Australia's progress towards hepatitis C elimination

Annual Report 2024





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### **Acknowledgement of Country**

The authors acknowledge the Traditional Owners of the Lands on which this report was produced, including the Boon Wurrung people of the Kulin nations (where the Burnet Institute is located) and the Gadigal people of the Eora nation (where the Kirby Institute is located). We pay respect to all Aboriginal and Torres Strait Islander people and recognise their cultural, spiritual, and educational practices, their ongoing connection to Lands, Waters, and Communities, and that sovereignty was never ceded.

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# Preface

Hepatitis C is a significant public health issue in Australia. Until direct-acting antivirals (DAAs) became available to all Medicare-eligible Australians with hepatitis C on 1 March 2016, there was a growing number of people living with hepatitis C, a rising burden of liver disease, and increasing rates of liver cancer and premature deaths attributed to long-term hepatitis C.<sup>(1)</sup> At the end of 2015 an estimated 162 590° people had chronic hepatitis C in Australia.<sup>(2,3,4)</sup> Aboriginal and Torres Strait Islander people are disproportionally affected by hepatitis C, representing 16% of all people living with hepatitis C at the end of 2015.<sup>(5)</sup> Unrestricted access to DAAs, a highly tolerable and effective medication,<sup>(6,7)</sup> through public subsidy since March 2016 means there is an opportunity to eliminate hepatitis C as a public health threat in Australia by 2030.

Australia is working towards eliminating hepatitis C as a public health threat by 2030. This elimination goal is in line with global targets set by the World Health Organization and targets included in Australia's National Hepatitis C Strategy 2018–2022.<sup>(8)</sup> To achieve hepatitis C elimination, efforts to increase testing, diagnosis, and engagement in care need to be combined with effective primary prevention measures to ensure we minimise new infections and maximise treatment uptake. Social, structural, and legal frameworks that criminalise drug use and stigmatise people who use drugs will hinder progress towards hepatitis C elimination. Disproportionate rates of incarceration among people who inject drugs, coupled with high rates of risk behaviour and the absence of primary prevention, means prison settings represent the highest concentration of hepatitis C infection and therefore are a priority setting for the response to hepatitis C.

To understand progress towards hepatitis C elimination, measurement and monitoring of trends in new infections, counts of people tested and treated, people receiving hepatitis C-related liver transplants, and people experiencing stigma and discrimination is required. These data also guide projections based on mathematical modelling. However, there is limited data available disaggregated by all priority settings and populations<sup>†</sup>, which hinders our ability to identify targeted strategies which may be effective and cost-effective. This is the sixth national report on progress towards hepatitis C elimination in Australia. It brings together national data from across the sector, to give an overview on progress towards eliminating hepatitis C in Australia. This report also highlights gaps in our knowledge and informs future directions in Australia's hepatitis C elimination response.

<sup>\*</sup> Estimate of people living with hepatitis C at the end of 2015 was derived as part of the National hepatitis C diagnosis and care cascade (Chapter Three).<sup>(2,3,4)</sup>

<sup>&</sup>lt;sup>+</sup> The Fifth National Hepatitis C Strategy 2018–2022 identifies six priority populations: people living with hepatitis C, people who inject drugs and/or accessing drug treatment programs, people who previously injected drugs, people in custodial settings, Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse backgrounds.<sup>(8)</sup>

# Acronyms

ACCHS	Aboriginal Community Controlled Health Services
BBV	blood borne virus
CI	confidence interval
DAA	direct-acting antiviral
GBM	gay, bisexual, and other men who have sex with men
HCV	hepatitis C virus
NSP	needle and syringe program
PHN	Primary Health Network
PBS	Pharmaceutical Benefits Scheme
RNA	ribonucleic acid
STI	sexually transmissible infection
SVR	sustained virological response

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# **Executive Summary**

Rates of new hepatitis C infections have steadily declined since 2016, seen through reductions in incidence among people attending primary care clinics and a sample of people who inject drugs. New estimates of HCV ribonucleic acid (RNA) prevalence among a sample of people who inject drugs show a considerable decline in prevalence since 2016. Data from this year's report show other promising signs, with increased testing seen in some settings including primary care, sexual health clinics, and Aboriginal Community Controlled Health Services. There remain areas for improvement though; data from the Australian Hepatitis and Risk Survey in Prisons indicates gaps in recent testing coverage. Further, cascades of care from community settings including primary care clinics and Aboriginal Community Controlled Health Services suggest some people were not engaged in care and treatment following diagnosis.

Between 2016 and the end of 2023, 105 940 individuals had been treated for hepatitis C (first treatment), including 5 499 people initiating treatment in 2023. Also, since 2016 there has been 13 465 prescriptions for retreatment. In 2023, there was, for the first time since 2016, an increase in the number of people receiving treatment compared to the previous year. Further, hepatitis C treatment initiations in prisons continue to represent a large and increasing proportion of all treatment initiations nationally (42% in 2023). Declines in hepatitis C-related transplants demonstrate how direct-acting antiviral treatment reduces the risk of developing liver disease and liver cancer.

There are however challenges in progress towards elimination. Modelling estimated that there remained 68 890 people living with hepatitis C at the end of 2023. As we move forward, and the population of people cured of hepatitis C continues to grow (already over 100 000 people), we need to ensure people's liver health is monitored, particularly by checking for liver cirrhosis, a key risk factor for liver cancer. Importantly, this report highlights that stigma and discrimination towards people at risk of and living with hepatitis C is prevalent. Further, this report highlights that primary prevention must remain a critical component of the response to hepatitis C and be strengthened. Up to 20% of people who inject drugs surveyed in 2023 reported borrowing needles or syringes, the primary method of hepatitis C transmission. Geographical data shows variation in treatment coverage, highlighting that equity must be at the forefront of the response to hepatitis C.

If Australia is to reach elimination by 2030, a range of interventions are urgently needed. Health promotion campaigns are needed to ensure priority populations are aware that hepatitis C treatment and retreatment is available to them and to encourage them to engage in care. Models of care need to be tailored to reach priority populations and provide wrap-around or flexible services that support effective linkage to care. A focus needs to be on engaging people within priority settings including drug treatment services, needle and syringe programs, services for people experiencing unstable housing, community corrections, and prisons. Given the success of scaling up testing and treatment models in prison, resources should be allocated to broaden the reach of these programs across the justice systems including in remand centres and across community corrections services to ensure these priority populations have equitable access to hepatitis C care. Ongoing investment is also needed to stop new infections, including in prisons, using the full suite of harm reduction programs.

Continued efforts to address stigma and discrimination related to hepatitis C and injecting drug use are needed. By providing person-centred care that recognises people's experiences of stigma, trauma and racism, and focusses on social, cultural, and emotional needs, in addition to medical needs, services can better support individuals throughout their hepatitis C journey. Alongside expanding models of care to reach priority populations, ensuring the workforce is adequately trained and equipped through education and skill development is critical to deliver appropriate care for people living with hepatitis C.

# Australia's progress towards hepatitis C elimination 2024

# Since **2016**

- Over ~105,900 individuals have been treated for the first time
- New infections have declined
- Fewer people need liver transplants for hepatitis C-related cirrhosis

# In 2023

- Increases in the number of people tested and treated were seen
- But over 70% of people who use drugs surveyed experienced stigma or discrimination
- And up to 20% of people in the community said they borrowed needles or syringes
- There remain ~68,900 people living with hepatitis C

## To eliminate hepatitis C by **2030** We need to...

... end stigma and discrimination

### ... maintain at least 4,000 people treated each year

We need to test more people so we can treat more people—and help them stay in care

... strengthen prevention to stop new infections





# One

### Newly acquired hepatitis C infections

Measuring the rate of new hepatitis C infections helps monitor strategies that aim to prevent ongoing transmission, including primary and secondary prevention (testing and treatment strategies). New acquisition of hepatitis C is best measured using an incidence rate, which describes the rate at which people test positive for hepatitis C virus (HCV) after previously testing negative. The direct measurement of incidence requires monitoring of repeat testing of individuals (i.e., HCV antibody and ribonucleic acid (RNA) tests) over time to detect new infections. It is therefore important to note that incidence rates are sensitive to changes in testing patterns, as occurred when testing initially increased after direct-acting antivirals (DAAs) were introduced in 2016. Also, regular and repeat testing among specific cohorts improves the reliability of incidence rates. Given these considerations, reliable data on rates of hepatitis C incidence remains limited.

Measuring changes in the rate of new infections of hepatitis C can be monitored through the number of notifications of hepatitis C among people aged 15–24 years.<sup>(4,9)</sup> These notifications may reflect broader incident infections because younger people are likely to have initiated injecting drug use relatively recently.<sup>(10)</sup>

Hepatitis C incidence measurement in Australia is also possible using data collated by the Australian Collaboration for Coordinated Enhanced Sentinel Surveillance of Sexually Transmissible Infections (STI) and Blood Borne Viruses (BBV; ACCESS),<sup>(11)</sup> which links individuals' diagnostic testing data over time.<sup>(12,13)</sup>

One ongoing study provides an estimate of hepatitis C incidence over time among people who inject drugs. The MIXMAX Melbourne Cohort is a prospective longitudinal cohort of people who inject drugs in Melbourne (2008 to the present).<sup>(14)</sup> Participants recruited from street drug markets by a combination of respondent driven sampling, street outreach, and snowball sampling participate in face-to-face interviews, scheduled annually. Since late 2009, blood has been collected at annual interviews using venepuncture, with samples tested for HCV antibody and HCV RNA. The hepatitis C sub-study of the MIXMAX Melbourne Cohort provides estimates of the change in hepatitis C incidence associated with subsidisation of DAAs for hepatitis C treatment in March 2016 among people who inject drugs.<sup>(15)</sup>

### PROGRESS ON REDUCING NEW INFECTIONS

Among men and women aged 20–24 years, the number of hepatitis C notifications has declined since 2016; there was however a notable increase in notifications in 2023 among men aged 20–24 years (Figure 1). The monitoring of hepatitis C notifications among people aged 15–24 years as a surrogate measure for hepatitis C incidence needs to consider unknown levels of testing and their influence on trends. The increase in notifications among 2023, particularly prisons.

Declines in hepatitis C incidence were observed among individuals tested at ACCESS primary care clinics and among HIV-positive gay and bisexual, and other men who have sex with men (GBM) tested at ACCESS GBM and sexual health clinics between 2016 and 2023 (Figures 2 and 3).

A substantial decline in hepatitis C incidence was observed among people who inject drugs participating in the MIXMAX Melbourne Cohort after subsidisation of DAAs for hepatitis C treatment in March 2016.

Improving the reliability of monitoring hepatitis C incidence trends will require improvements in surveillance coverage, as well as the refinement of methods to account for changes in testing patterns and their impact on hepatitis C notification and incidence rates. In addition, more data are needed to understand progress in reducing hepatitis C incidence in priority populations, as well as within specific geographic areas to help inform targeted strategies.

### Monitoring new hepatitis C infections

**Figure 1.** Number of hepatitis C (unspecified and newly acquired) notifications by age group and gender, 2016–2023



- Men 15-19 years -- Men 20-24 years -- Women 15-19 years -- Women 20-24 years

Source: Australian National Notifiable Diseases Surveillance System.<sup>(4,9)</sup>

Notes: Cases other than newly acquired were assigned as unspecified.





