Australia's progress towards hepatitis C elimination

Annual Report 2022





Suggested citation: Burnet Institute and Kirby Institute. Australia's progress towards hepatitis C elimination: annual report 2022. Melbourne: Burnet Institute; 2022.

ISBN: 978-0-646-86972-8 DOI: 10.26190/ge22-aq55

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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 1st 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 188 690<sup>\*</sup> people had chronic hepatitis C in Australia.<sup>(2,3,4)</sup> Further, at the end of 2015, of the 188 690 people living with hepatitis C, 29 680 (16%) were Aboriginal and Torres Strait Islander people.<sup>(6)</sup> In the past six years Australia has made great strides towards hepatitis C elimination. 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.

However at the end of 2020, an estimated 47% of people living with hepatitis C were yet to be treated, representing 117 800 people living with chronic hepatitis C at the end of 2020.<sup>(2,3,4)</sup> It is clear from data collated in this year's report that declines in testing and treatment are substantial and ongoing; without a reinvigoration of efforts to increase diagnosis, Australia will not achieve its elimination goals. To achieve hepatitis C elimination, DAA treatment needs to be combined with effective primary prevention measures, raised awareness about hepatitis C treatment and cure, and increased testing and linkage to care among people at risk of hepatitis C. Convenient, accessible, and acceptable models of care help to ensure all people living with hepatitis C service delivery should consider the overlap with common comorbidities such as substance use and mental health disorders. By providing person-centred care that focusses on social, cultural, and emotional needs, in addition to medical needs, services can better support individuals throughout their hepatitis C journey.

To understand progress towards hepatitis C elimination, monitoring trends in data to assess the impact of these components is required, from measurement of new infections, counts of people tested and treated, and people receiving hepatitis C-related liver transplants, through to projections based on mathematical modelling. This is the fourth 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. Future reports will aim to fill gaps identified and collate data for all priority populations<sup>†</sup> and settings.

<sup>\*</sup> Estimates of people living with hepatitis C at the end of 2020 were derived in 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>

# **Abbreviations**

ACCHS	Aboriginal Community Controlled Health Service
CI	confidence interval
DAA	direct-acting antiviral
GBM	gay, bisexual, and other men who have sex with men
HCV	hepatitis C virus
HIV	human immunodeficiency virus
IDU	injecting drug use
MBS	Medical Benefits Scheme
NSP	needle and syringe program
OAT	opioid agonist therapy
PBS	Pharmaceutical Benefits Scheme
PHN	Primary Health Network
RNA	ribonucleic acid
SVR	sustained virological response
UNSW	University of New South Wales
WHO	World Health Organization

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# **Executive Summary**

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 (WHO) and targets included in Australia's National Hepatitis C Strategy 2018–2022. Moving to unrestricted access to direct-acting antivirals (DAAs) for the treatment of hepatitis C in March 2016 provoked a catalytic change in Australia's hepatitis C response and meant the goal of elimination became possible.

Australia has made considerable progress towards elimination in recent years with 95 395 people initiating DAA treatment between March 2016 and the end of 2021. Where available, the data show that numbers/rates of current infections have declined, particularly among the priority population of people who inject drugs and among HIV-positive gay, bisexual, and other men who have sex with men (GBM). Of note there has been a significant and increasing contribution of prison-based hepatitis services in progressing Australia's elimination goals. In 2021, DAA treatment initiations in prison-based hepatitis services represented 41% of the total national DAA treatment initiations, an increase from 2019 (30%) and 2020 (37%). These data reflect the ongoing importance of supporting the justice sector to eliminate hepatitis C and underscore the crucial role prison hepatitis services play in reaching people at risk of hepatitis C and Australia achieving its elimination goals.

Despite Australia's success over the past six years an estimated 117 800 people were living with chronic hepatitis C at the end of 2020, highlighting the considerable challenge that remains to eliminate hepatitis C in Australia. Levels of hepatitis C testing, and therefore diagnosis and treatment have declined. Whilst this decrease in the number of people hepatitis C tested and treated was observed prior to the COVID-19 pandemic, the pandemic exacerbated the decline and continues to create additional challenges to accessing health care for people affected by hepatitis C. To ensure elimination goals are met health promotion campaigns are needed to ensure key risk populations are aware that treatment and retreatment is available to them and to encourage them to engage in care. Considerable effort and investment are also needed to support the provision of accessible, simplified, and convenient models of testing and treatment, to ensure people living with or at risk of hepatitis C access testing, are retained in care, and complete treatment in a timely fashion. This may include novel models of care such as point-of-care testing, peer-led models of care, testing and treatment in non-traditional settings such as pharmacies, and expanding drug treatment programs to include hepatitis C care. Expanding models of care also requires supporting the relevant workforce through education and skill development. As well, there needs to be ongoing investment in the prevention of new infections and reinfection through harm minimisation, including in prisons. Importantly, this report highlights that stigma and discrimination towards people at risk of and living with hepatitis C remains prevalent. Interventions to reduce stigma in the community and health care settings will be necessary to increase engagement with hepatitis C testing and treatment services and continue progress towards hepatitis C elimination.

# 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 prevention and secondary prevention (testing and treatment). New acquisition of hepatitis C is best measured using an incidence rate, which describes the rate at which people test positive for the 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 important to note that incidence rates are sensitive to changes in testing patterns, as occurred when testing initially increased after DAAs were introduced in 2016. Also, regular and repeat testing among specific cohorts improves the reliability of incidence rates. The data on rates of hepatitis C incidence remains somewhat 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>(4,9,10)</sup> These notifications may reflect incident infections because younger people are likely to have initiated injecting drug use (IDU) relatively recently.<sup>(11)</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 and Blood Borne Viruses (ACCESS),<sup>(12)</sup> which links individuals' diagnostic testing data over time.<sup>(13,14)</sup> ACCESS includes primary care clinics that provide specialist health services to people who inject drugs, such as needle and syringe programs (NSPs), opioid agonist therapy (OAT), 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 (see Methods, ACCESS section for details on included sites). HCV antibody test positivity of >10% at some of the primary care clinics included in ACCESS (see Chapter Two) suggest these specific sites represent key sentinel sites for monitoring changes in hepatitis C incidence and the impact of hepatitis C prevention efforts. ACCESS also includes clinics that specialise in the health of HIV-positive GBM (GBM and sexual health clinics). Testing data from 25 ACCESS sites across seven jurisdictions and 14 709 individuals were used in incidence rate measurement. Most primary care clinics in ACCESS are in Victoria (VIC), and most GBM and sexual health clinics are in VIC and New South Wales (NSW).

Study-specific data can highlight hepatitis C incidence within specific sub-groups of GBM including HIV-positive, HIV-negative, and HIV-negative and using pre-exposure prophylaxis (PrEP) men.<sup>(15)</sup> Further, a study of hepatitis C incidence among people who inject drugs provided a measurement of hepatitis C incidence prior to unrestricted access to DAAs, allowing for comparison with measurement of incidence post–unrestricted access to DAAs in 2016.<sup>(16)</sup>

## **PROGRESS ON REDUCING NEW INFECTIONS**

Among men and women aged 20–24 years, the number of hepatitis C notifications has declined since 2017 (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.

Declines in hepatitis C incidence were observed among individuals tested at ACCESS primary care clinics and among HIV-positive GBM tested at ACCESS GBM or sexual health clinics between 2012 and 2021 (Figures 2 and 3).

A specific study of GBM attending ACCESS clinics showed declines in hepatitis C incidence among HIV-positive GBM since increased availability of DAAs in 2016.<sup>(15)</sup>

A study of hepatitis C incidence among people who inject drugs reported a pooled adjusted incidence rate of 9.9 per 100 person-years (PY; 95% confidence interval (CI): 8.3–11.8). This incidence rate is equivalent to 4 126 new annual hepatitis C infections in 2015 (range 2 499–6 405).<sup>(16)</sup>

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, 2012–2021



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

**Source:** Australian National Notifiable Diseases Surveillance System.<sup>(4,9,10)</sup> **Notes:** Cases other than newly acquired were assigned as unspecified.





#### • Observed incidence rate - 95% CI

Source: ACCESS.(12)

**Notes:** N=7 190. Analysis includes nine sites: seven in VIC, one in Western Australia (WA), and one in Queensland (QLD). The WA site contributed data from 2016 onwards. 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 31st December 2021). 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, 2012–2021



#### • Observed incidence rate - 95% CI

#### Source: ACCESS.(12)

**Notes:** N=7 519. Analysis includes 16 sites: six in NSW, four in VIC, one in South Australia (SA), two in Australian Capital Territory (ACT), one in WA, one in QLD, and one in Tasmania (TAS). The TAS site contributed data from 2013 onwards. 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 31st December 2021). CI: confidence interval.

#### Monitoring hepatitis C incidence among gay, bisexual, and other men who have sex with men

Data from clinics participating in ACCESS located in seven jurisdictions in Australia were included in a study of hepatitis C incidence among GBM between 2009 and 2019. Among 6 744 HIV-positive GBM, overall hepatitis C incidence was 1.03 per 100 PY. In 2015, the incidence rate was 1.01 (95% CI: 0.73–1.42) per 100 PY and in 2019 the incidence rate was 0.23 (95% CI: 0.10–0.52) per 100 PY. Compared to 2015, incidence declined by 78.0% in 2019 (incidence rate ratio (IRR) 0.22; 95% CI: 0.09–0.55). Among 20 590 HIV-negative GBM, overall hepatitis C incidence was 0.20 per 100 PY, with no significant change over time. Among 11 661 HIV-negative GBM prescribed PrEP, overall hepatitis C incidence was 0.29 per 100 PY. In 2016, the incidence rate was 0.41 (95% CI: 0.22–0.76) per 100 PY and in 2019 the incidence rate was 0.08 (95% CI: 0.03–0.22) per 100 PY. Compared to 2016 (when PrEP became broadly available), incidence among HIV-negative GBM prescribed PrEP declined by 80.0% in 2019 (IRR 0.20; 95% CI:0.06–0.64).<sup>(15)</sup>

#### Monitoring hepatitis C incidence among people who inject drugs

A 2021 study pooled measurements of hepatitis C incidence prior to 2016, among people who inject drugs, allowing for comparison of incidence measurements after unrestricted access to DAAs. The study utilised published estimates of hepatitis C incidence among people who inject drugs in Australia, alongside corresponding estimates of NSP coverage and their protective effect to produce an adjusted pooled measurement of hepatitis C incidence in 2015. Five longitudinal studies, conducted between 2003 and 2015 were included, resulting in a pooled adjusted hepatitis C incidence rate of 9.9 per 100 PY (95% CI: 8.3–11.8). This incidence rate is equivalent to 4 126 new annual hepatitis C infections in 2015 (range 2 499–6 405).<sup>(16)</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>(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 IDU and HIV-positive GBM. ACCESS can provide data on consultations and hepatitis C testing among attendees of primary care and sexual health clinics, and within primary care, for the priority population of individuals accessing OAT; people prescribed OAT are likely to have a history of current, recent, or past IDU. 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 (4.4% had status not recorded, 6.5% were recorded as 'not stated', and 2.9% were Aboriginal and/or Torres Strait Islander). 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).

