase again.
2. **Find people who are missing out.** Testing should focus on communities, places and settings where people may still have hepatitis C or may be at risk of getting it again.
3. **Strengthen harm reduction.** People need access to sterile injecting equipment, opioid treatment, clear information and non-judgemental support in the community and in prison.
4. **Support people moving between prison and community.** People should be able to start or continue treatment without gaps when they enter or leave custody.
5. **Invest in trusted services.** Peer-led, Aboriginal community-controlled, community-based and outreach services help people feel safe and take the next step toward testing and cure.
6. **End stigma and discrimination.** Health, prison and justice staff need training, lived experience input and clear standards for respectful care.
7. **Use data to improve services.** Data should help identify who is missing out, where reinfection is happening and which services need more support.

Liver health

1. **Make liver cancer prevention a priority.** Liver health should be part of hepatitis work, not treated as a separate issue.
2. **Bring care together.** Liver care should connect with hepatitis care, cancer prevention, diabetes care, alcohol and other drug support, dietitian support, mental health care and primary care.
3. **Find people at risk earlier.** Health systems should help services identify people who need regular liver checks, scans or specialist support.
4. **Remove barriers to liver checks.** People should not miss out because scans, referrals, transport or appointments are too hard to access or too expensive.
5. **Build the liver health workforce.** NSW needs more liver nurses, care navigators, mobile services, pharmacist support and regional specialist support.
6. **Use clear and culturally safe messages.** Liver health information should be developed with communities and avoid language that causes fear or shame.
7. **Act on the bigger causes of poor liver health.** Housing, income, food access, alcohol and other social pressures can affect liver health and need action across government and services.
8. **Build public support for liver health.** Peer leaders, community champions and decision-makers should help make liver cancer prevention more visible and better funded.

Conclusion

NSW has the knowledge, tools and community leadership needed to improve hepatitis B, hepatitis C and liver health outcomes. The challenge now is to make care easier to access, safer to use and more responsive to the realities of people's lives.

This means investing in prevention, testing, treatment and regular liver checks, while also addressing stigma, racism, cost, language barriers, transport, Medicare access and the wider social pressures that affect health. It also means listening to people with lived experience and supporting peer workers, Aboriginal community-controlled services, multicultural organisations and local community leaders to shape what happens next.

The Summit's message was clear: elimination and better liver health are possible, but only if services are respectful, affordable, culturally safe and close to community. The next step is to take these recommendations and turn them into practical actions and programs to support the NSW strategies for elimination. This will take government, sector and community commitment; and most importantly, funding. It is not a big ask, it is a realistic expectation. The impact on people will be life changing and the outcome will be remarkable - *A world free of viral hepatitis.*

Hepatitis NSW
Working towards a world free of viral hepatitis

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