Observed incidence rate — 95% CI

Source: ACCESS.(11)

**Notes:** Analysis includes N=11 427 individuals and 30 181 tests (2009–2023) with data from 2016 shown for brevity. Analysis includes 16 sites: 14 in Victoria (VIC), one in Western Australia (WA), and one in Queensland (QLD). Primary care clinics see high caseloads of people at risk of hepatitis C and provide both specialist services to current or former people who inject drugs as well as general health services. First incident infection only included in analysis. Incident infection date was assigned as the midpoint between the positive HCV antibody or HCV RNA test date and previous HCV antibody negative test date. ACCESS collates data from January 2009. Individuals included tested HCV antibody negative on their first test observed and had at least one follow-up test (HCV antibody or HCV RNA or both) on or before 31 December 2023. Individuals were 15 years or older. CI: confidence interval.

**Figure 3.** Incidence of primary hepatitis C infection among HIV-positive GBM tested at ACCESS GBM or sexual health clinics, ACCESS, 2016–2023



#### Observed incidence rate — 95% CI

#### Source: ACCESS.(11)

**Notes:** Analysis includes N=9 157 individuals, 73 989 tests (2009–2023) with data from 2016 shown for brevity. Analysis includes 23 sites: 12 in New South Wales (NSW), four in VIC, two in South Australia (SA), two in WA, two in QLD, and one in Tasmania (TAS). GBM were classed as being HIV-positive for the entire calendar year of their diagnosis and were 15 years or older. First incident infection only included in analysis. Incident infection date was assigned as the midpoint between the positive HCV antibody or HCV RNA test date and previous HCV antibody negative test date. ACCESS collates data from January 2009. Individuals included tested HCV antibody negative on their first test observed and had at least one follow-up test (HCV antibody or HCV RNA or both) on or before 31 December 2023. CI: confidence interval.

#### Monitoring new hepatitis C infections among people who inject drugs

Analysis of longitudinal data from people who inject drugs participating in the MIXMAX Melbourne Cohort estimated hepatitis C incidence before and after universal access to DAAs in 2016. Pre-DAA (March 2010–February 2016) hepatitis C incidence was 6.4 per 100 person-years (PY; 24 cases, 374.5 PY, 95% confidence interval (CI):4.3, 9.6), declining to 1.2 per 100 PY (two cases, 164.5 PY, 95% CI: 0.3, 4.9) post-DAA (March 2016–December 2022). The estimated decline in hepatitis C incidence was 81% (incidence rate ratio: 0.19, 95% CI: 0.04, 0.80).<sup>(15)</sup>

## Two

### **Testing and diagnosis**

Eliminating hepatitis C in Australia relies on finding people living with chronic hepatitis C through diagnostic testing and facilitating appropriate care and treatment. Testing for the presence of HCV antibodies is used as an initial screening for hepatitis C infection. The presence of antibodies indicates exposure to HCV but does not indicate current infection. To diagnose current infection, HCV antibody positive individuals need an HCV RNA test.<sup>(16)</sup> Guidelines published in 2022 recommend clinicians request reflex testing for hepatitis C, meaning a laboratory proceeds to an HCV RNA test if HCV antibodies are detected.<sup>(17)</sup>

ACCESS collates data on consultations, HCV antibody and HCV RNA tests conducted, and test outcomes from sites that offer specialist services for people at risk of hepatitis C, including people currently or with a history of injecting drug use, and HIV-positive GBM.

The ATLAS network is an established national STI and BBV surveillance and research network specific to Aboriginal and Torres Strait Islander people.<sup>(18)</sup> Data from the ATLAS network for this report were provided by Aboriginal Community Controlled Health Services (ACCHS) located in urban, regional, and remote areas (65 ACCHS/sites). ATLAS provides trends in annual hepatitis C testing uptake, annual HCV antibody test uptake and positivity, the proportion of individuals receiving an HCV antibody test, and among those testing positive, the proportion then tested for HCV RNA or viral load.

The Australian Needle Syringe Program Survey is a sentinel surveillance system conducted annually at participating Needle and Syringe Program (NSP) sites across Australia (N=1 991 participants across 55 NSP sites in 2023). The number of respondents in 2020, 2021, and 2022 was lower than in previous years due to the ongoing impacts of the COVID-19 pandemic and public health measures designed to reduce community transmission in some jurisdictions and sites. The Australian Needle Syringe Program Survey asks about a range of risk and health-seeking behaviours, including hepatitis C testing. Respondents are invited to provide a dried blood spot sample for HCV antibody and HCV RNA testing. The proportion of respondents undergoing dried blood spot for HCV RNA testing has increased over time, with ~90% of respondents tested for HCV RNA in all years since 2020.<sup>(19)</sup>

Population-level monitoring of testing related to diagnosis of current hepatitis C infection can occur through the publicly available Medicare Benefits Schedule claims dataset, when item numbers are restricted to 69499 and 69500. These item numbers are specifically used for testing to detect HCV RNA and not used for tests associated with treatment monitoring.<sup>(20)</sup>

Specific studies can provide estimates of testing and diagnosis among priority populations or within specific settings. The Australian Hepatitis C Point-of-Care Testing Program has implemented point-of-care HCV antibody and HCV RNA testing within specific settings during 2022 and 2023. Whilst finalised data were unavailable for this report, data presented here should be interpreted in the context that additional testing conducted by this program is occurring, including in community (including community corrections) and prison settings.<sup>(21)</sup>

The National Prisons Hepatitis Network collates data from jurisdictional Justice Health services and provides the number of individuals who received testing for hepatitis C in 2023.<sup>(22)</sup> There were 96 prisons in the network in 2023 and data were collated from 93 prisons across eight states and territories. Of the 93 prisons providing data, 78 prisons across six jurisdictions reported the number of individuals HCV antibody tested via venepuncture testing and test positivity, and 79 prisons across seven jurisdictions reported the number of individuals HCV RNA tested and test positivity.

The Australian Hepatitis and Risk Survey in Prisons has been planned as a repeated cross-sectional bio-behavioural survey of representative populations of people in prison in each jurisdiction in Australia. The first round of the study was conducted from April 2022 to June 2023.<sup>(23,24)</sup> The study provides estimates of HCV antibody and HCV RNA prevalence, from study-based point-care-testing of participants, as well as self-reported history of testing and treatment.

The MIXMAX Melbourne Cohort is a prospective longitudinal cohort study of people who inject drugs in Melbourne (2008 to current).<sup>(14)</sup> The hepatitis C sub-study of the cohort provides estimates of the change in hepatitis C prevalence associated with universal access to DAA therapies. The prevalence of hepatitis C infection was defined as the number of people HCV RNA positive divided by the number of people with a complete hepatitis C test in each period. A complete hepatitis C test was defined as an HCV RNA test or a negative HCV antibody test.<sup>(15)</sup>

### **PROGRESS ON DIAGNOSIS OF HEPATITIS C INFECTION**

Across the most recent eight years of data (2016–2023) within ACCESS primary care clinics, annual hepatitis C test uptake (HCV antibody or HCV RNA) was stable with 7% (6 731/101 301) of people who attended a consultation in 2023 tested for hepatitis C (Figure 4). Among HIV-positive GBM, annual hepatitis C test uptake stabilised in 2023 to 47% (4 221/9 026) of men tested (Figure 5). Among individuals ever prescribed opioid agonist therapy at ACCESS clinics, annual hepatitis C test uptake increased to 11% (919/8 632) of people who attended in 2023 tested for hepatitis C (Figure 6). Among Aboriginal and Torres Strait Islander people, the number of people tested increased in 2023 compared to 2022, with annual hepatitis C test uptake remaining stable with 30% (777/2 597) of people who attended in 2023 tested for hepatitis C (Figure 7).

# PROGRESS ON DIAGNOSIS OF HEPATITIS C INFECTION (CONTINUED)

Within ACCESS primary care clinics, HCV antibody testing and HCV antibody positivity data highlight that the number of people tested in primary care clinics for HCV antibody increased year-on-year between 2020 and 2023. HCV antibody positivity among men was 10% (259/2 605) in 2023, almost half the antibody positivity among men in 2017 (18%, 460/2 523) (Figure 8). Among HIV-positive GBM, HCV antibody positivity in 2023 was 0.9% (34/3 914) (Figure 9). Among individuals ever prescribed opioid agonist therapy, HCV antibody positivity remained high, with 41% (132/320) positivity among men and 40% (57/141) among women in 2023 (Figure 10). Among Aboriginal and Torres Strait Islander people, there was an increase in the number of both men and women tested in 2023 to the highest number observed since 2016. HCV antibody positivity among men was 6% (28/440) among women was 10% in 2023 (24/233) in 2023 (Figure 11).

In the ATLAS network, annual hepatitis C test uptake (HCV antibody or HCV RNA) increased in 2023 to 8% (5 130/63 109) (Figure 12). An increase in the number of individuals HCV antibody tested was observed year-on-year between 2016 and 2023. While more HCV antibody tests were among women compared to men, higher positivity was observed for men, and this remained consistent between 2016 and 2023 (Figure 13). Between 2016 and 2023, 8% (1 316/16 899) of ACCHS clients tested for HCV antibodies were positive and 73% (961/1 316) were subsequently tested for HCV RNA or viral load (Figure 14). It is important to note that universal screening for hepatitis C is not recommended and within ACCHS—as elsewhere—testing should be based on individual risk assessment between clients and practitioners.

Approximately half of Australian Needle Syringe Program Survey respondents reported testing for hepatitis C in the previous year. Across most jurisdictions the proportion of respondents tested in 2023 remains lower than pre–2020 levels (Figure 15). There was slightly higher uptake of hepatitis C testing among men (Figure 16), and among Indigenous respondents (Figure 17). In 2023, overall HCV antibody positivity among respondents was 45% (745/1 663), the seventh consecutive year that positivity was <50%, following two decades of HCV antibody positivity  $\geq$ 50% (all years between 1999 and 2016). In 2023, 51% (244/476) of Indigenous respondents were HCV antibody positive, an increase from 36% (154/431) observed in 2022, but consistent with pre-2021 levels.<sup>(19)</sup>

### PROGRESS ON DIAGNOSIS OF HEPATITIS C INFECTION (CONTINUED)

Among Australian Needle Syringe Program Survey respondents tested for HCV RNA, the proportion with current infection (weighted by HCV antibody status and gender from 2015–2019) declined from 51% (496/978) to 12% (197/1 646) between 2015 and 2023. Among men, the proportion with current infection declined from 53% (350/658) to 13% (140/1 038) between 2015 and 2023. Among women, the proportion with current infection declined from 45% (141/311) to 10% (56/578) between 2015 and 2023 (Figure 18).<sup>(25)</sup>

From the beginning of 2017, Medicare claims for HCV RNA tests related to hepatitis C diagnosis have declined steadily year-on-year to 2022; there was however an increase between 2022 (n=11 674 tests) and 2023 (n=13 222 tests) (Figure 19).