The ATLAS network is an established national sexually transmissible infections (STIs) and blood-borne viruses (BBVs) surveillance network specific to Aboriginal and Torres Strait Islander peoples. Data from the ATLAS network for this report was provided by Aboriginal Community Controlled Health Services located in urban, regional, and remote areas (34 services). ATLAS can provide 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, and treatment uptake—the proportion of HCV RNA positive individuals prescribed DAA treatment.<sup>(18)</sup>

The Australian Needle Syringe Program Survey (ANSPS) is an annual survey of attendees at participating NSP sites across Australia (37 NSPs in 2021). In 2020, COVID-19 related restrictions meant the ANSPS was not conducted in VIC and once again in 2021, COVID-19 related restrictions meant the ANSPS was conducted at a reduced number of services and overall recruitment was approximately 30% less than previous years. The ANSPS asks about a range of risk and health-seeking behaviours, including hepatitis C testing. Dried blood spot laboratory testing for HCV antibody was conducted, and HCV RNA testing was performed among those who tested HCV antibody positive if there was sufficient dried blood spot sample remaining after HCV antibody testing.<sup>(19)</sup>

Population-level monitoring of testing related to diagnosis of current hepatitis C infection can occur through the publicly available Medical Benefits Scheme (MBS) 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>

Study-specific data can offer more in-depth analysis of hepatitis C testing among priority populations, including people accessing drug treatment.<sup>(21)</sup> Also, study data on the effects of COVID-19 related restrictions on hepatitis C testing can provide insights into how the pandemic may have hindered progress towards hepatitis C elimination.<sup>(22)</sup>

# Testing and diagnosis

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

Across ACCESS sites, a decline in hepatitis C testing activity was seen in 2020 and 2021, with larger declines seen within primary care clinics compared to GBM or sexual health clinics; most primary care clinics are in VIC, the jurisdiction with longer periods of COVID-19 related restrictions in 2020 and 2021.

Within ACCESS primary care clinics, from 2012, annual hepatitis C test uptake (HCV antibody or HCV RNA) remained stable through to 2019 at ~9.0% of attendees tested, with a decline seen in 2020, that continued into 2021 to 5.8% of attendees tested (Figure 4). Within ACCESS GBM or sexual health clinics, among HIV-positive GBM annual test uptake increased through to 2017, remained relatively stable, with a decline then seen between 2019 and 2020, which stabilised in 2021 to 48.1% of attendees tested (Figure 5). Within ACCESS primary care clinics, among individuals ever prescribed OAT, annual test uptake peaked in 2016 then declined through to 2020 and 9.1% of attendees tested in 2021 (Figure 6). Within sexual health clinics, among Aboriginal and Torres Strait Islander peoples, annual test uptake has increased since 2012 to 31.3% of attendees were tested in 2021, the highest proportion observed 2012–2021 (Figure 7).

Within ACCESS primary care clinics, the annual number of HCV antibody tests was largely stable 2012–2017, with an increase in the number of people tested 2018–2019, then fewer people were tested in 2020 and 2021; more testing occurred among women than men (Figure 8). Within ACCESS GBM or sexual health clinics, among HIV-positive GBM, the annual number of HCV antibody tests steadily increased through to 2019, followed by a decline in 2020 and 2021 (Figure 9). Within ACCESS primary care clinics, among individuals ever prescribed OAT, the annual number of HCV antibody tests was largely stable among women, and fewer women than men were tested. The annual number of men HCV antibody tested was largely stable 2012–2017, with an increase 2018–2019, then a decline in 2020 and 2021 (Figure 10). Within sexual health clinics, among Aboriginal and Torres Strait Islander peoples, the annual number of HCV antibody tests increased 2012–2018, with fewer people tested in 2019 and 2020, followed by an increase in 2021 (Figure 11).

Within ACCESS primary care clinics, HCV antibody positivity declined from 2018 onwards with positivity higher among men compared to women (Figure 8). Within ACCESS GBM or sexual health clinics, among HIV-positive GBM, HCV antibody positivity remained stable 2012–2021 (Figure 9). Within ACCESS primary care clinics, among individuals ever prescribed OAT, HCV antibody positivity remained at >60% 2012–2021 with minimal difference between men and women in positivity (Figure 10). Within sexual health clinics, among Aboriginal and Torres Strait Islander peoples, HCV antibody positivity declined from a peak in 2012 through to 8.7% in 2021 (Figure 11).

# PROGRESS ON DIAGNOSIS OF HEPATITIS C INFECTIONS (CONTINUED)

In the ATLAS network, annual hepatitis C test uptake (HCV antibody or HCV RNA) decreased in 2021 to 8.2%, compared to a peak in test uptake of 11.5% in 2019, an observation likely explained by the impact of COVID-19 on health service activities (Figure 12). Annual HCV antibody test positivity was stable 2016–2021, with 5.5% of people HCV antibody tested, testing positive in 2021 (Figure 13). Between 2016 and 2021, 6.4% (1 679/26 243) of ACCHS clients tested for HCV antibodies were positive and 53.4% (896/1 679) were subsequently tested for HCV RNA or viral load (Figure 14). More hepatitis C tests (HCV antibody or HCV RNA) were among women compared to men and this remained consistent between 2016 and 2021 (Figure 15). It is important to note that testing for hepatitis C within ACCHSs is risk-based and not intended to meet whole population-level coverage.

Approximately half of ANSPS respondents reported testing for hepatitis C in the previous year. In 2021, in some jurisdictions, there was an increase in the proportion of respondents tested, notably NSW and Northern Territory (NT) returned to pre–2020 levels of testing (Figure 16). There was limited difference in hepatitis C test uptake by gender (Figure 17), and by Indigenous status (Figure 18). In 2021, overall HCV antibody positivity among ANSPS respondents was 36.4% (522/1 435), the fifth consecutive year that positivity was <50%, following two decades of HCV antibody positivity  $\geq$ 50% (all years between 1999 and 2016). Between 2015 and 2020, at least half of ANSPS respondents of Aboriginal and/or Torres Strait origin were HCV antibody positive, however positivity was <50% in 2021.<sup>(19)</sup>

Among ANSPS respondents tested for HCV RNA, positivity (weighted by HCV antibody status and gender) declined from 50.7% (496/978) to 16.1% (214/1 328) between 2015 and 2021. Among men HCV RNA tested, positivity declined from 53.2% (350/658) to 17.7% (148/835) between 2015 and 2021. Among women, HCV RNA positivity declined from 45.3% (141/311) to 13.1% (62/474) between 2015 and 2021 (Figure 19).

From the beginning of 2017, Medicare claims for HCV RNA tests related to hepatitis C diagnosis declined steadily to the end of 2018 and have remained largely stable since (Figure 20).

A study of HCV antibody testing among people prescribed OAT highlights low levels of testing despite evidence of high HCV antibody positivity.<sup>(21)</sup> Analysis of the effects of the COVID-19 pandemic on hepatitis C testing showed moderate declines in testing post periods of COVID-19-related restrictions and a slow recovery to pre–pandemic levels of testing (which were already in decline).<sup>(22)</sup>

#### Monitoring hepatitis C testing

**Figure 4.** Number of individuals attending ACCESS primary care clinics and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ACCESS, 2012–2021



#### Source: ACCESS.(12)

**Notes:** Analysis includes nine sites: seven in VIC, one in WA, and one in QLD. The WA site contributed data from 2016 onwards. 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 and contributed one consultation and one test per year.





#### Source: ACCESS.(12)

**Notes:** Analysis includes 16 sites: six in NSW, four in VIC, one in SA, two in ACT, one in WA, one in QLD, and one in TAS. The TAS site contributed data from 2013 onwards. 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.



**Figure 6.** Number of individuals ever prescribed OAT attending ACCESS primary care clinics and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ACCESS, 2012–2021

#### Source: ACCESS.(12)

**Notes:** Analysis includes nine sites: seven in VIC, one in WA, and one in QLD. The WA site contributed data from 2016 onwards. 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 OAT between January 2009 and December 2021, and contributed one consultation and one test per year.



**Figure 7.** Number of Aboriginal and Torres Strait Islanders attending ACCESS sexual health clinics and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ACCESS, 2012–2021

#### Source: ACCESS.<sup>(12)</sup>

**Notes:** Analysis includes seven sites: four in NSW, one in VIC, one in ACT, 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 individuals who attended included clinics 2012–2021 for a consultation (N=850 984), 4.4% had no Aboriginal or Torres Strait Islander status recorded (missing), 6.5% were recorded as 'not stated', 86.2% were neither Aboriginal nor Torres Strait Islander, and 2.9% were Aboriginal and Torres Strait Islander.



## **Figure 8.** Number of individuals tested for HCV antibody at ACCESS primary care clinics and proportion of HCV antibody tests positive by gender, ACCESS, 2012–2021



#### Source: ACCESS.<sup>(12)</sup>

**Notes:** Analysis includes nine sites: seven in VIC, one in WA, and one in QLD. The WA site contributed data from 2016 onwards. 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 and contributed one test per year. Individuals recorded as 'Other' sex or sex not recorded were not included due to small sample size.





#### Source: ACCESS.<sup>(12)</sup>

**Notes:** Analysis includes 16 sites: six in NSW, four in VIC, one in SA, two in ACT, one in WA, one in QLD, and one in TAS. The TAS site contributed data from 2013 onwards. 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.



## **Figure 10.** Number of individuals ever prescribed OAT tested for HCV antibody at ACCESS primary care clinics and proportion of HCV antibody tests positive by gender, ACCESS, 2012–2021



#### Source: ACCESS.<sup>(12)</sup>

**Notes:** Analysis includes nine sites: seven in VIC, one in WA, and one in QLD. The WA site contributed data from 2016 onwards. 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 OAT between January 2009 and December 2021, and contributed one test per year. Individuals recorded as 'Other' sex or sex not recorded were not included due to small sample size.