In 2023, HCV antibody testing pathology data were collated across 78 prisons, by the National Prisons Hepatitis Network. A total of 20 804 individuals were HCV antibody tested and 24% (5 012/20 804) of individuals were positive. HCV antibody test positivity ranged from 3 to 35% between jurisdictions. Across 79 prisons from which HCV RNA testing pathology data were collected, a total of 10 746 individuals were HCV RNA tested in prisons of which 26% (2 773/10 746) were positive; HCV RNA test positivity ranged from 7 to 34% between jurisdictions.

A total of 1 599 people in prison were enrolled in the Australian Hepatitis and Risk Survey in Prisons study April 2022–June 2023. The national prevalence estimate among people in prison for HCV antibody was 32% (95% CI: 29–35) and for HCV RNA was 8% (95% CI: 6–10). Among people who reported having ever injected drugs, HCV RNA prevalence was 15% (95% CI: 12–19). There were wide variations in HCV prevalence across jurisdictions (Figure 20). Self-reported data on uptake of hepatitis C testing shows that 36% (weighted proportion) of participants reported any hepatitis C test in the past 12 months (Figure 21).

Among 1 497 people who inject drugs recruited into the MIXMAX Melbourne Cohort, 1 083 had at least one hepatitis C test and were included in analysis of prevalence 2010–2022. Hepatitis C viraemic prevalence was stable at 52% (95% Cl: 48–56) March 2010–February 2016. An estimated a decline of 17% (prevalence ratio: 0.83, 95% Cl: 0.73–0.94) was observed in 2016, followed by a sustained decline of 14% per annum thereafter (prevalence ratio: 0.86, 95% Cl: 0.82–0.90) (Figure 22).

### **Monitoring hepatitis C testing**





Source: ACCESS.(11)

**Notes:** Analysis includes 16 sites: 14 in VIC, one in WA, and one in QLD. Primary care clinics see high caseloads of people at risk of hepatitis C and provide both specialist services to current or former people who inject drugs as well as general health services. Clinic attendances included in-person and telehealth consultations. Individuals were 15 years or older and contributed one consultation and one test per year.



**Figure 5.** Number of HIV-positive GBM attending ACCESS GBM or sexual health clinics and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ACCESS, 2016–2023

Source: ACCESS.(11)

**Notes:** Analysis includes 23 sites: 12 in NSW, four in VIC, two in SA, two in WA, two in QLD, and one in TAS. Clinic attendances included in-person and telehealth consultations. GBM were classed as being HIV-positive for the entire calendar year of their diagnosis, were 15 years or older, and contributed one consultation and one test per year.





#### Source: ACCESS.(11)

**Notes:** Analysis includes 16 sites: 14 in VIC, one in WA, and one in QLD. Primary care clinics have high caseloads of people at risk of hepatitis C and provide both specialist services to current and former people who inject drugs as well as general health services. Clinic attendances included in-person and telehealth consultations. Individuals were 15 years or older, had at least one electronic medical record of a prescription for opioid agonist therapy between January 2009 and December 2023, and contributed one consultation and one test per year.





#### Source: ACCESS.(11)

**Notes:** Analysis includes 11 sites: seven in NSW, two in QLD, one in VIC, and one in SA. Clinic attendances included in-person and telehealth consultations. Individuals were 15 years or older and contributed one consultation and one test per year. Overall, of unique individuals who attended included clinics 2013–2023 for a consultation (N=398 095), 8% of people had no Aboriginal or Torres Strait Islander status recorded (missing), 6% were recorded as `not stated', 82% were neither Aboriginal nor Torres Strait Islander people, and 4% were Aboriginal and Torres Strait Islander people).







#### Source: ACCESS.(11)

**Notes:** Analysis includes 16 sites: 14 in VIC, one in WA, and one in QLD. Primary care clinics have high caseloads of people at risk of hepatitis C and provide both specialist services to current and former people who inject drugs as well as general health services. Individuals were 15 years or older and contributed one test per year. Individuals recorded as a gender other than man or woman were not reported due to small sample size. Individuals included either had no previous HCV antibody test recorded in ACCESS since 2009 or had previously tested HCV antibody negative. Individual's HCV antibody tests after an HCV antibody positive test being observed were excluded from analysis.



**Figure 9.** Number of HIV-positive GBM tested for HCV antibody at ACCESS GBM or sexual health clinics and proportion of HCV antibody tests positive, ACCESS, 2016–2023

#### Source: ACCESS.(11)

**Notes:** Analysis includes 23 sites: 12 in NSW, four in VIC, two in SA, two in WA, two in QLD, and one in TAS. GBM were classed as being HIV-positive for the entire calendar year of their diagnosis, were 15 years or older, and contributed one test per year. Individuals included either had no previous HCV antibody test recorded in ACCESS since 2009 or had previously tested HCV antibody negative. Individual's HCV antibody tests after an HCV antibody positive test being observed were excluded from analysis.



### **Figure 10.** Number of individuals ever prescribed opioid agonist therapy tested for HCV antibody at ACCESS primary care clinics and proportion of HCV antibody tests positive by gender, ACCESS, 2016–2023



#### Source: ACCESS.(11)

**Notes:** Analysis includes 16 sites: 14 in VIC, one in WA, and one in QLD. Primary care clinics have high caseloads of people at risk of hepatitis C and provide both specialist services to current and former people who inject drugs as well as general health services. Individuals were 15 years or older, had at least one electronic medical record of a prescription for opioid agonist therapy between January 2009 and December 2023, and contributed one test per year. Individuals recorded as a gender other than man or woman were not reported due to small sample size. Individuals included either had no previous HCV antibody test recorded in ACCESS since 2009 or had previously tested HCV antibody negative. Individual's HCV antibody tests after an HCV antibody positive test being observed were excluded from analysis.



**Figure 11.** Number of Aboriginal and/or Torres Strait Islander people tested for HCV antibody at ACCESS sexual health clinics and proportion of HCV antibody tests positive, ACCESS, 2016–2023

#### Source: ACCESS.(11)

**Notes:** Analysis includes 11 sites: seven in NSW, two in QLD, one in VIC, and one in SA. Individuals were 15 years or older and contributed one test per year. Individuals recorded as a gender other than man or woman were not reported due to small sample size. Individuals included either had no previous HCV antibody test recorded in ACCESS since 2009 or had previously tested HCV antibody negative. Individual's HCV antibody tests after an HCV antibody positive test being observed were excluded from analysis.



**Figure 12.** Number of individuals attending ACCHS and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ATLAS network, 2016–2023

Source: ATLAS Indigenous Primary Care Surveillance and Research Network, 2016–2023.<sup>(18)</sup>

**Notes:** Individuals defined as people aged 15 years or older, who visited a doctor, nurse, or Aboriginal health practitioner ('medical consultations') between 2016 and 2023.





Men tested 📃 Women tested 🛛 -- Men proportion positive 🚽 Women proportion positive

Source: ATLAS Indigenous Primary Care Surveillance and Research Network, 2016–2023.<sup>(18)</sup>

**Notes:** Individuals defined as people aged 15 years or older, who visited a doctor, nurse, or Aboriginal health practitioner ('medical consultations') between 2016 and 2023. Number of people tested per year as follows: 2016: 805 men, 1 272 women; 2017: 1 059 men, 1 516 women; 2018: 921 men, 1 451 women; 2019: 1 109 men, 1 804 women; 2020: 690 men, 1 232 women; 2021: 582 men, 939 women; 2022: 1 182 men, 1 892 women; 2023: 1 501 men, 2 344 women.

**Figure 14.** Hepatitis C testing cascade: number and proportion of individuals attending ACCHS tested for HCV antibody or RNA and among those tested, the number and proportion testing positive, ATLAS network, aggregated for years 2016–2023



Source: ATLAS Indigenous Primary Care Surveillance and Research Network, 2016–2023.<sup>(18)</sup>

**Notes:** Individuals defined as people aged 15 years or older, who visited a doctor, nurse, or Aboriginal health practitioner ('medical consultations') between 2016 and 2023. 'Ever HCV antibody positive' was defined as having had a positive test result at any time since data collection began (1st January 2016) until end of the sample period (December 2023). \*A total of 178 816 individuals aged 15 years or older attended medical appointments between 2016 and 2023, of whom 9.5% (16 899/178 816) had an HCV antibody test. †Of those tested for HCV antibody, 7.8% (1 316/16 899) tested HCV antibody positive. ‡Of those HCV antibody positive, 73.0% (961/1 316) had an HCV RNA test following HCV antibody positivity of which §35.5% (341/961) were HCV RNA positive.

**Figure 15.** Proportion of Australian Needle Syringe Program Survey respondents self-reporting recent (past 12 months) hepatitis C testing by jurisdiction, 2016–2023



Source: Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

Notes: No participant recruitment occurred in VIC in 2020.



### **Figure 16.** Proportion of Australian Needle Syringe Program Survey respondents reporting recent (past 12 months) hepatitis C testing by gender, 2016–2023

**Source:** Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

Notes: No participant recruitment occurred in VIC in 2020.





Source: Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

Notes: No participant recruitment occurred in VIC in 2020.



### **Figure 18.** Number of Australian Needle Syringe Program Survey respondents tested for HCV RNA and proportion positive by gender, 2016–2023

Men tested 📕 Women tested 🛛 -- Men proportion positive 🚽 Women proportion positive

2019

Source: Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

2020

2021

2022

0

2023

Year

Notes: No participant recruitment occurred in VIC in 2020. Weighted for gender and HCV antibody status 2015–2019.



**Figure 19.** Number of claims to Medicare for items 69499 and 69500 (detection of HCV RNA, new infections only), 2016–2023

Source: Medicare Australia Statistics.(20)

0

2016

2017

2018

**Notes:** Medicare Benefits Schedule item numbers (69499 and 69500) are used for testing to detect current hepatitis C infection which are not used for tests associated with treatment monitoring. Prison-based testing not included in Medicare Benefits Schedule data.

#### Monitoring testing and diagnosis among people in prison and people who inject drugs

**Figure 20.** Prevalence of hepatitis C among people in prison by (A) HCV antibody, (B) HCV RNA overall, and (C) HCV RNA among people who reported ever injecting drugs, Australian Hepatitis and Risk Survey in Prisons, April 2022–June 2023



Source: Adapted from Bah et al., Int J Drug Policy 2024, (23) and Bah et al., The Lancet Reg Health Western Pac 2024. (24)

**Notes:** A total of 1 599 people in prison were enrolled and all participants were tested for HCV antibody. Participants who were HCV antibody positive were then tested for HCV RNA. The study sample sizes for each jurisdiction were: NT n=254; SA n=300; NSW n=327; TAS n=171; QLD n=248; WA n=299. For all of the national prevalence estimates, the sample size in each jurisdiction was weighted by the prisoner population size of that jurisdiction and the distribution of gender, and First Nations identity among people in prison, based on data from the Australian Bureau of Statistics in 2022.<sup>(27)</sup> CI: confidence interval.





Source: Adapted from Bah et al., Int J Drug Policy 2024,<sup>(23)</sup> and Bah et al., The Lancet Reg Health Western Pac 2024.<sup>(24)</sup>

Figure 22. Proportion of people who inject drugs participating in the MIXMAX Melbourne Cohort HCV RNA positive before and after subsidisation of DAAs in March 2016, March 2010–December 2022



Notes: CI: confidence interval.

# Three

### Uptake of direct-acting antiviral treatment

Achieving hepatitis C elimination in Australia relies on strengthening primary prevention strategies and ensuring people who are diagnosed with chronic hepatitis C access care, treatment and cure, especially those at risk of transmitting their infection to others.<sup>(28,29,30)</sup> DAAs for the treatment of hepatitis C have a high cure rate, are highly tolerable,<sup>(6,7)</sup> and following listing on the Pharmaceutical Benefits Scheme (PBS) in March 2016, are available at minimal cost to Medicare-eligible Australians.

### Treatment uptake

The monitoring treatment uptake in Australia and the National Retreatment projects provide estimates of the number of individuals initiating DAA treatment, and retreatment, between March 2016 and December 2023, recorded in the PBS database. DAA treatment initiations (first treatment) by jurisdiction and provider type are described.<sup>(31)</sup> As the PBS data does not capture reason for retreatment, retreatment data from the REACH-C cohort<sup>(32,33)</sup> and a statistical technique (Random Forest machine learning model) were used to classify records in the PBS data as being retreatment for reinfection or treatment failure.<sup>(34)</sup>

The Australian Needle Syringe Program Survey provides annual self-reported hepatitis C treatment uptake among people who inject drugs attending NSPs.<sup>(19)</sup>

The National Prisons Hepatitis Network collated data from 93 prisons across eight jurisdictions on the number of individuals who received DAA treatment for hepatitis C in 2023.<sup>(22)</sup> The PBS database provides an estimate of the total number of individuals who commenced treatment in 2023 (first treatment or a retreatment episode).<sup>(31)</sup>

The Australian Hepatitis and Risk Survey in Prisons provides data on self-reported history of treatment uptake among people in prison enrolled in the study April 2022–June 2023.<sup>(23,24)</sup>

### Cascades of care

ACCESS data from primary care clinics provides a hepatitis C care cascade for patients; the cascade reflects the status of individuals at 31 December 2023 and includes individuals with evidence of ever being diagnosed HCV RNA positive who had a clinical consultation between 2016 and 2023.<sup>(11,35)</sup>

The ATLAS network provides a cascade of care using patient data of treatment uptake (proportion of HCV RNA positive individuals prescribed DAA treatment) and HCV RNA testing after treatment.<sup>(18)</sup> Undetectable HCV viral load was defined as individuals testing negative for HCV RNA or HCV viral load following their DAA treatment, during the study period (2016–2023).

The 2023 national hepatitis C diagnosis and care cascade is a population-level cross-sectional cascade estimated annually as part of the *HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report.*<sup>(2,3,4)</sup> Using available data, mathematical modelling, and accounting for uncertainties, the number of people in each stage of the diagnosis and care cascade in Australia at the end of 2023 were

estimated including the number of people living with chronic hepatitis C in Australia, the number and proportion of people who have been diagnosed, the number who received antiviral treatment (for primary infection and reinfection), the number cured and the number of new infections.

### **PROGRESS ON INCREASING TREATMENT UPTAKE**

### Treatment uptake

Between March 2016 and December 2023, an estimated 105 947 people living with chronic hepatitis C initiated DAA therapy (first treatment), including 32 458 people in 2016, 21 249 in 2017, 15 355 in 2018, 11 433 in 2019, 8 215 in 2020, and 6 563 in 2021, 5 175 in 2022, and 5 499 in 2023. There were 13 465 retreatments between 2016 and 2023 (Figure 23). There were variations in uptake by jurisdiction (Figure 24). Hepatitis C treatment initiations declined through 2019–2022 with 2022 having the lowest number of people treated in the DAA era; however there was an increase in the number of people treated between 2022 and 2023. Declining numbers of treatment initiations by specialists were not offset by increased numbers of initiations by non-specialists (Figure 25). Analyses of retreatment by reason and gender highlights men have been retreated more than women and mostly for reinfection (Figure 26).

Lifetime treatment uptake among Australian Needle Syringe Program Survey respondents rose considerably among both men and women, from 30% (137/459) in 2016 to 76% (205/270) in 2023 among men and 26% (47/182) to 72% (93/129) among women (Figure 27).

In 2023, 3 414 individuals were initiated on hepatitis C DAA treatment in prisons across all Australian jurisdictions. This represents 42% (3 414/8 077) of all individuals receiving at least one hepatitis C treatment episode in Australia in 2023. The number of individuals initiated on treatment nationally and by jurisdiction is presented in Figure 28 and Table 1. In 2023, across the various jurisdictions, the proportion of individuals initiated on treatment in the prisons ranged from 4 to 75% of the jurisdictional total. The commencement of treatment for hepatitis C within prisons varies across jurisdictions in relation to the prevalence of infection, the size of the population of people in prison, the number of people previously treated in prison or the community, hepatitis C testing activities, and the number of new diagnoses (see Chapter Two for numbers of individuals HCV RNA tested and test positivity in prisons in 2023). The proportion of people treated in prisons has increased each year: 25% (2019), 31% (2020), 31% (2021), and 35% (2022). It is important to note that previous reports used the total number of treatment initiations<sup>(36)</sup> whereas the 2023 data are the number of individuals treated.

The majority (85%, weighted proportion) of participants in the Australian Hepatitis and Risk Survey in Prisons study who were ever hepatitis C treatment eligible self-reported being treated (Figure 29).

### PROGRESS ON INCREASING TREATMENT UPTAKE (CONTINUED)

### **Cascades of care**

At the end of 2023, among those with a clinical consultation at ACCESS primary care clinics between 2016 and 2023 and an HCV RNA positive test recorded in ACCESS (N=5 295), 54% (2 873/5 295) had initiated treatment and of those treated, 48% (1 376/2 873) had an HCV RNA test >eight weeks post-treatment, of which 93% (1 276/1 376) were HCV RNA negative (Figure 30).

Over the eight years of the ATLAS network data (2016–2023), of those ACCHS clients with a detected HCV viral load, 40% (138/341) were recorded to then receive DAA treatment and 59% (82/138) of the clients prescribed DAA treatment received further HCV RNA testing after eight weeks within the same health service. Of those retested after treatment initiation, 59% (48/82) had an undetectable HCV viral load (Figure 31). The ATLAS network is currently investigating the steps in the testing and treatment cascade where major decreases are observed, to determine the reasons driving this apparent loss from care. This may include initiation of treatment in health services not participating in ATLAS.

The hepatitis C diagnosis and care cascade modelling estimated that at the end of 2023, 68 890 people were living with hepatitis C. During 2023, 5 500 people received DAA treatment for primary infection, and there were 1 910 treatment initiations for reinfection (Figure 32).

### Monitoring treatment uptake





Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(31)</sup>

Notes: Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases.


**Figure 24.** Estimated number of individuals initiating DAA treatment by jurisdiction, PBS database, 2018–2023

Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(31)</sup>

Notes: Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases.





Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(31)</sup>

**Notes:** Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases. Nurse practitioners have been authorised to prescribe DAA therapy for hepatitis C treatment since June 2017.



**Figure 26.** Estimated proportion of individuals initiating DAA treatment and retreatment by gender, PBS database, 2018–2023

Source: Monitoring hepatitis C treatment uptake in Australia and National Retreatment Project.<sup>(31)</sup>
Notes: Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases.



**Figure 27.** Proportion of Australian Needle Syringe Program Survey respondents who tested HCV antibody positive, self-reporting lifetime history of hepatitis C treatment by gender, 2016–2023

Source: Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

**Notes:** Includes respondents who tested HCV antibody positive and excludes those self-reporting spontaneous hepatitis C clearance. No participant recruitment occurred in VIC in 2020.



**Figure 28.** Number of individuals receiving DAA treatment in prison versus in the community nationally and by jurisdiction, National Prisons Hepatitis Network and PBS database, 2023

## Table 1. Number of individuals who received DAA treatment in prison versus in the community, nationally and by jurisdiction, National Prisons Hepatitis Network and PBS database, 2023

	National	NSW	VIC	QLD	WA	SA	ACT	TAS	NT
2023									
Number of prisons*	96	33 <sup>†</sup>	14	14	17	9	1	б	2
Number of individuals who received DAA treatment in prisons	3 414	1 027	236	1 796	287	15	11	40	2
Total number individuals who received treatment (PBS database)	8 077	2 927	1 340	2 402	860	295	69	136	48

Source: State and Territory Justice Health authorities via the National Prisons Hepatitis Network.<sup>(22)</sup> Monitoring treatment uptake in Australia.<sup>(31)</sup>

**Notes:** \*Number of adult prisons in the network. †Data were collected from 30 prisons. The proportion of all people treated in prisons nationally was calculated using the number of people who initiated treatment reported by jurisdictional prison hepatitis services as a proportion of all people treated derived from the PBS database. 'Community' treatment initiations are therefore defined as all people treated in the PBS database minus all people treated reported by jurisdictional prison hepatitis services. Individuals are counted once per year and treatment may be first treatment or retreatment.





Source: Adapted from Bah et al., Int J Drug Policy 2024,<sup>(23)</sup> and Bah et al. The Lancet Reg Health Western Pac 2024,<sup>(24)</sup>

**Notes:** Denominator population is people ever eligible for treatment, defined as those with detectable HCV RNA (study-conducted test), regardless of the history of treatment or those HCV antibody positive (study-conducted test) who had a self-reported history of treatment. Participants diagnosed for hepatitis C were defined as those ever treatment eligible who had ever been told by a health professional that they had chronic hepatitis C. Hepatitis C cure was defined by a positive HCV antibody and undetected HCV RNA among those who had received treatment (study-conducted test). Those without 'cure' (i.e., study-conducted HCV RNA positive) includes people who have not responded to treatment or those who may have achieved a sustained virological response (SVR) but were reinfected.

#### **Cascades of care**

**Figure 30.** Hepatitis C treatment cascade at ACCESS primary care clinics: number of individuals hepatitis C diagnosed, number and proportion of individuals who initiated treatment, and tested for HCV RNA post-treatment initiation, 2016–2023



Source: ACCESS.<sup>(11)</sup> Updated from Traeger et al., PLOS One 2020.<sup>(35)</sup>

**Notes:** Cascade includes individuals with evidence of ever being diagnosed HCV RNA positive, i.e., a positive HCV RNA test result recorded in ACCESS since 2009. The cascade reflects the status of individuals on 31 December 2023 and is restricted to individuals who had a clinical consultation between 2016 and 2023. Includes individuals attending ACCESS primary care clinics (same primary care clinics as other ACCESS sections in report). \*Treatment initiation was indicated by the presence of an electronic medical record of a prescription of DAA therapy recorded at an ACCESS clinic. Individuals were assumed to have progressed through preceding cascade stages if evidence of reaching a subsequent stage was present.