**Figure 11.** Number of Aboriginal and Torres Strait Islanders tested for HCV antibody at ACCESS sexual health clinics and proportion of HCV antibody tests positive, ACCESS, 2012–2021

#### Source: ACCESS.(12)

**Notes:** Analysis includes seven sites: four in NSW, one in VIC, one in ACT, and one in SA. Clinic attendances included in-person and telehealth consultations. Individuals were 15 years or older and contributed one test per year.



## **Figure 12.** Number of individuals attending ACCHSs and proportion tested for HCV (HCV antibody only or HCV antibody and RNA or HCV RNA only), ATLAS network, 2016–2021

Source: ATLAS sexual health surveillance network, 2016–2021.<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 2021.





Source: ATLAS sexual health surveillance network, 2016–2021.<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 2021.

**Figure 14.** Hepatitis C testing cascade: number and proportion of individuals attending ACCHSs tested for HCV antibody or RNA and among those tested, the number and proportion testing positive, ATLAS network, aggregated for years 2016–2021



Source: ATLAS sexual health surveillance network, 2016–2021.<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 2021. '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 2021). 'A total of 136 379 individuals aged 15 years or older attended medical appointments between 2016 and 2021, of whom 19.2% (26 243/136 379) had an HCV antibody test. tOf those tested for HCV antibody, 6.4% (1679/26 243) tested HCV antibody positive. <sup>‡</sup>Of those HCV antibody positive, 53.4% (896/1679) had an HCV RNA test following HCV antibody positivity of which <sup>§</sup>50.4% (452/896) were HCV RNA positive.



**Figure 15.** Proportion of HCV tests (HCV antibody only or HCV antibody and RNA or HCV RNA only) at ACCHSs by gender, ATLAS network, 2016–2021

Source: ATLAS sexual health surveillance network, 2016–2021.<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 2021. Number of people tested per year as follows: 2016: 2 070 men, 3 117 women; 2017: 2 710 men, 3 754 women; 2018: 2 806 men, 3 723 women; 2019: 3 193 men, 4 314 women; 2020: 2 641 men, 3 869 women; and 2021: 2 576 men, 3 975 women.





**Source:** Australian Needle Syringe Program Survey. National Data Report 2017–2021.<sup>(19)</sup> **Notes:** No participant recruitment occurred in VIC in 2020.





**Source:** Australian Needle Syringe Program Survey. National Data Report 2017–2021.<sup>(19)</sup> **Notes:** No participant recruitment occurred in VIC in 2020.



## **Figure 18.** Proportion of ANSPS respondents reporting recent (past 12 months) hepatitis C testing by Indigenous status, 2012–2021

Source: Australian Needle Syringe Program Survey. National Data Report 2017–2021.<sup>(19)</sup>Notes: No participant recruitment occurred in VIC in 2020.





Men tested Women tested -- Men proportion positive — Women proportion positive

**Source:** Australian Needle Syringe Program Survey. National Data Report 2017–2021;<sup>(19)</sup> Australian Needle Syringe Program Survey 25 year National Data Report 1995–2019.<sup>(23)</sup>

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



**Figure 20.** Number of claims to Medicare for items 69499 and 69500 (detection of HCV RNA, new infections only), 2012–2021

Source: Medicare Australia Statistics.<sup>(20)</sup>

**Notes:** MBS 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 MBS data.

#### Monitoring hepatitis C testing among people accessing drug treatment

An analysis of HCV antibody testing among patients attending ten ACCESS clinics located in VIC (N=5 429 individuals) who had not previously tested positive for HCV antibody and received their first recorded OAT prescription between 1st January 2012 and 31st December 2019 demonstrated low levels of testing despite high test positivity. Approximately one in six individuals (17.3%, 940/5 429) received an HCV antibody test in the 12 months following their first recorded OAT prescription. Over half of individuals who were tested (56.0%, 524/935) received a positive HCV antibody test result.<sup>(21)</sup> Uptake of HCV antibody testing estimated in this study was lower than self-reported estimates among similar populations. Among ETHOS Engage study participants (71.8%, 1719/2 395 reporting current OAT),<sup>(24)</sup> in Wave 1, 87.2% (1 250/1 433) and in Wave 2, 87.0% (1 053/1 211) of participants had ever HCV antibody tested.<sup>(25,26)</sup> Among respondents of the 2021 ANSPS (30.0% of all respondents (443/1 474) reporting current OAT), 77.8% (1 147/1 474) had ever HCV antibody tested and 46.5% (686/1 474) had tested in the past 12 months (see Figure 16).<sup>(19)</sup>

#### Monitoring the effects of the COVID-19 response on hepatitis C testing

To examine how COVID-19 related restrictions changed uptake of HCV antibody and HCV RNA testing, data from 11 ACCESS clinics located in VIC which specialise in the care of people who inject drugs were included in an interrupted time-series analysis. Data from all services during the 125 weeks between 1st January 2019 and 25th May 2021 were included. Pre-COVID, an average of 80.6 HCV antibody and 25.7 HCV RNA tests were performed each week; note a declining trend was observed prior to COVID-19-related lockdowns. After the first lockdown in VIC (April 2020), there was an immediate drop of 23.2 HCV antibody tests and 8.6 HCV RNA tests per week (equivalent to a 30.9% and 46.0% drop, respectively). After the second lockdown (July 2020), there was an immediate drop of 17.2 HCV antibody tests and 4.6 HCV RNA tests per week (equivalent to a 26.2% and 33.3% drop, respectively). Some recovery in HCV antibody testing in the months following the lockdowns was observed but the average level of HCV antibody testing had not returned to pre–pandemic levels by the end of May 2021.<sup>(22)</sup>

# Three

## Uptake of direct-acting antiviral treatment

Achieving hepatitis C elimination in Australia relies on maintenance of 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>(27,2,28,29)</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 PBS in March 2016, are available at minimal cost to Medicare-eligible Australians.

#### Treatment uptake

The monitoring treatment uptake in Australia project provides estimates of the number of individuals initiating DAA treatment, and retreatment, between March 2016 and December 2021. DAA treatment initiations (first treatment) by jurisdiction and provider type are described.<sup>(30)</sup>

The ANSPS 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 hepatitis service providers on the number of DAA treatments initiated in 103 (2019), 94 (2020), and 95 (2021) prisons across eight states and territories (Table 1).<sup>(31)</sup> The monitoring treatment uptake in Australia project uses PBS data of DAA dispensations for all individuals who initiated DAA therapy between March 2016 and December 2021 including treatment initiated in prison.<sup>(30)</sup> While in-prison treatments cannot be reliably delineated from community treatments in the PBS database, the proportion of treatment initiations that were among people in prison can be measured by assessing prison treatment numbers relative to the total number of individuals accessing DAA treatment in the community.

Justice-involved non-incarcerated populations are at risk of hepatitis C but not often the focus of testing and treatment interventions. There are service gaps for justice-involved populations who have never been to prison, as well as those who have been recently released from prison. Relevant study-specific and program data were included to give important indicators for linkage to hepatitis C care for justice-involved non-incarcerated populations including the C-LINK study,<sup>(32)</sup> a Prison Transition Service in QLD,<sup>(33)</sup> and a pilot program offering hepatitis C diagnosis and treatment in three community corrections sites in south-east QLD.<sup>(34)</sup>

#### Retreatment

The National Retreatment Project includes all individuals with hepatitis C who initiated DAA treatment through the PBS and were retreated. As the PBS data does not capture reason for retreatment, retreatment data from the REACH-C cohort<sup>(35,36)</sup> were used to train a Random Forest machine learning model to classify retreatment for reinfection or treatment failure.<sup>(37)</sup>

#### Cascades of care

ACCESS data from primary care clinics provided a hepatitis C care cascade; the cascade reflects the status of individuals at 31st December 2021 and includes individuals who had a clinical consultation within the five years prior (2016-2021).<sup>(12,38)</sup>

The ATLAS network provided 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 (2016–2021).

The National hepatitis C diagnosis and care cascade is estimated annually as part of the HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report<sup>(2,3,4,9)</sup> providing a general estimate of hepatitis C treatment uptake and cure to the end of 2020.

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

#### Treatment uptake

Between March 2016 and December 2021, an estimated 95 395 people living with chronic hepatitis C initiated DAA therapy, including 33 201 people in 2016, 20 969 people in 2017, 15 209 in 2018, 11 314 in 2019, 8 228 in 2020, and 6 474 in 2021 (Figure 21), with variations in uptake by jurisdiction (Figure 22). The months following the listing of DAAs on the PBS in March 2016 saw the peak in hepatitis C treatment initiations. Declining numbers of treatment initiations by specialists were not offset by increased numbers of initiations by non-specialists (Figure 23).

Overall lifetime treatment uptake among ANSPS respondents rose considerably from 28.6% (184/643) in 2016 to 61.8% (191/309) in 2021 (Figure 24).

In 2021, 2 639 individuals commenced hepatitis C treatment in prisons across all Australian jurisdictions. This is estimated to represent 40.8% (2 639/6 474) of all hepatitis C treatment episodes in Australia in 2021, highlighting the importance of the prison sector in national elimination efforts. The number of treatment initiations recorded in each jurisdiction is presented in Figure 25 and Table 1. In 2021, across the various jurisdictions, the proportion of DAA initiations occurring in the prisons ranged from 9.6% to 72.8% of the jurisdictional total. These data do not distinguish between first and subsequent treatments (retreatments), either because of reinfection or treatment failure. Emerging evidence of hepatitis C reinfections in prisons<sup>(39,40,41)</sup> underscores the need to differentiate first and subsequent treatments in future data collations and to monitor reinfection rates.

The commencement of treatment for hepatitis C within prisons varies across jurisdictions according to the prevalence of disease within the jurisdiction, the size of the prison population, the number of people previously treated in prison or the community, and the number of new diagnoses. While the most recent nation-wide estimate (2016) of HCV antibody positivity among people in prison was 22.2%, the prevalence varies considerably between jurisdictions<sup>(42)</sup> reflecting differences in the characteristics of people incarcerated and in particular the proportion of people incarcerated who have histories of IDU. As only the total annual number of treatment initiations is provided, without reliable information on the numbers of people eligible for treatment in prison, comparison of individual programs between jurisdictions is not possible.

The National Prisons Hepatitis Network aims to harmonise data collection and indicators across jurisdictions and initiate systematic surveillance studies. Future reports will aim to provide more comprehensive data on hepatitis C diagnoses and treatments by jurisdiction over time.

# PROGRESS ON INCREASING TREATMENT UPTAKE (CONTINUED)

The C-LINK study randomised 46 people with untreated hepatitis C infection released from prison in VIC between October 2018 and March 2020 to a care navigator intervention or standard care. Of 22 people randomised to the intervention—which involved linkage to hepatitis C care, telephone consultation, subsidised OAT for the duration of DAA treatment, and reimbursements for out-of-pocket expenses including DAA dispensing fees—72.7% (16/22) commenced DAA treatment. Of the 24 people randomised to standard care—referral to a general practitioner—33.3% (8/24) commenced DAA treatment, of whom three (of five) did so upon reincarceration. Among those prescribed DAAs, the median time between release from prison and DAA prescription was 21 days (interquartile range 11–42 days) for care navigation and 82 days (interquartile range 44–99 days) for standard care participants.<sup>(32)</sup>

The Prison Transition Service also models a centralised referral pathway for people transitioning in or out of prison between four south-east QLD correctional centres and community service providers. The program received 336 referrals between February 2019 and December 2020 and 277 of these people were referred on to other services for testing, results, treatment initiation, linkage to care for replacement of lost medication, and/or connection to other services.<sup>(33)</sup> A pilot program offering hepatitis C diagnosis and treatment in three community corrections sites in south-east QLD recorded testing 148 people for hepatitis C of whom 33 (22.3%) were HCV RNA positive and 21 clients initiated DAA treatment (with six referred to a tertiary specialist).<sup>(34)</sup>

#### Retreatment

The National Retreatment Project included 95 272 individuals who initiated DAA therapy through the PBS 2016–2021, of whom 7.3% received retreatment (n=6 980). Among the 6 980 individuals retreated, the total number of retreatments was 8 196 (that is some people were retreated more than once). The model classified 51.8% (95% CI: 46.7–53.6%; n=3 614) as due to reinfection and 48.2% (95% CI: 46.4–53.3%; n=3 366) as due to treatment failure.

Retreatment for reinfection increased steadily over the study period from 14 episodes in 2016 to 1 092 in 2020, then stabilised in 2021. Corresponding with the availability of pangenotypic and salvage regimens, retreatment for treatment failure increased from 73 in 2016 to 1 077 in 2019, then declined to 515 in 2021, consistent with large declines in the uptake of initial treatment (Figure 26). There were variations in retreatment by jurisdiction for reinfection (Figure 27) and treatment failure (Figure 28), consistent with previously described jurisdictional variations in treatment initiations (Figure 22).

# PROGRESS ON INCREASING TREATMENT UPTAKE (CONTINUED)

#### Cascades of care

At the end of 2021, among those with a clinical consultation at ACCESS primary care clinics between 2016 and 2021 and an HCV RNA positive test recorded in ACCESS (N=4 297), 54.2% (2 329/4 297) had initiated treatment and of those treated, 49.0% (1 141/2 329) had an HCV RNA test >8 weeks post-treatment, of which 92.7% (1 058/1 141) were HCV RNA negative (Figure 29).

Over the six years of the ATLAS network data (2016–2021), 330 (18.9% of the 1750 ever HCV RNA tested), individuals received DAA treatment from an ACCHS participating in the ATLAS network. Of those prescribed DAAs, 37.3% (123/330) were tested for HCV RNA or viral load following treatment. Of those with an HCV RNA or viral load test post-treatment, 86.2% (106/123) appeared to achieve an undetectable HCV viral load (Figure 30).

National hepatitis C diagnosis and care cascade modelling estimated 117 800 people were living with hepatitis C at the end of 2020 (Figure 31).
#### Monitoring treatment uptake

**Figure 21.** Estimated number of individuals initiating DAA treatment and the proportion of individuals living with chronic hepatitis C who initiated DAA treatment by jurisdiction, PBS database, March 2016–December 2021



Proportion treated Proportion untreated

Number of individuals initiating treatment, March 2016–December 2021

Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(30)</sup>

**Notes:** Includes individuals initiating first treatment; data of the second or further courses of treatment are available from the Monitoring treatment uptake project. Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases. Estimated proportion of individuals living with chronic hepatitis C who initiated DAA treatment was based on people living with chronic hepatitis C at the end of 2015 (N= 188 690)<sup>(4)</sup> and does not encompass individuals with new infections from the end of 2015, some of whom will have been treated. Jurisdiction data were not available for 16 individuals; these individuals contributed to the national estimates only.





Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(30)</sup>

**Notes:** 2016 Q1 is data from March 2016 only. Treatment numbers may vary from previous or future reports due to refinements made to the PBS data between releases.



**Figure 23.** Estimated number of individuals initiating DAA treatment by prescriber type, PBS database, March 2016–December 2021

Source: Monitoring hepatitis C treatment uptake in Australia.<sup>(30)</sup>

**Notes:** 2016 Q1 is data from March 2016 only. 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. 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.



**Figure 24.** Proportion of ANSPS respondents who tested HCV antibody positive, self-reporting lifetime history of hepatitis C treatment by gender, 2012–2021

Source: Australian Needle Syringe Program Survey. National Data Report 2017–2021.<sup>(19)</sup>

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

**Figure 25.** Number and estimated proportion<sup>\*</sup> of individuals who initiated DAA treatment in prison versus in the community by jurisdiction, National Prisons Hepatitis Network and PBS Database, 2019, 2020, and 2021





**Table 1 (Figure 25 cont.).** Number and estimated proportion<sup>\*</sup> of individuals who initiated DAA treatment in prison versus in the community by jurisdiction, National Prisons Hepatitis Network and PBS Database, 2019, 2020, and 2021

	National	NSW	VIC	QLD	WA	SA	ACT	TAS	NT
2019									
Number of prisons	102	39	14	14	17	9	2 <sup>a</sup>	5	3 <sup>b</sup>
Number of individuals initiating DAA treatment in prisons*	3 360	1 281	569	1008	341	85	20	45	11
Total individuals treated (PBS database)	11 312	3 842	2 606	2 622	1 195	607	122	211	107
2020									
Number of prisons	96	32 <sup>c</sup>	15	14	18	9	1	5	2
Number of individuals initiating DAA treatment in prisons*	3 005	1048	472	1068	234	79	22	77	5
Total individuals treated (PBS database)	8 224	2 767	1 631	2 126	918	448	89	186	59
2021									
Number of prisons	97 <sup>d</sup>	35°	14	14	17	9	1	5	2
Number of individuals initiating DAA treatment in prisons*	2 639	676	308	1 252	270	77	9	41	6
Total individuals treated (PBS database)	6 474	2 001	1 262	1 719	814	363	94	172	49

Sources: State and Territory justice health authorities via the National Prisons Hepatitis Network.<sup>(3)</sup> Monitoring treatment uptake in Australia.<sup>(30)</sup>

**Notes:** <sup>•</sup>The proportion of all treatments that were initiated in prisons was estimated using the actual number of treatments reported by jurisdictional hepatitis services as a proportion of all treatments derived from the PBS database. PBS treatment numbers may vary from previous or future reports due to refinements made to PBS data between releases (2019 and 2020 data from 2021 release of data). <sup>a</sup>One prison and one mental health correctional facility; <sup>b</sup>Two prisons and one youth detention; <sup>c</sup>Between 2019 and 2020, five prisons closed. For 2020, data were collected from 31 public prisons (January–December) and one private prison (January–June only), data were not collected from two private prisons. <sup>a</sup>Data were collected from 95 prisons; <sup>e</sup>Data were collected from 32 public prisons; data were not collected from three private prisons.

#### **Monitoring retreatment**

**Figure 26.** Estimated number of individuals retreated for hepatitis C reinfection (A) or treatment failure (B), National Retreatment Project, 2016–2021



-- Total retreatment for reinfection — First retreatment for reinfection 🥒 95% CI Year-Quarter



#### Source: National Retreatment Project.<sup>(37)</sup>

**Notes:** Includes all individuals with hepatitis C who initiated DAA treatment through the PBS and were retreated, 2016–2021. As the PBS data does not capture reason for retreatment, retreatment data from the REACH-C cohort were used to train a Random Forest machine learning model to classify retreatment for reinfection or treatment failure. Of individuals initiating DAAs through the PBS between 2016 and 2021 (N=95 272), 7.3% received retreatment (n=6 980). The model classified 51.8% (95% CI: 46.7–53.6%; n=3 614) as reinfection and 48.2% (95% CI: 46.4–53.3%; n=3 366) as treatment failure.





Source: National Retreatment Project.(37)





Source: National Retreatment Project.(37)

#### **Cascades of care**

**Figure 29.** 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, 2016–2021



Source: ACCESS.<sup>(12)</sup> Updated from Traeger et al., *PLOS One*. 2020.<sup>(38)</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 31st December 2021 and is restricted to individuals who had a clinical consultation within the five years prior (2016–2021). 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 30.** Hepatitis C treatment cascade: number and proportion of individuals attending ACCHSs 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 2016–2021

Source: ATLAS sexual health surveillance network, 2016–2021.(18)

**Notes:** Individuals defined as people aged 15 years or older, who visited a doctor, nurse, or Aboriginal health practitioner ('medical consultations') 2016–2021. 'Undetectable viral load' defined as testing negative for HCV RNA or HCV viral load following DAA treatment. A total of 136 379 individuals aged 15 years or older attended medical appointments between 2016 and 2021. 'Of individuals who were ever HCV RNA tested, 18.9% (330/1750) were prescribed DAA treatment. <sup>†</sup>Of those prescribed DAAs, 37.3% (123/330) had an HCV RNA test following treatment, of whom <sup>†</sup>86.2% (106/123) had an undetectable viral load and 13.8% (17/123) were either positive or not tested (data unavailable to define these 13 further).



#### Figure 31. The hepatitis C diagnosis and care cascade, 2020

Source: Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2021.<sup>(2,3,4,9)</sup>

**Notes:** An estimated 117 810 people were living with hepatitis C at the end of 2020. Between 2016 and 2020, almost 90 000 people in Australia had been treated with DAAs, meaning that in this period, 43% of all people living with hepatitis C, including those who had been cured, had received treatment.<sup>(4)</sup>

# 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 (HCC) 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 liver cancer. Due to this, observed declines in cases of liver cancer are likely to be delayed. Further, for people with hepatitis C-related HCC who achieve cure, improved liver function post cure may allow curative treatments for HCC 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 (ANZLITR) collates data on the primary diagnosis of liver transplant recipients.

Further in-depth analysis of the ANZLITR data completed in 2021 has been able to provide additional insights into transplants by aetiology.<sup>(43)</sup> In the ANZLITR all liver transplants have up to four underlying liver disease aetiologies listed; all adult (16 years and older) liver transplants with hepatitis C recorded as a primary, secondary, tertiary, or quaternary indication for transplantation in the study by Howell et al. were included as hepatitis C cases. Further, the Howell et al. study estimated the trends in average number of annual transplants before and after unrestricted access to DAAs for the treatment of hepatitis C commenced in 2016.