**Figure 31.** Hepatitis C treatment cascade: number and proportion of individuals attending ACCHS tested for HCV RNA and prescribed DAAs, and among those treated, the number and proportion who appeared to achieve an undetectable HCV viral load, ATLAS network, aggregated for years 2016–2023

Source: ATLAS Indigenous Primary Care Surveillance and Research Network, 2016–2023.<sup>(18)</sup>

**Notes:** Individuals defined as people aged 15 years or older, who visited a doctor, nurse, or Aboriginal health practitioner ('medical consultations') 2016–2023. 'Undetectable viral load' defined as testing negative for HCV RNA or HCV viral load following DAA treatment. A total of 178 816 individuals aged 15 years or older attended medical appointments between 2016 and 2023. \*Of individuals who were HCV RNA tested following an HCV antibody positive test, 35% (341/961) tested positive. \*\*Of those who tested HCV RNA positive, 40% (138/341) were then prescribed DAA treatment. †Of those prescribed DAAs, 59% (82/138) had an HCV RNA test following treatment, of whom ‡59% (48/82) had an undetectable viral load and 41% (34/82) were either positive or not tested (data unavailable to define these 34 further). Clinician notes/reason for HCV RNA testing was not obtained by ATLAS to further classify individuals who were HCV RNA tested but were not positive (65%; 620/961, not HCV RNA positive). If those with evidence of DAA treatment are inferred as HCV RNA positive, the proportion of positive HCV RNA testing is higher, approaching 50%.

## **Figure 32.** The 2023 hepatitis C diagnosis and care cascade, HIV, viral hepatitis and sexually transmissible infections in Australia, Annual Surveillance Report



**Source:** Updated by Kirby Institute, from the *HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2023.*<sup>(2,3,4)</sup>

**Notes:** Numbers in the figure rounded for clarity. The care cascade was estimated using mathematical modelling; mathematical modelling uses available data from observational research studies and administrative datasets to derive estimates like the population prevalence of hepatitis C, accounting for uncertainties. Living with hepatitis C is the estimated number of individuals in the overall population who had detectable HCV RNA in 2023; diagnosed with hepatitis infection is the estimated number of individuals living with chronic HCV in 2023 who have been previously diagnosed (HCV antibody positive or HCV RNA); HCV RNA confirmed hepatitis C is the estimated number of individuals who are confirmed with HCV from RNA testing; received DAA treatment is the observed number of individuals who received treatment in 2023 for primary infection and reinfection; and cured is the estimated number of treated individuals who achieved undetectable HCV RNA post-treatment in 2023.

## Four

## Hepatitis C-attributable morbidity: transplantations

Reducing hepatitis C-related mortality is a key goal of global and national hepatitis C elimination targets. Given the elevated risk of hepatocellular carcinoma among people with cirrhosis, even after hepatitis C cure, morbidity and mortality remain important outcomes to monitor.

People with cirrhosis who are cured through DAA therapy have a very low risk of progression to liver failure but remain at risk (albeit reduced compared to those not cured) of hepatocellular carcinoma. Due to this, observed declines in cases of hepatocellular carcinoma are likely to be delayed. Further, for people with hepatitis C-related hepatocellular carcinoma who achieve cure, improved liver function post cure may allow for curative treatments for hepatocellular carcinoma other than liver transplantation. However, reductions in the incidence of liver failure and subsequent liver transplants due to liver failure are useful indicators in monitoring long-term outcomes achievable though hepatitis C elimination efforts.

No national registry collates data on morbidity and mortality outcomes among people diagnosed with hepatitis C. However, the Australia and New Zealand Liver and Intestinal Transplant Registry collates data on the primary diagnosis of liver transplant recipients.

## PROGRESS ON REDUCING HEPATITIS-C ATTRIBUTABLE MORBIDITY: TRANSPLANTATIONS

The number of individuals who were recipients of a liver transplant and had a primary diagnosis of hepatitis C cirrhosis declined in the past eight years (Figure 33).

Data on mortality, morbidity, and other outcomes related to hepatitis C in Australia are scarce, a gap that requires urgent action. Monitoring the long-term outcomes of those living with hepatitis C and the effect of primary and secondary prevention on mortality and morbidity is crucial for evaluating strategies to eliminate hepatitis C.



**Figure 33.** Number of Australian adult liver transplant recipients by primary diagnosis and year of first transplant, Australia and New Zealand Liver and Intestinal Transplant Registry, 2018–2023

Source: Australia and New Zealand Liver and Intestinal Transplant Registry.(37)

Notes: Australian transplant recipients only. Adults defined as 16 years or older. NAFLD: non-alcoholic fatty liver disease.

## **Five**

# Stigma and discrimination experienced by people living with hepatitis C

Stigma is a significant barrier to testing, diagnosis, and treatment for hepatitis C, and is therefore important to address if progress in these areas is to be achieved. Understanding how and where hepatitis C-related stigma is both expressed and experienced can provide context to other indicators, such as any lack of progress in testing, treatment uptake, and maintained engagement with healthcare services across populations of people living with or at risk of hepatitis C, among specific groups, or within particular settings. Shame, fear, experiences of discrimination, and concerns about privacy can all contribute to individuals not disclosing their engagement in risk practices (e.g., injecting drug use) and therefore not being offered hepatitis C testing. This then flows on to individuals not receiving timely diagnosis and treatment.

Standardised population-level monitoring of stigma related to hepatitis C and injecting drug use has been undertaken in Australia since 2016, with measures developed and implemented as part of the Stigma Indicators Monitoring Project.<sup>(38)</sup> Indicators of experienced stigma were included in surveys of people who inject drugs and people diagnosed with hepatitis C, between 2016 and 2023.

## **PROGRESS ON REDUCING STIGMA**

In 2023, the Stigma Indicators Monitoring Project surveyed a national sample of people who inject drugs. Over three-quarters of the participants surveyed (77%, 470/612) reported experiencing any stigma or discrimination in relation to their injecting drug use within the past 12 months. This proportion has not significantly changed over time (Figure 34). Among those participants who had ever been diagnosed with hepatitis C, 52% (140/267) reported experiencing any stigma or discrimination in relation to their hepatitis C within the past 12 months. Reports of hepatitis C-related stigma have also not significantly changed over time (Figure 35). Survey participants were also asked if healthcare workers had treated them negatively or differently to other people in the past 12 months. In 2023, 69% (419/608) of people who inject drugs reported any negative or different treatment from healthcare workers due to their injecting drug use, including 21% (128/608) who indicated that this had often or always occurred (Figure 36).

There is some evidence in the literature regarding positive short-term effects of stigma intervention initiatives,<sup>(39,40,41)</sup> however, these effects tend to attenuate over time. Further research is needed to identify effective means of positively influencing attitudes towards people living with hepatitis C and people who inject drugs and how to more widely increase public support for reducing stigma. There is also a need to investigate underlying beliefs that act as root causes of stigma towards people who inject drugs and people living with hepatitis C to inform targeted intervention efforts. Beyond individual attitudes, institutional policies and structures can create environments that reinforce stigma. It is therefore essential to address structural stigma in order to minimise barriers to health care access and enhance the effectiveness of individual-level stigma interventions.

Regular monitoring of stigmatising experiences among people who inject drugs and people living with hepatitis C (including those who do not inject drugs) is required, within healthcare settings and more widely, as is continued monitoring of expressed stigma towards these groups by the general public and healthcare workers. Measuring stigma from these varied perspectives is necessary to understand any changes in experiences and effects of stigma over time, as well as the impact of any interventions to reduce stigma. There is therefore a need for ongoing investment into a range of complementary approaches to reducing stigma at interpersonal, institutional, and structural levels in health care and more broadly.



**Figure 34.** Reports of injecting drug use-related stigma or discrimination in the past 12 months by people who inject drugs, 2016–2023

Notes: "N/A" was not provided as a response option after 2016.





Source: Stigma Indicators Monitoring Project.<sup>(43)</sup>

Notes: "N/A" was not provided as a response option after 2016.

Source: Stigma Indicators Monitoring Project.<sup>(42)</sup>





Source: Stigma Indicators Monitoring Project.<sup>(42)</sup>

Notes: "N/A" was not provided as a response option after 2016.

# Six

## **Primary prevention**

Key actions for preventing the transmission of hepatitis C include a focus on reducing receptive sharing of needles, syringes, and injecting equipment. Measuring the availability and distribution of sterile injecting equipment and monitoring the injecting behaviours of people who inject drugs provides important indicators for assessment of hepatitis C prevention efforts.

The Needle Syringe Program National Minimum Data Collection reports annually on needles and syringes distributed in community settings nationally, providing an overview of activity to prevent re-use of needles and syringes, as well as estimates of coverage and people who inject drugs population size.<sup>(44)</sup> Despite new hepatitis C infections occurring in Australia's prisons,<sup>(45,46,47)</sup> no regulated needle and syringe distribution programs currently operate in Australian custodial settings.

The annual Australian Needle Syringe Program Survey<sup>(19)</sup> and the Illicit Drug Reporting System ask participants about episodes of recent receptive sharing.<sup>(48)</sup>

The Gay Community Periodic Survey provides national estimates on injecting drug use among GBM and gives specific insights into injecting drug use among GBM by HIV status.<sup>(49,50)</sup>

### PROGRESS ON PREVENTION OF HEPATITIS C ACQUISITION

The number of needles and syringes distributed in Australia is generally stable; in 2022 (the latest complete year of data) an increase in the number of needles and syringes distributed compared to 2021 was recorded (Figure 37).

Among respondents in the Australian Needle Syringe Program Survey who injected in the past month, approximately one in five reported past month receptive sharing of needles and syringes and this proportion has remained stable over the past ten years (2016–2023) (Figure 38).

The Illicit Drug Reporting System has shown a stable trend between 2016 and 2023 in the receptive and distributive sharing of needles and syringes with borrowing of needles reported by 5% of respondents and lending needles reported by 7% of participants in 2023 (Figure 39).

Data from the Gay Community Periodic Survey shows that injecting drug use is more prevalent among HIV-positive than HIV-negative GBM, with little change in the prevalence of self-reported injecting between 2016 and 2023 (Figure 40).





Source: Needle Syringe Program National Minimum Data Collection. National Data Report 2023.<sup>(44)</sup>Notes: July–December 2023 data not available at the time of reporting.



**Figure 38.** Proportion of Australian Needle Syringe Program Survey respondents reporting re-use of someone else's needles and syringes in the past month, 2016–2023

Source: Australian Needle Syringe Program Survey. 25-year National Data Report 1995–2019.<sup>(26)</sup> Australian Needle Syringe Program Survey. National Data Report 2019–2023.<sup>(19)</sup>

**Notes:** Not reported not included. Injection risk behaviour variables are presented among those who injected in the previous month, not the entire sample. For 2016 to 2023, sample size was (in order): 1 993, 2 314, 2 452, 2 333, 1 173, 1 259, 1 581, and 1 748.



**Figure 39.** Proportion of respondents reporting borrowing and lending of needles, sharing of injecting equipment, and re-use of needles in the past month, national, Illicit Drug Reporting System, 2016–2023

**Figure 40.** Proportion of GBM who reported any drug injection in the six months prior to the survey by HIV status, national, Gay Community Periodic Survey, 2016–2023



Source:Annual Report of Trends in Behaviour 2024: HIV and STIs in Australia. (49,50)Notes:Unadjusted data.

Source: Australian Drug Trends 2023: key findings from the National Illicit Drug Reporting System (IDRS) Interviews.<sup>(48)</sup> Notes: \*Includes spoons, water, tourniquets, and filters.

# Seven

## Health equity mapping

To help achieve Australia's hepatitis C elimination targets, it is important to ensure that treatment uptake is high in all jurisdictions and there is equity in access to treatment between regions, including metropolitan, rural, and regional Australia.