Study-specific data provided insights into the reductions in end-stage complications of hepatitis C, including liver failure and cancer, following unrestricted access to DAAs.

# 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 32).

The number of adult liver transplants for hepatitis C steadily increased from 5 in 1990 to 97 in 2016, then fell to 73 in 2019 (Figure 33). Linear regression modelling showed that prior to unrestricted access to DAAs, across the 1990–2015 time-period there was a significant mean increase of 3.5 adult liver transplants performed for hepatitis C per year. However, between 2016 and 2019 there was a significant mean decrease of 7.9 adult liver transplants per year for hepatitis C (Figure 34).

There are scarce data on mortality, morbidity, and other outcomes related to hepatitis C, 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 32.** Number of Australian adult liver transplant recipients by primary diagnosis and year of first transplant, 2001–2021

Source: Australia and New Zealand Liver and Intestinal Transplant Registry.<sup>(44)</sup>

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





Source: Adapted from Howell et al., Liver Transplantation. 2021.<sup>(43)</sup>

**Notes:** N=5 460 for the whole registry cohort and n=5 254 for the diagnostic categories shown (other diagnostic categories not shown). HCV cases include HCV-related liver failure and HCV-related HCC. Diagnostic categories are non-exclusive. HBV: hepatitis B virus; ALD: alcoholic liver disease; NAFLD: non-alcoholic fatty liver disease.





Observed number — Average number - DAA introduction

Year

Source: Adapted from Howell et al., Liver Transplantation. 2021.<sup>(43)</sup>

Notes: N=1526. Includes both hepatitis C-related liver failure and hepatitis C-related HCC cases.

#### Monitoring hepatitis C-related liver cirrhosis and hepatocellular carcinoma

The PRECISE study, conducted at a major tertiary hospital in Melbourne, VIC, used prospectively collected transient elastography (Fibroscan) report data to determine trends in hepatitis C-related liver cirrhosis incidence from 9th April 2010 to 27th April 2021. A total of 10 622 Fibroscans were performed on 8 727 individuals during the study period. Among those individuals who underwent Fibroscan, 38.2% (3 358/8 798) had chronic hepatitis C. Among those diagnosed with cirrhosis, the proportion due to hepatitis C increased from 12.0% (66/549) in 2010 to a peak at 38.0% in 2016 (696/1 831), then declined to 2.0% (6/296) in 2021.<sup>(45)</sup>

The HOMER2 study,<sup>(46)</sup> conducted across eight major tertiary health networks in Greater Melbourne, VIC, prospectively collected data on all people with a new diagnosis of HCC (incident HCC cases) with HCC diagnosed between 18th October 2021 and 17th October 2022. In a six-month interim-analysis, a total of 125 incident HCC cases were included. The proportion of HCC attributable to hepatitis C was 24.0% (30/125). Of the people with hepatitis C-related HCC, 73.3% (22/30) had received a sustained virological response (SVR) result from DAA therapy prior to HCC diagnosis; median time to diagnosis of HCC from date of SVR was 46 months (interquartile range 27–72 months). Despite high rates of treatment uptake among those diagnosed with hepatitis C-related HCC, only 30.0% (9/30) were diagnosed through a HCC surveillance program with six-monthly ultrasound.<sup>(47)</sup>

# **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, to achieve progress in these areas. Understanding experiences of hepatitis C-related stigma can provide context to other indicators, such as any lack of progress in testing and treatment uptake overall, among specific groups, or within settings. Shame, fear, experiences of discrimination, and concerns about privacy can all contribute to individuals not disclosing their engagement in risk practices (e.g., IDU) 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 hepatitis C-related stigma has been undertaken in Australia since 2016, with tools developed as part of the Stigma Indicators Monitoring Project available to provide insights into experiences of stigma related to hepatitis C and IDU.<sup>(48)</sup> The Stigma Indicators Monitoring Project periodically includes indicators of the experience and expression of stigma in cross sectional surveys of priority population groups, health care workers, and the general public.

An indicator of stigma experienced by people living with hepatitis C and people who inject drugs was included in surveys of Australian people who inject drugs and people living with hepatitis C between 2016 and 2021. The indicator has also been included in cohort studies of people who inject drugs, namely Enhancing Treatment of Hepatitis C in Opioid Substitution Settings (ETHOS) Engage<sup>(24)</sup> and EC Experience.<sup>(49)</sup> ETHOS Engage is a national cohort study of people with a history of IDU; participants either reported recent IDU (in the past six months) or were receiving OAT. Participants were enrolled through drug and alcohol clinics, OAT clinics, and NSPs (25 sites in Wave 1 and 21 sites in Wave 2, across NSW, QLD, SA, and WA, May 2018 to June 2021). The EC Experience prospective cohort included 292 people who inject drugs recruited between 2018 and 2020 from selected public and private health services. Questions exploring stigma related to hepatitis C infection and IDU were asked at baseline and follow-up interviews.

## **PROGRESS ON REDUCING STIGMA**

Previously reported monitoring data have highlighted the continued prevalence of expressed stigma towards people living with hepatitis C and people who inject drugs within Australian health care settings. As was noted in the Australia's progress towards hepatitis C elimination: annual report 2021,<sup>(26)</sup> 36.3% of health care workers self-reported that they would behave negatively towards other people because of their hepatitis C, and 69.2% would behave negatively towards other people because of their IDU. This context of expressed stigma is important to consider when monitoring any progress towards reducing stigma experienced by people living with hepatitis C and people who inject drugs.

In 2021, the Stigma Indicators Monitoring Project surveyed a community-based sample of people who inject drugs. Over half of the participants who had been diagnosed with hepatitis C (54.1%) reported any past-year experience of stigma or discrimination in relation to their hepatitis C. This proportion has remained stable since 2016 (Figure 35). A significantly larger proportion of people who inject drugs (82.6%) reported any past-year experience of stigma or discrimination in relation to their IDU. This included more than one-quarter of the sample (26.9%) who indicated that they had 'often' or 'always' experienced IDU-related stigma or discrimination within the past year in any context (that is, not specific to a health care setting; Figure 36). No difference was evident between reported stigma or discrimination in 2018 and 2021.

Identifying factors that are associated with experiencing stigma or discrimination is an important step in developing strategies to reduce stigma. Within the 2021 community-based sample of people who inject drugs, experiences of stigma (in relation to either IDU or hepatitis C) were not associated with gender, identifying as Aboriginal or Torres Strait Islander, or being born overseas, suggesting that stigma was equally prevalent across each of the demographic characteristics. Age was correlated with experiences of both IDU- and hepatitis C-related stigma, with younger participants being more likely to report experiencing stigma or discrimination within the past year.

Anticipation of experiencing stigma or discrimination can have serious consequences on health care utilisation among affected groups. In 2021, the Stigma Indicators Monitoring Project found that 71.5% of the community-based sample of people who inject drugs (N=724) had delayed accessing health care within the past year to avoid negative treatment by health care workers. Similarly large proportions reported that they had not told health care workers about their drug use (76.9%), had downplayed their need for pain relief medication (72.9%), had not attended a follow-up appointment (72.6%), or had looked for alternative services (69.4%).<sup>(50)</sup> The high levels of stigma or discrimination experienced by participants within this community sample appear to have created significant barriers to their engagement with appropriate health care services and support.

## PROGRESS ON REDUCING STIGMA (CONTINUED)

The barriers that stigma and discrimination form to accessing health care are further explored by comparing results from the community-based sample of people who inject drugs with those recruited from services to participate in cohort studies (i.e., ETHOS Engage and EC Experience). Compared with the community-based sample of people who inject drugs, participants attending treatment services (in both cohort studies) reported less frequent experiences of stigma or discrimination. For example, 34.3% of ETHOS Engage participants who had been diagnosed with hepatitis C (Figure 37) and 43.6% of baseline EC Experience participants who were currently living with hepatitis C reported any experience of stigma or discrimination within the past year in relation to their hepatitis C (Figure 38). Within these studies, IDU-related stigma was more common than hepatitis C-related stigma (57.5% of ETHOS Engage participants and 68.6% of baseline EC Experience participants). Further analysis of EC Experience data has shown that a complex relationship exists between stigma and health service utilisation. Notably, accessing a larger number of different health services was found to be associated with increased odds of experiencing stigma related to IDU within the past year.<sup>(51)</sup> These findings suggest that people who experience stigma may be likely to seek alternative services or that accessing a larger number of services may increase the likelihood of people who inject drugs experiencing stigma through their increased contact with the health care system.

The lack of change over time in reported experiences of stigma by people living with hepatitis C and people who inject drugs should be considered within the context of minimal focussed intervention efforts. Despite evidence from small scale interventions that have demonstrated reduced stigma as an outcome, including sharing of lived experience<sup>(52)</sup> and involvement of peer workers in health care delivery,<sup>(53,54)</sup> the lack of action does reflect the limited funding to date for large-scale interventions aimed at addressing stigma within the broader community and in health care settings. For stigma towards people living with hepatitis C and people who inject drugs to be meaningfully addressed, a system-wide perspective must be taken to address systemic and structural factors that contribute to stigma and discrimination, as well as considering any other behaviours, identities, conditions, or characteristics that might be the target of stigma.<sup>(55)</sup>

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 health care settings and more widely, as is continued monitoring of expressed stigma towards these groups by the general public and health care 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.



# **Figure 35.** Reports of hepatitis C-related stigma or discrimination in the past 12 months by people living with hepatitis C, 2016–2021

Source: Stigma Indicators Monitoring Project.<sup>(48)</sup> 2021 data Stigma Indicators Monitoring Project, unpublished data.
Notes: "N/A" was not provided as a response option after 2016. Details of sample sizes available in the Methods section.





Source: Stigma Indicators Monitoring Project.<sup>(48)</sup> 2021 data Stigma Indicators Monitoring Project, unpublished data.
Notes: "N/A" was not provided as a response option after 2016. Details of sample sizes available in the Methods section.

# **Figure 37.** Reports of hepatitis C- and IDU-related stigma or discrimination in the past 12 months by people who inject drugs, ETHOS Engage, Wave 2 (November 2019–June 2021)



Source: ETHOS Engage study.<sup>(24)</sup> Wave 2 data, ETHOS Engage study, unpublished data.
Notes: N=791 respondents for hepatitis C-related stigma experiences, and N=1 211 respondents for IDU-related stigma experiences.





Source: EC Experience.<sup>(49)</sup> Baseline data from EC Experience cohort (2018–2022), unpublished data.

**Notes:** Participants were only asked the question about hepatitis C-related stigma if they were living with hepatitis C at the time of the interview. Baseline data only. N=124 respondents for hepatitis C-related stigma experiences and N=300 respondents for IDU-related stigma experiences.

# Six

## **Prevention of hepatitis C acquisition**

Key actions for preventing the primary transmission of hepatitis C 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 provide important indicators for assessment of hepatitis C prevention efforts.

The Needle Syringe Program Minimum Data Collection (NSP MDC) reports annually on needles and syringes distributed in community settings nationally, providing an overview of activity to prevent re-use of needles and syringes.<sup>(56)</sup> Despite new hepatitis C infections occurring in Australia's prisons,<sup>(39,40,41)</sup> no regulated needle and syringe distribution programs currently operate in Australian custodial settings.

The annual ANSPS<sup>(19)</sup> and the Illicit Drug Reporting System (IDRS)<sup>(57)</sup> questionnaires ask participants about episodes of receptive sharing to identify trends in injecting practices.

ETHOS Engage is a national cohort study of people with a history of IDU. ETHOS Engage collects self-reported data on injecting behaviour. This study can provide estimates of injecting behaviour including among participants previously treated for hepatitis C, enabling the monitoring of trends in behaviour that can be a risk for reinfection.<sup>(24)</sup>

The Gay Community Periodic Survey provides national estimates on IDU among GBM and gives specific insights into IDU among GBM by HIV status.<sup>(58,59)</sup>

## **PROGRESS ON PREVENTION OF HEPATITIS C ACQUISITION**

The number of needles and syringes distributed in Australia has increased steadily over the past decade and in 2019 the highest number of needles and syringes distributed since 2007 was recorded (Figure 39).

Approximately one in five respondents in the ANSPS reported receptive sharing of needles and syringes in the past month and this proportion has remained relatively stable over the past nine years (Figure 40).

Among participants in the ETHOS Engage cohort study most participants in Wave 1 (84.0%) and Wave 2 (79.3%) reported no receptive sharing in the past month (Figure 41). Among participants that reported being previously treated for hepatitis C, again most participants reported no receptive sharing in the past month in Wave 1 (85.2%) and Wave 2 (83.3%; Figure 42).

The IDRS has shown declines over time in the receptive and distributive sharing of needles and syringes with borrowing of needles reported by <10% of respondents since 2012 and lending needles reported by 10% of participants in 2021 (Figure 43).

Data from the Gay Community Periodic Survey shows that IDU is more prevalent among HIV-positive than HIV-negative GBM, with little change in the prevalence of self-reported injecting over the past 10 years (Figure 44).



**Figure 39.** Number of needle and syringe units distributed by public and pharmacy sector, NSP NMDC, 2007–June 2021

Source: Needle Syringe Program National Minimum Data Collection: National Data Report 2021.<sup>(56)</sup>Notes: July–December 2021 data not available at the time of reporting.

**Figure 40.** Proportion of ANSPS respondents reporting re-use of someone else's needles and syringes in the past month, 2012–2021



Source: Australian Needle Syringe Program Survey. National Data Report 2017–2021.<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 2012 to 2021, sample size was (in order): 2 127, 2 111, 2 141, 2 071,1 993, 2 314, 2 452, 2 333, 1 173, and 1 259.

**Figure 41.** Proportion of respondents reporting re-use of someone else's needles and syringes in the past month, ETHOS Engage, A: Wave 1 (May 2018–September 2019) and B: Wave 2 (November 2019–June 2021)



Source: ETHOS Engage study.<sup>(24)</sup> Wave 1 and Wave 2 data, ETHOS Engage study, unpublished data.

**Notes:** Participants were asked "How many times in the last month have you used a needle and/or syringe after someone else had already used it?". Wave 1 N=921 respondents and Wave 2 N=777.

**Figure 42.** Proportion of respondents previously treated for hepatitis C reporting re-use of someone else's needles and syringes in the past month, ETHOS Engage, A: Wave 1 (May 2018–September 2019) and B: Wave 2 (November 2019–June 2021)



Source: ETHOS Engage study.<sup>(24)</sup> Wave 1 and Wave 2 data, ETHOS Engage study, unpublished data.

**Notes:** Participants were asked "How many times in the last month have you used a needle and/or syringe after someone else had already used it?". Wave 1 N=324 respondents and Wave 2 N=312.



**Figure 43.** Proportion of respondents reporting borrowing and lending of needles, sharing of injecting equipment, and re-use of needles in the past month, national, IDRS, 2000–2021

- Borrowed needles - Lent needles - Shared other equipment\* - Re-used needle

Year

Source: Australian Drug Trends 2021. Key findings from the National Illicit Drug Reporting System (IDRS) Interviews.<sup>(56)</sup>Notes: Collection of data about re-use of needles began in 2008. \*Includes spoons, water, tourniquets, and filters.





Source: Annual Report of Trends in Behaviour 2021: HIV and STIs in Australia.<sup>(58,59)</sup> Notes: Unadjusted data.

# Seven

## Health equity mapping

To 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>(60)</sup>

The Viral Hepatitis Mapping Project experienced unavoidable delays in accessing up-to-date data for this year's report. However, given the importance of highlighting geographical differences in access to treatment, and that there are unlikely to be substantial changes in the trends, the data as of end of 2020 (based on the 2020 diagnosis and care cascade and estimate of people living with hepatitis C at the end of 2015) has been included.

## **PROGRESS TOWARDS EQUITY**

#### Treatment uptake

Treatment uptake at the end of 2020 was highest in Western VIC PHN, the only PHN in Australia to have already reached the 2022 National Strategy target of 65% uptake. Other PHNs with higher treatment uptake included Gippsland, Adelaide, North Coast, and South Eastern Melbourne. The lowest treatment uptake was seen in Western QLD, NT, Country WA, Northern QLD, and Central and Eastern Sydney (Figures 45 and 46).

# Hepatitis C treatment uptake compared to the national average level: 50% higher 50% lower

Figure 45. Geographic variation in hepatitis C treatment uptake, March 2016–December 2020

Source: The National Viral Hepatitis Mapping Project (WHO Collaborating Centre for Viral Hepatitis, The Doherty Institute).<sup>(60)</sup>

**Notes:** Hepatitis C prevalence estimates based on mathematical modelling incorporating population-specific prevalence and Australian Bureau of Statistics population data. Note that the prevalence estimates are based on the 2020 diagnosis and care cascade. Treatment data sourced from Department of Human Services Medicare statistics.

#### Figure 46. Hepatitis C treatment uptake variation in Australia by PHN, March 2016–December 2020

Equity



Source: The National Viral Hepatitis Mapping Project (WHO Collaborating Centre for Viral Hepatitis, The Doherty Institute).<sup>(60)</sup>

**Notes:** Hepatitis C prevalence estimates based on mathematical modelling incorporating population-specific prevalence and Australian Bureau of Statistics population data. Note that the prevalence estimates are based on the 2020 diagnosis and care cascade. Treatment data sourced from Department of Human Services Medicare statistics.

# **Eight** Modelling

Mathematical models are useful tools for identifying key issues affecting 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 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 if key regions or sub-populations are being left behind in the elimination response.

### **PROGRESS TOWARDS ELIMINATION**

Burnet Institute modelling was used to estimate the economical benefit of providing patients with incentives to complete hepatitis C testing and/or treatment (Figure 47). An increasing number of people who inject drugs have been treated for hepatitis C since 2016 therefore the number of people living with hepatitis C has declined. Fewer people with current infection means that the cost of finding someone with hepatitis C increases, and it becomes more important that people are retained in care once diagnosed. Theoretically, there is a point at which it is more cost-efficient to provide financial incentives to retain someone in care, versus having them become lost to follow-up and having to start again and find someone else with hepatitis C.

Modelling was undertaken to assess what incentive values would be reasonable from an economic perspective, for different incentive amounts to achieve the improvements in retention in care needed to maintain the same overall (1) average cost per testing completion and (2) average cost per treatment initiation.<sup>(61)</sup> Estimates of average cost per person tested/treated were taken from Eliminate Hepatitis C (EC) Testing Campaign held during July and August 2019.<sup>(62)</sup> All costs paid by the government health care system and partner institutions for the campaign event, pathology, staff time and equipment use were included.

## **PROGRESS TOWARDS ELIMINATION (CONTINUED)**

- During the testing campaign the average cost per person with hepatitis C who completed testing (received their HCV RNA-positive result) was AUD\$3 215, and the average cost per diagnosed person (HCV RNA positive) initiating treatment was AUD\$1 055.
- The overall average cost per person initiating treatment was AUD\$5 878\*.
- As an example of the modelling results for testing, in the EC Testing Campaign study, at baseline 62.5% (15/124) of people completed testing. If an AUD\$500 incentive was given, and incentives improved the proportion retained to 74.0%, using incentives would be "break-even" (it would be the same average cost per person completing testing even with the cost of the incentive added).
- As an example of the modelling results for treatment, in the EC Testing Campaign study, at baseline 66.6% (10/15) of diagnosed people, initiated treatment. If an AUD\$200 incentive was given, and incentives improved the proportion retained to 83.0%, using incentives would be "break-even" (it would be the same average cost per diagnosed person initiating treatment even with the cost of the incentive added).
- These results suggest that relatively large incentives can be economically beneficial because they retain people in care thus reducing the costs of having to find new people.
- If baseline retention in care or HCV RNA positivity was lower than the 62.5% the model used, incentives only needed to deliver smaller improvements in retention to break even (see further results in Palmer et al., sensitivity analysis).<sup>(61)</sup>
- In settings with high rates of loss to follow-up after testing or diagnosis, or in settings with low HCV RNA positivity, financial incentives to improve retention in care are likely to be more beneficial.

The costs associated with finding and diagnosing people with hepatitis C infection represent a substantial proportion of the overall hepatitis C care cascade costs. If financial incentives can improve retention in care, even modestly, particularly in settings or population groups with high rates of loss to follow-up, they are likely to deliver better testing and treatment outcomes for the same unit costs.

Average cost per person completing testing = total testing costs/number completing testing. Average cost per diagnosed person commencing treatment = total treatment costs/number commencing treatment.