The following data were collected and reported by the Viral Hepatitis Mapping Project, WHO Collaborating Centre for Viral Hepatitis at the Doherty Institute, funded by the Australian Government Department of Health. These data provide detail on hepatitis C prevalence, management, and treatment uptake by Primary Health Networks (PHNs) compared to the national average, giving insight into geographic diversity in these outcomes.<sup>(51)</sup>

### PROGRESS TOWARDS EQUITY

Treatment uptake at October 2023 was highest in the Western VIC, Gippsland, Adelaide, North Coast, and Hunter New England and Central Coast PHNs. The lowest treatment uptake was seen in NT, Western QLD, Central and Eastern Sydney, and Country WA (Figures 41 and 42).

ork	Western VIC					35%			
two	Gippsland				29	9% -			
Ne	Adelaide				26%	б —			
lth	North Coast				23%				
lea	Hunter New England and Central Coast			15	5%				
ž	North Western Melbourne			119	ó				
nai	South Eastern Melbourne			11%					
Prii	Country SA			11%					
	Central OLD, Wide Bay, Sunshine Coast			8%					
	Eastern Melbourne			7% -					
	Murray (VIC)			4% —					
	Perth South			3%					
	South Eastern NSW			2% —					
	TAS			1% —					
	Brisbane South			0%					
	NATIONAL AVERAGE			0%					
	Perth North		-5%						
	Gold Coast		-6%						
	Darling Downs and West Moreton		-7%						
	Nepean Blue Mountains		-9%						
	Western NSW		-10%						
	Northern Sydney		-11%						
	South Western Sydney		-11%						
	Northern QLD		-11%						
	Western Sydney		-11%						
	ACT		-12%						
	Brisbane North		-12%						
	Murrumbidgee		-14%						
	Country WA		-16%						
	Central and Eastern Sydney		-19%						
	Western QLD	-45%							
	NT	-56%							
	-7	70 -60 -50 -40	-30 -20 -10 (	0 10 2	0 30	40	50	60	70
		Treatment	t uptake variatio	on from t	he nati	ional	aver	age	(%)

Figure 41. Hepatitis C treatment uptake variation in Australia by PHN, March 2016–October 2023

Source: The National Viral Hepatitis Mapping Project (WHO Collaborating Centre for Viral Hepatitis, The Doherty Institute).<sup>(51)</sup> Notes: Hepatitis C treatment uptake variation estimates based on treatment (PBS) data sourced from Medicare statistics and hepatitis C notifications according to geographic region.





Source: The National Viral Hepatitis Mapping Project (WHO Collaborating Centre for Viral Hepatitis, The Doherty Institute).<sup>(51)</sup>

**Notes:** Hepatitis C treatment uptake variation estimates based on treatment data (PBS database) sourced from Medicare statistics and hepatitis C notifications according to geographic region.

## Eight Modelling

Mathematical models are useful tools for identifying factors influencing the likelihood of Australia eliminating hepatitis C as a public health threat. Over the past decade, several models have highlighted the cost-effectiveness and feasibility of hepatitis C treatment and elimination. There is ongoing work in this area, in particular focussing on the coverage of interventions required to ensure Australia meets its elimination targets (e.g., increased testing), the cost-effectiveness of these interventions, how funds can be spent optimally to achieve elimination, and modelling and mapping to identify where key regions or sub-populations are being left behind in the elimination response.

### **PROGRESS TOWARDS ELIMINATION**

With annual treatment uptake in 2023 increasing to 5 499 people treated, modelling from the Kirby Institute showed that hepatitis C incidence and treatment coverage goals would be met under all three treatment scenarios (optimistic, intermediate, and pessimistic). In an optimistic scenario, annual treatment numbers increase and are maintained at 6 874 (25% increase from the 2023 level) each year from 2024 onwards, meeting the goal by 2027. In an intermediate scenario (considered a realistic treatment uptake) annual treatment numbers are maintained at 2023 levels; 5 499 each year from 2024 onwards, with the goal met by 2029. In a pessimistic scenario, annual treatment numbers decline and are maintained at 4 124 (25% decrease from the 2023 level) each year from 2024 onwards, meeting the goal by 2030 (Figure 43 and Table 2).

This model produces estimates of the number of people living with hepatitis C and the resulting time trends by first producing a specific estimate for 2015. The number of people living with hepatitis C at the end of 2015 was first estimated using observed cumulative notifications, estimated spontaneous clearance, mortality, and migration rates, and an estimate for the percentage of people undiagnosed. In addition, the model mortality rates are calibrated to match empirical data from the NSW linkage study to best reflect the number of cases of decompensated cirrhosis, hepatocellular carcinoma, and liver-related death. The resulting model estimates are compared to available measured data to ensure they are valid and as accurate as possible. This process is repeated annually and can result in changes to the model estimates from year to year due to the availability of new data and information.

Modelling by the Burnet Institute compared the cost-effectiveness of laboratory reflex testing to other hepatitis C testing approaches. In 2022, the *Australian recommendations for the management of hepatitis C virus infection* consensus statement recommended clinicians request reflex HCV RNA testing if HCV antibody testing is positive, and the Royal College of Pathologists of Australasia endorsed laboratory-initiated reflex HCV RNA testing of HCV antibody positive or indeterminate samples without the need for clinician request.<sup>(17,52)</sup> These recommendations for reflex HCV RNA testing aimed to prevent unnecessary healthcare visits for additional venepuncture, making it simpler for people to find out their hepatitis C status and access treatment. The effect of these initiatives on historically poor rates of follow-up HCV RNA testing<sup>(53,36)</sup> are yet to be described. The modelling aimed to estimate the effects of universal uptake of laboratory reflex testing on hepatitis C treatment completion and associated healthcare costs. It focussed on people who inject drugs attending community-based health services who had never been treated for hepatitis C.

# PROGRESS TOWARDS ELIMINATION (CONTINUED)

The model described a cohort of 1 000 simulated people undergoing testing, of whom 120 had chronic hepatitis C. It estimated the number of people living with hepatitis C treated with DAAs and the costs to the healthcare system after the cohort had either tested negative, been lost to follow-up, or completed treatment. Three scenarios were modelled in which different testing approaches were applied: (1) no reflex testing (pre-2022 standard of care); (2) reflex laboratory testing, and (3) a sequential point-of-care HCV antibody and HCV RNA test strategy. Model inputs of HCV antibody and HCV RNA prevalence were from the 2022 Australian Needle Syringe Program Survey,<sup>(19)</sup> loss to follow-up proportions were from clinical studies and surveillance data,<sup>(53,54,55)</sup> and test performance estimates were from validation studies.<sup>(56,57)</sup> Diagnosis and pre-treatment assessment costs came from published estimates<sup>(58,59)</sup> and the Medicare Benefits Schedule.<sup>(60)</sup> Hepatitis C treatment costs were based on the estimated average price paid per course by the Australian Government between March 2016 and February 2021 (\$13 495).<sup>(61)</sup>

For all scenarios, most of the overall cost was the cost of treatment for people with hepatitis C infection (\$17 663 per completion in each scenario). Additional costs of diagnosis, pre-treatment assessment, and of treating people with false-positive point-of-care test results were on average \$2 399 per completion in the no reflex testing scenario, \$1 973 per completion in the reflex laboratory testing scenario, and \$2 808 per completion in the point-of-care scenario (Figure 44).

Figure 45 focusses on these additional costs attributable to the testing approach (leaving aside the costs of antiviral treatment of those infected). Effectiveness (number of treatment completions) and costs per 1 000 people screened are shown for each scenario. The modelling suggested that uptake of reflex laboratory testing improved the efficiency of laboratory-based hepatitis C diagnosis, while point-of-care approaches provide additional benefit but at higher short-term costs. The model estimated that reflex testing cost modestly more than the no reflex testing approach to screening, but increased treatment completions from 23 to 33. The point-of-care strategy was substantially more costly but resulted in the highest number of treatment completions—40. These findings emphasise the potential benefits of policies that improve the efficiency of existing hepatitis C laboratory testing approaches by enabling and encouraging routine reflex testing in addition to roll out of new testing technologies that expand reach.

**Figure 43.** Annual change in people living with chronic hepatitis C, hepatitis C incidence (all), treatment coverage, and liver-related deaths (viraemic and cured) in Australia 2030 (2010–2030) with WHO HCV elimination targets (dotted lines: Panel B: -- 80% and -- 90% reductions in incidence, Panel C: -- 80% eligible treated, and Panel D: -- 65% reduction in deaths)



#### Table 2. Scenarios for the annual number of people in Australia receiving DAA

Treatment roll-out scenarios	2020	2021	2022	2023	Post-2024
Pessimistic roll-out	8 215	6 563	5 175	5 499	4 124
Intermediate roll-out	8 215	6 563	5 175	5 499	5 499
Optimistic roll-out	8 215	6 563	5 175	5 499	6 874

Source: Updated from Kwon et al., J Viral Hepat 2019<sup>(2)</sup> and Kwon et al., PLoS One 2021.<sup>(3)</sup>

**Notes:** Treatment coverage is calculated among people who have ever been diagnosed (numerator: the cumulative number of people treated since the end of 2015; denominator: the cumulative number of people cured since the end of 2015 plus the number of people who have ever been diagnosed and are still living in 2022). We assumed a pessimistic roll-out scenario corresponding to 25% less people being treated with DAA therapy than 2023, an intermediate roll-out scenario corresponding to the annual number treated equalling the number in 2023, and an optimistic scenario where the annual number treated increased 25% more than the 2023 level. The annual number of people treated for all three scenarios in the earlier years is as follows: 2015 (interferon plus DAA): 4720; 2016: 32 458; 2017:21 249; 2018:15 355; and 2019: 11 433.



**Figure 44.** Estimated costs (2023 \$AUD) of hepatitis C treatment initiation strategies for treatment-naive people who inject drugs

Source: Adapted from Baille et al. 2024. (personal communication, Joseph Doyle, Burnet Institute).

**Notes:** The no reflex testing scenario is laboratory HCV antibody and laboratory HCV RNA (re-collection of venepuncture sample). The reflex laboratory scenario is laboratory HCV antibody and laboratory HCV RNA in one venepuncture collection. The point-of-care scenario is point-of-care HCV antibody test and point-of-care HCV RNA test. AUD: Australian Dollar.





Source: Adapted from Baille et al. 2024.(personal communication, Joseph Doyle, Burnet Institute).

**Notes:** Costs of diagnosis, assessment, and for point-of-care, treatment initiation of those HCV RNA negative. Dashed lines show 95% uncertainty intervals from 1 000 probabilistic draws. AUD: Australian Dollar.

# **Methods**

This report brings together national data sources to assess Australia's progress towards eliminating hepatitis C. Some data were not included due to unavailability at the time of reporting; future reports will aim to provide the most comprehensive picture possible.