<sup>\*</sup> This does not add to the average cost per person completing testing plus the average cost per diagnosed person initiating treatment due to loss to follow-up:

**Figure 47.** For different incentive values (a) the percentage of HCV RNA-positive people that need to complete testing (receive their HCV RNA-positive result) and (b) the percentage of HCV RNA diagnosed people that need to initiate treatment to maintain the same unit cost



Source: Adapted from Palmer et al. J Viral Hepatitis. 2021.<sup>(61,62)</sup>

# 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.

#### 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>(12,13,14)</sup> ACCESS focusses on recruiting sites that serve priority populations, including people who inject drugs and HIV-positive GBM. 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

Data from 27 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 (nine sites (one site has three health services counted as one site and one site has eight health services counted as one site)), and sexual health clinics (seven sites) and primary care clinics specialising in the health of GBM (nine sites). Seven sexual health clinics were used for analysis of hepatitis C testing among Aboriginal and Torres Strait islander peoples; two clinics were not the same as those included in the analysis of hepatitis C testing among HIV-positive GBM. Primary care clinics included seven in VIC, one in WA, and one in QLD; of these clinics six had onsite NSPs and all nine clinics had OAT providers at the time of reporting. GBM clinics included three in VIC, three in NSW, one in ACT, and one in TAS. Sexual health clinics included for analysis of Aboriginal and Torres Strait Islander peoples were one in VIC, four in NSW, one in ACT. 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 GBM

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.

#### 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.

#### 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.

#### **ATLAS network**

The ATLAS network is a STI and BBV sentinel surveillance network representative of ACCHSs led by Professor James Ward and Dr Clare Bradley 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>(10)</sup> and helps us understand the burden of disease due to STIs and BBVs among Aboriginal and Torres Strait Islander peoples.

The ATLAS network currently includes 34 ACCHSs largely associated with five 'clinical hubs' across QLD (two hubs), NSW, SA, and the Kimberley, WA. Regular reports addressing 12 performance measures are provided to ACCHSs 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.

#### Monitoring hepatitis C treatment uptake in Australia

The methods for the estimations have been described in detail elsewhere.<sup>(30)</sup> In brief, the total PBS data of DAA dispensation for all individuals who initiated treatment between March 2016 and December 2021 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 however have been previously reported by the project. Prescriber speciality was based on the prescriber derived major speciality codes recorded by 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.

Estimates of people living with hepatitis C were derived from the National hepatitis C diagnosis and care cascade 2020.<sup>(2,3,4,9)</sup>

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

Data on new treatment initiations in Australia's prisons were collated by the National Prisons Hepatitis Network. For some jurisdictions, there were some annual differences in the number and type of prisons included in data collection. Data from both public and private prisons were included for all jurisdictions except NSW. For NSW in 2020, data were included from 31 public prisons (January–December) and one private prison (January–June only); data from two private prisons were not included. For NSW in 2021, data were included from 32 public prisons; data from three private prisons were not included. For the ACT in 2019, treatment initiations were included for one mental health correctional facility which was excluded in 2020. For the NT in 2019, treatment initiations were included for one juvenile justice facility which was not included in 2020 and 2021.

#### Australian Capital Territory

Data on newly initiated hepatitis C therapies were entered by clinical staff, reviewable from electronic medical records and auditable from pharmacy and MedChart Electronic Medication Management.

#### New South Wales

Data were collected via the Pharmacy dispatch report when medications were dispensed to centres.

#### Northern Territory

Data 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, data were confirmed by pharmacy records.

#### Queensland

Data were obtained directly from Prisoner Health Services in each facility as part of the annual Hepatitis C Treatment Uptake Progress Report.

#### South Australia

Paper-based health records were used in prisons. The number of treatment initiations was based on pharmacy prescriptions filled.

#### Tasmania

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

#### Victoria

Data were sourced from the Department of Justice and Community Safety (Victorian Government), based on the monthly State-wide Hepatitis Program worksheet reported by St Vincent's Hospital Melbourne.

#### Western Australia

The number of treatment initiations is based on pharmacy prescriptions filled, cross checked against data recorded on the WA Department of Justice electronic patient health record (EcHO).

#### 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.

Methods associated with additional analysis of ANZLITR data are published elsewhere.<sup>(43)</sup>

#### Viral Hepatitis Mapping Project

Full details of the methods used by the Viral Hepatitis Mapping Project and additional data and results can be accessed through the project website.<sup>(60)</sup>

In brief, hepatitis C prevalence is derived by applying published national prevalence estimates to each geographic area proportionally according to the distribution of diagnosed cases reported in national notifications. All positive diagnoses of HCV antibody or HCV RNA are legally required to be reported to jurisdictional departments of health by the diagnosing laboratory.

Estimates were based on diagnosed cases which occurred during the period 2007–2016, selected as the most representative of current residents of a geographic area. Prevalence data are adjusted to account for residents of correctional facilities and correct the resulting skewed rates according to area. However higher hepatitis C screening rates in a particular area could inflate the estimated prevalence and therefore reduce estimated treatment uptake.

Treatment uptake is derived by dividing the number of people receiving treatment by the total estimated population living with hepatitis C in each geographic area. Treatment data are sourced from Australian Government Department of Human Services Medicare data and include all individuals who received DAA treatment through the PBS between March 2016 and June 2020. Each person living with chronic hepatitis C was counted only once. Treatment data are derived using postcode of residence and may be affected by prison geography if Medicare records are updated to reflect a prison as an incarcerated individual's area of residence. Further exploration of the impact of treatment in prisons on geographic measures will be provided in future reports. Treatment uptake variation is generated by comparing the uptake in a given PHN to the national average, and calculating percentage difference.

All data are geographically mapped to regions using postcode of residence as recorded in administrative data.

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

For more information about the development of the stigma indicator, see Broady et al.<sup>(48)</sup>

#### Survey of people who inject drugs and people living 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.

In 2018, the Stigma Indicator was included in a paper survey of people who inject drugs (n=592), including a sub-sample who had lived experience of hepatitis C (n=274). Participants were recruited via Australian Injecting and Illicit Drug Users League state-based member organisations.
In 2021, the Stigma Indicator was included in a survey of people who inject drugs (n=724), including a sub-sample who had lived experience of hepatitis C (n=292). Participants were recruited via Australian Injecting and Illicit Drug Users League state-based member organisations and were given the option of completing a paper survey or an online version.

#### Enhancing Treatment of Hepatitis C in Opioid Substitution Settings (ETHOS) Engage study

ETHOS Engage is an observational cohort study that recruited participants from OAT sites, drug and alcohol treatment sites, and NSPs. ETHOS Engage participants had either recent IDU (past six months) or were currently receiving OAT. The study collected baseline data using a questionnaire and conducted point-of-care tests for hepatitis C.<sup>(24)</sup>

#### EC Experience cohort 2018–2022

The EC Experience prospective cohort included 292 people who inject drugs recruited between 2018 and 2020 from selected public and private health services. Questions exploring stigma related to hepatitis C infection and IDU were asked at baseline and follow-up interviews.<sup>(49)</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 (UNSW) 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>(58,59)</sup>

#### Modelling the Australian response to hepatitis C

Methods associated with the Burnet Institute's modelling of the use of financial incentives have been published in detail.<sup>(61,62)</sup>

#### Publicly available data

#### Notifications of hepatitis C

Notifications of newly acquired hepatitis C were acquired from the National Notifiable Diseases Surveillance System<sup>(10)</sup> with details and notifications requirements, procedures, and case definitions available from the Australian Government Department of Health.<sup>(64)</sup> Notifications are also reported annually in the HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report.<sup>(4,9)</sup>

#### Medicare claims for HCV RNA testing

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

#### The Australian Needle Syringe Program Survey

The ANSPS is published annually, with full details of methods included.<sup>(19)</sup>

#### 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>(4,9)</sup> with methods associated with the cascade described in detail.

#### Needle Syringe Program National Minimum Data Collection

The Needle Syringe Program National Minimum Data Collection is published annually, with full details of methods included.<sup>(56)</sup>

#### The Illicit Drug Reporting System

The Illicit Drug Reporting System publishes an annual report, with full details of methods included.<sup>(57)</sup>

# Acknowledgements

This report was funded by the EC Australia Partnership with support from the Paul Ramsay Foundation.

#### **Consultation with community**

The following organisations are thanked for their generous contributions during consultation processes:

Australian Federation of AIDS Organisations (AFAO) Australian Injecting and Illicit Drug Users League (AIVL) Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) Hepatitis Australia National Aboriginal Community Controlled Health Organisation (NACCHO) National Association of People with HIV Australia (NAPWHA) NSW Community Restorative Centre (CRC)

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

As a national surveillance system, ACCESS receives core funding from the Australian Government Department of Health. The Burnet Institute gratefully acknowledges the contribution to this work of the Victorian Operational Infrastructure Support Program.

ACCESS is a collaboration between the Burnet Institute, Kirby Institute, and NRL Quality, and we gratefully acknowledge the role of all collaborating institutions and individuals.

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

Members of the Burnet Institute surveillance group who contributed to the data collection, processing, analysis, and reporting in preparation of this report were (in alphabetical order): Jason Asselin, Nyssa Watson, Carol El-Hayek, Long Nguyen, Thi Nguyen, Victoria Polkinghorne, and Michael Traeger. Margaret Hellard and Mark Stoové made additional contributions to interpretation and reporting of the results.

We gratefully acknowledge the contribution of the members of the ACCESS Executive Committee (in alphabetical order): Jason Asselin, Burnet Institute; Allison Carter and Htein Linn Aung, Kirby Institute; Wayne Dimech, NRL Quality; Basil Donovan, Kirby Institute; Rebecca Guy, Kirby Institute; Margaret Hellard, Burnet Institute and Mark Stoové, Burnet Institute.

We gratefully acknowledge the contribution of the ACCESS Advisory Committee members and the contribution of clinicians and practitioners at participating clinics. The sites that contributed data to this report were (in alphabetical order):

Adelaide Sexual Health, Bendigo Community Health, Canberra Sexual Health, Centre Clinic, cohealth (eight sites), Dandenong SuperClinic, Deen Street Clinic, Docker Street and South Wangaratta Medical Centres, East Sydney Doctors, Hobart Place General Practice, Holdsworth House, Hunter New England Sexual Health, Far Western Sexual Health, Frankston Healthcare Medical Centre, GP on Beaufort, Medeco Medical Centre Inala, MediClinic Clayton, Melbourne Sexual Health Centre, North Richmond Community Health, North Sydney Sexual Health, Northside Clinic, Prahran Market Clinic, Royal Prince Alfred Sexual Health, Stonewall Medical Centre, Tasmanian Sexual Health, Taylor Square Private Clinic, and Western Sydney Sexual Health Centre.