#### Notifications of hepatitis C

Notifications of newly acquired hepatitis C were from the National Notifiable Diseases Surveillance System<sup>(9)</sup> with details and notifications requirements, procedures, and case definitions available from the Australian Government Department of Health and Ageing.<sup>(62)</sup> Notifications are also reported annually in the *HIV*, *viral hepatitis and sexually transmissible infections in Australia: annual surveillance report.*<sup>(4,9)</sup>

#### Australian Collaboration for Coordinated Enhanced Sentinel Surveillance of Sexually Transmissible Infections and Blood Borne Viruses

ACCESS was established to monitor STI and BBV testing and test outcomes among priority populations.<sup>(11,12,13)</sup> ACCESS focusses on recruiting sites that serve priority populations, including people who inject drugs and HIV-positive ACCESS collates data on consultations, hepatitis C testing and test outcomes from participating sites. Please note that the data included in this report may differ to those presented in previous or subsequent reports due to the availability of expanded data and associated enhancement of analytical, linkage, and processing methods.

#### Record linkage

Individuals' electronic medical records were linked between sites using a linkage code and probabilistic matching so that consultation, testing and test outcome data account for individuals attending more than one ACCESS site.

#### Sites

ACCESS includes primary care clinics that provide specialist health services to people who inject drugs, such as NSP, opioid agonist therapy, and hepatitis C testing and treatment. ACCESS sites include both specialist and general health services, where attendees may be people currently injecting, people who previously injected drugs, or people who have never injected drugs. Also, a subset of sexual health clinics participating in ACCESS that had data available for this report, had high completion of the Aboriginal and Torres Strait Islander status of individuals in their patient management systems. Of unique individuals who attended included clinics 2013–2023 for a consultation (N=398 095), 8% of people had no Aboriginal or Torres Strait Islander status recorded (missing), 6% were recorded as 'not stated', 82% were neither Aboriginal nor Torres Strait Islander people, and 4% were Aboriginal and Torres Strait Islander people. When restricted to individuals contributing one test per year, data from the ACCESS sites can be used to describe trends in test uptake (tests conducted divided by consultations) and positivity (positive tests divided by tests conducted).

Data from 41 sites in total were used and stratified into primary care clinics that specialise in the health of people who inject drugs as well as providing general primary care (16 sites, one site has three health services counted as one site and one site has eight health services counted as one site), and primary care clinics specialising in the health of GBM (12 sites) and sexual health clinics (11 sites). Eleven sexual health clinics were used for analysis of hepatitis C testing among Aboriginal and Torres Strait islander people; all 11 clinics were included in the analysis of hepatitis C testing among HIV-positive GBM.

Primary care clinics included 14 in VIC, one in WA, and one in QLD; of these clinics seven had onsite NSPs and all 14 clinics had opioid agonist therapy providers at the time of reporting. Primary care clinics specialising in the health of GBM included five in NSW, three in VIC, two in WA, one in SA, and one in TAS. Sexual health clinics included seven in NSW, two in QLD, one in VIC, and one in SA. Sexual health clinics included for analysis of Aboriginal and Torres Strait Islander people were seven in NSW, two in QLD, one in VIC, and one in SA. ACCESS continues to expand and refine its system; therefore, future reports will include data from additional sites.

#### Gay, bisexual, and other men who have sex with men

Individuals classified as GBM were males who:

- were recorded as gay or bisexual in an ACCESS clinic's patient management system, or
- had ever had a rectal swab for chlamydia or gonorrhoea at an ACCESS clinic,<sup>(63)</sup> or
- were HIV-positive and had ever had a syphilis test at an ACCESS clinic (algorithm developed by Burnet Institute based on syphilis epidemiology and prevalence among HIV-positive GBM populations in VIC).

Note that at the GBM clinics, only a small proportion of individuals could be classified on recorded sexuality alone, meaning that classification of individuals as GBM at these clinics is based largely on STI testing history criteria within the algorithm.

#### HIV-positive gay and bisexual men

Individuals defined in ACCESS as HIV-positive GBM:

- had a positive HIV diagnostic test result recorded at an ACCESS clinic, or
- had an HIV viral load test result in an ACCESS clinic's patient management system, and
- were defined as GBM using the algorithm outlined above.

HIV status could only be determined if a history of HIV diagnostic or viral load testing was recorded at a site within the ACCESS network.

#### Incidence definition

Individuals were included in the incidence estimate if they were HCV antibody negative and HCV RNA negative or HCV antibody negative and HCV RNA testing was not performed during their first testing episode recorded by ACCESS from 2009 (at risk for primary infection). Time-at-risk was defined as the cumulative time between everyone's first negative test (HCV antibody) and last test (HCV antibody and/or HCV RNA). Time-at-risk was assigned to the calendar year in which it occurred for annual incidence estimates.

Incident hepatitis C cases were defined as:

- acute infection (HCV antibody negative and HCV RNA positive after an HCV antibody negative),
- antibody seroconversion (HCV antibody positive after an HCV antibody negative), or
- HCV RNA positive after an HCV antibody negative in the absence of an HCV antibody test.

Date for incident infection was assigned as the midpoint between the positive test (HCV antibody or HCV RNA) and prior HCV antibody negative test. Only individuals' first incident infection recorded in ACCESS were included in analyses.

#### Consults

To account for the effects of the COVID-19 pandemic on consultation data, consultations that were associated with a SARS-CoV-2 pathology test request were excluded.

#### Test uptake

Annual test uptake was defined as number of individuals tested divided by number of individuals who attended a consultation, with individuals only counted once a year. Clinic attendances included in-person and telehealth consultations.

#### **Proportion positive**

Annual positivity was defined as number of individuals tested positive divided by number of individuals tested, with individuals only counted once a year. Individual's HCV antibody tests after an HCV antibody positive test being observed were excluded from analysis.

#### Treatment

Treatment initiation was inferred by presence of an electronic medical record prescription for hepatitis C treatment stored in patient management systems of participating clinics.

#### MIXMAX Melbourne Cohort hepatitis C sub-study

#### Hepatitis C incidence

The study measured the incidence of primary (first) hepatitis C infection, defined as HCV antibody negative with a subsequent positive hepatitis C test (HCV antibody or HCV RNA). Participants were eligible for inclusion in this analysis if they had an HCV antibody negative test with at least one subsequent hepatitis C test to access infection outcome. Time zero was defined as the date of the first HCV antibody negative test. Participants were censored at the estimated date of infection calculated using the midpoint method, or the last negative HCV antibody test, whichever came first.

Changes in incidence of primary hepatitis C infection following DAA introduction were estimated using a before-after approach, implemented using Poisson regression. The pre-DAA period was defined as March 2010 to February 2016, the DAA access period was defined as March 2016 to February 2022.

#### Hepatitis C prevalence

The study measured the prevalence of current hepatitis C infection, defined as HCV RNA positive. The prevalence of hepatitis C infection was defined as the number of people HCV RNA positive divided by the number of people with a complete hepatitis C test. A complete hepatitis C test was defined as an HCV RNA test with a valid result or an HCV antibody negative test without a valid HCV RNA test. Those with an HCV antibody negative test without a valid HCV RNA test. Those with an HCV antibody negative test without to have current hepatitis C infection. Those with an HCV antibody positive result without a valid HCV RNA test were excluded from the prevalence analysis.

Hepatitis C prevalence was estimated annually in intervals spanning March to February to coincide with the introduction of universal DAA access in March 2016. Estimates were calculated from March 2010 to February 2022.

Changes in prevalence of hepatitis C infection following DAA introduction were estimated using an interrupted time series approach, implemented using log-binomial generalised estimating equations.<sup>(15)</sup>

#### ATLAS network

The ATLAS network is a STI and BBV sentinel surveillance and research network representative of ACCHS led by Professor James Ward from the University of Queensland Poche Centre for Indigenous Health. ATLAS is funded through the National Health and Medical Research Council, Medical Research Future Fund, and Commonwealth Department of Health, and includes many of Australia's leading public health researchers among its investigator group. ATLAS augments the National Notifiable Disease Surveillance System<sup>(18)</sup> and helps us understand the burden of disease due to STIs and BBVs among Aboriginal and Torres Strait Islander people. The ATLAS network currently includes 65 ACCHS largely associated with six 'clinical hubs' across QLD (two hubs), NSW, SA, and the Kimberley, WA, and VIC. Regular reports addressing 12 performance measures are provided to ACCHS to assess clinical practice and drive continuous quality improvement initiatives internally. Data were also aggregated at the hub, jurisdictional, and national level and used to inform clinical guidelines and to guide future research questions.

Currently, three performance measures focus on hepatitis C testing and management: hepatitis C testing rate (proportion of individuals receiving an HCV antibody test and among those testing positive, the proportion then tested for HCV RNA or HCV viral load), hepatitis C treatment uptake (proportion of HCV RNA positive individuals prescribed DAA treatment), and SVR (proportion of individuals who, after having been prescribed DAA treatment, achieve an undetectable HCV viral load).

The goal of hepatitis C testing is not to test the entire patient population, but rather the population at risk of hepatitis C. The ATLAS network recognises that its current surveillance approach is limited by an inability to capture data on chronic/historical hepatitis C infection diagnosed prior to 2016 and not being actively managed by the ACCHS. Surveillance data is dynamic and subject to change. The more conservative count for HCV antibody testing reported in 2023 is due to data refinement. Previous years' data are likely an overestimate. It must also be noted that a change in methodology now limits case inclusion to clients HCV RNA tested following a positive HCV antibody test, not clients recorded as ever being tested for HCV RNA. Similarly, only clients prescribed DAA treatment following a recorded HCV RNA positive result were included in this year's analysis. This change reduces case counts but improves our knowledge of the cascade of care in ACCHS.

#### The Australian Needle Syringe Program Survey

The Australian Needle Syringe Program Survey National, led by Professor Lisa Maher, provides serial point prevalence estimates of HIV and HCV antibody prevalence, HCV RNA prevalence and monitors sexual and injecting behaviour among people who inject drugs in Australia. The Australian Needle Syringe Program Survey is conducted annually at more than 50 NSP services over a one-to-two-week period in October each year. Participants complete a brief self-administered questionnaire and provide a capillary blood sample which is subsequently tested for HIV and HCV antibodies and HCV RNA. The Australian Needle Syringe Program Survey National Data Report is published annually, including full details of the methodology.<sup>(19)</sup>

#### Medicare claims for HCV RNA testing

Data tables of Medicare claims are available through Medicare Australia Statistics.<sup>(20)</sup>

#### **National Prisons Hepatitis Network**

Data on HCV antibody and HCV RNA testing, test positivity, and individuals initiated on DAA treatment in 2023 in Australia's prisons were collated by the National Prisons Hepatitis Network from prison-based hepatitis services.

For some jurisdictions, there were differences in the number and type of prisons included in data collection. For NSW, data were included from 30 public prisons; data from three private prisons were not included. For VIC, data were not included from one prison between July and December 2023 only.

#### Australian Capital Territory

Data on hepatitis C testing and treatment (DAA) were obtained from patients' medical records via the Digital Health Record.

#### New South Wales

Treatment data (DAA) were collected via the pharmacy dispatch reports of when medications were dispensed to prison centres. The data corresponding to HCV antibody and HCV RNA testing numbers were obtained by using a software script-generated data extraction from existing pathology results in Justice Health electronic Health System (JHeHS) for the period of interest.

#### Northern Territory

Hepatitis C testing data were provided by Territory Pathology who provide the pathology services to the NT Prisons. Treatment data (DAA) were obtained through the Viral Hepatitis Service's hepatitis C clinical database that records treatment initiations. Accuracy and completeness of data were dependent on the quality of the data recorded by the clinicians. For Darwin Correctional Centre, data were confirmed by pharmacy records.

#### Queensland

Hepatitis C testing data were obtained from AUSLAB which is an integrated laboratory information system incorporating pathology, clinical measurements, forensics and public health laboratories. It provides real-time results which are uploaded by the pathology labs. Treatment data (DAA) were obtained directly from Prisoner Health Services in each facility as part of the annual Hepatitis C Treatment Uptake Progress Report.

#### South Australia

Hepatitis C testing data were obtained from the contracted pathology provider (SA Pathology Service). Paper-based health records were used in prisons.; the number of treatment initiations (DAA) was based on records of pharmacy prescriptions filled.

#### Tasmania

Hepatitis C Treatment Program data were collected from dispensing records maintained by the Correctional Primary Health Service Pharmacy.

#### Victoria

Data were sourced from the Department of Justice and Community Safety (Victorian Government). Treatment data (DAA) were collected from dispensing records of the pharmacy database maintained by St Vincent's Hospital Melbourne.

#### Western Australia

Hepatitis C testing data were obtained through the contracted pathology provider. The number of treatment initiations (DAA) was based on pharmacy prescriptions filled, cross checked against prisoner data recorded on the WA Department of Justice electronic patient health record.

#### **Australian Hepatitis and Risk Survey in Prisons**

The Australian Hepatitis and Risk Survey in Prisons study has been planned as a repeated cross-sectional bio-behavioural survey of representative populations of people in prison in each jurisdiction in Australia. The first round of the study was conducted from April 2022 to June 2023.<sup>(23,24)</sup> Twenty-three representative state-run prison centres from six jurisdictions (NSW, NT, QLD, SA, TAS, and WA) were selected as study sites. These jurisdictions collectively housed 83% of people in prison in Australia in 2022.<sup>(27)</sup> In most jurisdictions, a minimum of one-quarter of the prisons were selected as sites for study enrolment, using a strategy that considered the available infrastructure in each prison for feasibility, while ensuring representation of all prison security classes (minimum, medium, maximum), remoteness of prison location, female prisons, and prisons with a predominant population of First Nations people.

All people in selected prisons, including those on remand and those sentenced, who provided informed consent and were able to speak English were eligible to participate in the study. At each prison, the study population was selected randomly using computer-generated random numbers from the list of all people present in the prison.

All participants provided informed written consent. For each participant, an interviewer-administered survey was conducted by trained study nurses, and included questions about: demographics; risk behaviours for blood-borne viruses, previous HIV, hepatitis B virus, and hepatitis C testing and treatment; and hepatitis B virus vaccination.

Participants provided saliva and fingerstick whole blood samples for point-of-care testing for HIV antibody (HIV Ab), hepatitis B virus surface antigen (HBsAg), HCV antibody and HCV RNA. HCV Ab testing was performed using OraQuick® HCV Rapid Antibody Test (OraSure Technologies, USA) with saliva samples. Participants with a positive HCV antibody test were offered point-of-care HCV RNA testing with a fingerstick whole blood sample, using the Xpert® HCV Viral Load Fingerstick test (Cepheid, USA; lower limit of quantification of 100 IU/mL). HBsAg testing was performed using Alere Determine™ II HBsAg test (Alere International, Ireland) with fingerstick whole blood samples. HIV Ab testing was performed using the OraQuick Advance® Rapid HIV-1/2 Antibody Test (Orasure Technologies, USA) with saliva samples.

For all of the national prevalence estimates, the sample size in each jurisdiction was weighted by the prisoner population size of that jurisdiction and the distribution of gender, and First Nations identity among people in prison, based on data from the Australian Bureau of Statistics in 2022.<sup>(27)</sup>

#### Monitoring hepatitis C treatment uptake in Australia

The methods for the estimations have been described in detail elsewhere.<sup>(31)</sup> In brief, the total PBS data of DAA dispensation for all individuals who initiated treatment between March 2016 and December 2023 in Australia were used to estimate the number of individuals initiating DAA treatment, and for all subgroup analyses of DAA uptake. The data of the second or further courses of treatment (for treatment failure or hepatitis C reinfection) were not included where indicated. Prescriber speciality was based on the prescriber derived major speciality codes recorded by the PBS. In this coding system, medical trainees (i.e., registrars) are also considered as specialists. The proportion of treatment initiations by prescriber type between 2019 and 2021 should be interpreted cautiously given the increasing number of unidentified prescriber type in these years. Jurisdictions are based on the patient residence at the time of treatment prescription.

#### Hepatitis C cascade of diagnosis and care

The estimates for the hepatitis C cascade of diagnosis and care are published annually in the *HIV*, *viral hepatitis and sexually transmissible infections in Australia: annual surveillance report*,<sup>(4)</sup> with methods associated with the updated cascade described in detail.

#### Modelling the Australian response to hepatitis C

Methods associated with the Kirby Institute's modelling have been previously published.<sup>(2,3,4,36)</sup>

The hepatitis C cascade estimates and outputs from the hepatitis C model are reviewed annually to ensure they are consistent with available epidemiological data. This includes updating parameter values and input data from clinical studies as results become available. This can lead to major changes in the estimates for the number of hepatitis C and hepatitis C-related liver disease burden and mortality. Observational studies are used for both model inputs and model calibration, in particular the Australian Needle Syringe Program Survey, the ETHOS Engage study, and the SEARCH study (emergency department screening) have reported hepatitis C treatment coverage of greater than 80% in NSW.<sup>(19,64,65,66)</sup> Model estimates can differ from observed studies; discrepancies may be due to an overestimate of the number of people living with hepatitis C in Australia. Two plausible reasons for this overestimation are: 1) a substantial number of duplicate hepatitis C notifications due to interstate movement, and 2) the possibility of false-positive notifications in low-prevalence settings. The percentage of notifications that are interstate duplicates and the proportion that are false positive is currently unknown. However, a study in QLD is investigating the proportion of notifications that are false positives, and the model may be revised accordingly in the future analyses.

#### Reinfection and retreatment

The previous model did not track the number of people who were reinfected with hepatitis C. Once an individual received treatment and was cured, they were assumed to have the same risk of hepatitis C infection as before, with no distinction between primary infection and reinfection in the model. This year, the model has incorporated reinfection and retreatment, by distinguishing individuals who are cured and subsequently reinfected. Based on a recent study,<sup>(67)</sup> the reinfection incidence rate among people who inject drugs who were cured with DAA therapy between 2015 and 2021 was 9.5 per 100 person-years. Given that very few reinfections occur among those with cirrhosis, the model assumed that most reinfections occur in the F0–F2 stage of the disease and have distributed the retreated population across disease stages using data from the ETHOS study. The model was then calibrated with retreatment data from the PHASE study, which examined reinfection-related retreatment using PBS data (updated from Carson et al.).<sup>(34)</sup>

#### Australia and New Zealand Liver and Intestinal Transplant Registry

The primary diagnosis at the first liver transplant of each adult patient (aged 16 years or older) who underwent a transplant at one of the five Australian liver transplant centres were sourced from the Australia and New Zealand Liver and Intestinal Transplant Registry.

#### **Stigma Indicators Monitoring Project**

For more information about the development of the stigma indicator, see Broady et al.<sup>(38)</sup>

#### Survey of people who inject drugs and people diagnosed with hepatitis C

In 2016, the Stigma Indicator was included in an online survey of people who inject drugs (n=124) and people living with hepatitis C (n=108). The survey was promoted through a range of community organisations and online forums.

Between 2018 and 2023, the Stigma Indicator was included in paper surveys of people who inject drugs (n=592–612), including sub-samples who had lived experience of hepatitis C (n=267–274). Participants were recruited via Australian Injecting and Illicit Drug Users League state-based member organisations. From 2021, participants were also given the option of completing an online version of the survey.

#### **Needle Syringe Program National Minimum Data Collection**

The Needle Syringe Program National Minimum Data Collection, led by Professor Lisa Maher, provides data from all Australian jurisdictions incorporating the following three components: needle syringe program service type and location, non-identifiable client occasions of service, and needle syringe distribution. The Needle Syringe Program National Minimum Data Collection National Data Report is published annually, with full details of methods included.<sup>(19)</sup>

#### The Illicit Drug Reporting System

The Illicit Drug Reporting System publishes an annual report, with full details of methods included.<sup>(48)</sup>

#### **Gay Community Periodic Survey**

The Gay Community Periodic Survey is a repeated, cross-sectional survey of GBM conducted using time-location sampling at gay venues, events, and clinics, supplemented by online recruitment. The Centre for Social Research in Health (University of New South Wales) conducts the survey in seven Australian states and territories, with community-based recruitment focussed on metropolitan areas. Its methods are described in detail elsewhere.<sup>(49,50)</sup>

#### Viral Hepatitis Mapping Project

Details of the Viral Hepatitis Mapping Project are published in full elsewhere.<sup>(51)</sup>

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GRHANITE<sup>™</sup> developers in the Health and Biomedical Informatics Centre at the University of Melbourne provide systems, software, and support to ACCESS.

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### ATLAS network

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### **National Prisons Hepatitis Network**

#### Australian Capital Territory

Justice Health, Primary Health, Mental Health, Justice Health and Alcohol and Drug Services, Canberra Health Services:

Dr Aleksandar Misev (Visiting Medical Officer, from 2022)

#### New South Wales

Dr Cristina Sotomayor-Castillo, Katherine Tree, Tracey Brown, Tom Wright, and Colette McGrath (Population Health, Justice Health and Forensic Mental Health Network)

#### Northern Territory

Dr Catherine Marshall (Viral hepatitis Service, Royal Darwin Hospital, NT Health) Jaclyn Tate-Baker (Nurse Practitioner Viral hepatitis Service, Royal Darwin Hospital, NT Health) A/Prof Rob Baird (Territory Pathology, NT Health)

#### Queensland

Carla Gorton (Communicable Diseases Branch, Department of Health) Graham Kraak (Offender Health and Wellbeing, Department of Health, Prisoner Health Services staff)

## South Australia

Andrew Wiley (Director, SA Prison Health Services) Dr Tom Turnbull (Medical Director, SA Prison Health Services, from April 2021) Anton Colman (Nurse Consultant, Hepatology, Royal Adelaide Hospital) Tom Rees (Manager, STI and BBV Section Communicable Disease Control Branch, SA Health) Prison health staff, Local Health Network Viral Hepatitis Nurses, Hepatitis SA

## Tasmania

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#### Victoria

Statewide Hepatitis Program, St Vincent's Hospital Melbourne Custodial Health, Western Health Victorian Department of Justice and Community Safety

#### Western Australia

Dr Joy Rowland (Director Medical Services, WA Department of Justice) Holly Beasley (Senior Project Officer BBV, WA Department of Justice) Dr Heather Lyttle (HCV GP Prescriber, WA Department of Justice) Michelle Stamatopoulos (Clinical Nurse Hepatitis C, WA Department of Justice) WA tertiary hospital hepatology services Health Services Department of Justice prison clinical staff across WA

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# **Data contributors**

















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