#### ATLAS network

The ATLAS project was established by National Health and Medical Research Council CRE Grant 1100302: The Australian Centre of Research Excellence in Aboriginal Sexual Health and Blood-Borne Viruses (CRE-ASH). ATLAS is now based at the University of Queensland's Poche Centre for Indigenous Health and is funded by National Health and Medical Research Council Partnerships Grant GNT2006987 and Medical Research Future Fund Primary Healthcare Research Data Infrastructure Grant PHRDI000054.The ATLAS investigator group gratefully acknowledge the contribution and support of our five clinical hubs (Apunipima Cape York Health Council, Institute of Urban Indigenous Health, Aboriginal Health and Medical Research Council of NSW, Aboriginal Health Council of SA, and Kimberley Aboriginal Medical Services), as well as the individual ACCHSs participating in the ATLAS network.

#### Australian Needle Syringe Program Survey

We would like to acknowledge the many people who assist each year in the development and conduct of the ANSPS, particularly the clients, staff, and managers at participating NSP services. We also appreciate the dedication and vision of the founding members of the project and the late Dr Margaret MacDonald who was responsible for the development and conduct of the ANSPS from 1995 until 2003. Special thanks go to Mr Philip Cunningham, Senior Scientist and Operations Manager, Ms Beth Catlett, Dried Blood Spot Coordinator, Mr Mitchell Starr, Senior Hospital Scientist, Ms Thidarat Danwilai, Technical Officer, Mr Michael Palmer, Technical Officer, and Mr Andrew Kelly, Technical Officer at the NSW State Reference Laboratory for HIV at St Vincent's Hospital and St Vincent's Centre for Applied Medical Research. We also appreciate the assistance provided by Ms Louise Geddes and Ms Rachel McCleave from the Kirby Institute. In 2021, the project received support and input from the following members of the ANSPS National Advisory Group: Ms Jennifer Taleski (ACT); Ms Kate Patten (NSW); Mr David Decolongon (NT); Mr Bruce Surman, Mr Rob Gerrie, and Ms Michelle Spudic (SA); Ms Myf Briggs (TAS); Mr Gary Morris and Ms Terrie Spall (VIC); Ms Jude Bevan (WA); Ms Melanie Walker, Ms Lauren Bradley, Mr Sav Gollapally, and Mr Adrian Gorringe (Australian Injecting and Illicit Drug Users League); and Ms Sue Heard, Dr Jenny Iversen, and Professor Lisa Maher (Kirby Institute). We would particularly like to thank Mr Robert Kemp (QLD) for chairing the ANSPS National Advisory Group. The ANSPS is funded by the Australian Government Department of Health.

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

#### Australian Capital Territory

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

Dr Katerina Lagios (Clinical Director, to 2021) Dr Cameron Edgell (Acting Clinical Director, from 2021) Ruth Evans (Clinical Lead Chronic and Complex Care Justice Health) Melanie Gordon (Population Health Nurse Justice Health) Dannielle Nagle (Operational Director Justice Health)

#### New South Wales

Greg Chequelman, 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 (Clinical Nurse Consultant, Viral hepatitis Service, Royal Darwin Hospital, NT Health) Dy Kelaart (District Manager, Prison Health Services, Central Australia Region, NT Health)

#### Queensland

Robert Kemp (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 Daniel Pronk (Medical Director, SA Prison Health Services, to March 2021) 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)

#### Tasmania

Deborah Siddall (Forensic Health Services) Dr Chris Wake (Forensic Health Services, Clinical Director to 2021) Dr David Onu (Forensic Health Services, Clinical Director from 2021)

#### Victoria

State-wide Hepatitis Program, St Vincent's Hospital Melbourne, Justice 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) 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

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

Michael Fink (Director) and Mandy Byrne (Manager), Victorian Liver Transplant Unit, Austin Health

Australian Liver Transplant Units:

Geoff McCaughan, Australian National Liver Transplant Unit, Royal Prince Alfred Hospital Peter Hodgkinson, QLD Liver Transplant Service, Princess Alexandra Hospital John Chen, SA Liver Transplant Unit, Flinders Medical Centre Robert Jones, VIC Liver Transplant Unit, Austin Health Bryon Jaques, WA Liver Transplantation Service, Sir Charles Gairdner Hospital

#### **Viral Hepatitis Mapping Project**

These data are 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 and conducted in partnership with the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine.

The authors acknowledge the following organisations for provision of data used in the Project:

Australian Bureau of Statistics Australian Government Department of Health Australian Government Department of Human Services Kirby Institute, UNSW Queensland Health Victorian Government Department of Health and Human Services

We would also like to acknowledge the oversight and guidance of the Epidemiology and Public Health Research Advisory Group, WHO Collaborating Centre for Viral Hepatitis.

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

The Stigma Indicators Monitoring Project is funded by the Australian Government Department of Health. The project team would like to thank study participants for their valuable contribution to the research and each of the organisations who assisted with participant recruitment.

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

The Needle Syringe Program National Minimum Data Collection (NSP NMDC) project is grateful for support and input from the following members of the NSP NMDC Reference Group in 2021: Ms Jenny Taleski (ACT); Ms Kate Patten (NSW); Mr David Decolongon (NT); Mr Robert Kemp (QLD); Mr Stephen Lymb and Mr Bruce Surman (SA); Ms Myf Briggs (TAS); Mr Gary Morris and Ms Terrie Spall (VIC); Ms Jude Bevan (WA); Ms Melanie Walker and Ms Lauren Bradley (Australian Injecting and Illicit Drug Users League); Mr Sione Crawford (Harm Reduction Victoria); and Mr Charles Henderson and Dr Mary Ellen Harrod (NSW Users and AIDS Association). We also appreciate the valuable assistance provided by Ms Stephanie Stephens (ACT), Mr Benet Brogan (QLD), Ms Kendall Robertson (SA), Mr Rob Knight (VIC), Ms Teneille Wisby and Mr David Worthington (WA), and NSP attendees and staff and managers at NSP services. The NSP NMDC is funded by the Australian Government Department of Health.

#### Enhancing Treatment of Hepatitis C in Opioid Substitution Settings (ETHOS) Engage study

ETHOS Engage is funded by a National Health and Medical Research Council Partnership Project grant, including funding from NSW Health and Merck/MSD.

The ETHOS Engage study thanks all participants who took part. We first give special acknowledgement to the following peer workers and organisations who helped invaluably with participant recruitment in ETHOS Engage Wave 1 and Wave 2:

The NSW Users and AIDS Association (NUAA): Sara Adey, Rodd Hinton, Melanie Joyce, Cheryl Woods, Alain Jenart, Hope Everingham, Louisa Jansen, and Lucy Pepolim Youth Link Needle and Syringe Program, Cairns: Kathy Clark Hepatitis South Australia: Lisa Carter and Carol Holly Harm Reduction Western Australia: Lyn Murphy and Joel Iliffe

We would also like to thank the contributions of members of the ETHOS Engage Study Group:

#### Protocol Steering Committee

Jason Grebely (Kirby Institute, UNSW Sydney), Gregory Dore (Kirby Institute, UNSW Sydney), David Silk (Kirby Institute, UNSW Sydney), Nicky Bath (LGBTI Health Programming and Development), Carla Treloar (Centre for Social Research in Health, UNSW Sydney), Andrew Milat (Centre for Epidemiology and Evidence, NSW Health), Adrian Dunlop (Hunter New England Local Health District), Janaki Amin (Macquarie University, Kirby Institute, UNSW Sydney), Jo Holden (Population Health Strategy & Performance, NSW Health), Carolyn Murray (Population Health Strategy & Performance, NSW Health), Charles Henderson (NUAA), Kyle Leadbeatter (Hepatitis NSW), Emma Day (ASHM), Nikitah Habraken (ASHM), Olivia Dawson (ASHM), Louisa Degenhardt (National Drug and Alcohol Research Centre, UNSW Sydney), Clarke Scott (Centre for Addiction Medicine, Nepean Blue Mountains Local Health District), and Phillip Read (Kirketon Road Centre)

#### Coordinating Centre (The Kirby Institute, UNSW Sydney)

Jason Grebely (Co-Principal Investigator), Gregory Dore (Co-Principal Investigator), Maryam Alavi (Supervisor), David Silk (Clinical Project Coordinator), Heather Valerio (PhD candidate), Shane Tillakeratne (Data Manager), Philippa Marks (Clinical Trials Manager), Indika Jayasinghe (Laboratory Coordinator), Maria Martinez (Laboratory Coordinator), Hannah Reid, Valerie Gleeson, Jodi Van Dyk, Gerard Estivill Mercade, Alison D. Marshall, Stephanie Obeid, Samira Hosseini Hooshyar, Beth Catlett, Andrey Verich, Anna Conway, Amanda Erratt, and Alice Wheeler (campaign day implementation)

#### Site Principle Investigators

Nadine Ezard (Rankin Court), David Reid (Illawarra Shoalhaven Local Health District), Carla Gorton (Cairns Sexual Health Service), Jeremy Hayllar (Metro North Hospital and Health Service, Brisbane), Thao Lam (Western Sydney Local Health District), Adrian Dunlop (Hunter New England Local Health District), Prasun Datta (Nepean Blue Mountains Local Health District), Alex Wade (Mid North Coast Local Health District), Sally Spruce (Mid North Coast Local Health District), Vicky Cock (Drug and Alcohol Services, South Australia), Mark Cornwell (Northern NSW Local Health District), Krista Zohrab (Northern NSW Local Health District), Michael Christmass (Next Step, Perth), Craig Connelly (Next Step, Perth), Angela Cooper (Townsville Hospital and Health Services), and Mark Montebello (Northern Sydney Local Health District)

#### Site Coordinators

Robert Cherry (Rankin Court), Julie Dyer (Rankin Court), Shikha Arawal (Rankin Court), Elke Press (Rankin Court), Nadine Horasak (Youth Link Needle and Syringe Program, Cairns), Rhondda Lewis (Cairns Sexual Health Service), Astrid Carthew (Youth Link Needle and Syringe Program, Cairns), Daniel Morris (Youth Link Needle and Syringe Program, Cairns), Kathy Donohue (Youth Link Needle and Syringe Program, Cairns), Kathy Griffiths (Biala), Jason Dalla Lana (Biala), Sue Shin (Biala), Connie Graf (Illawarra Shoalhaven Local Health District), Adele Hampson (Illawarra Shoalhaven Local Health District), Siyu Qian (Illawarra Shoalhaven Local Health District), Danielle Brown (Illawarra Shoalhaven Local Health District), Amber Lautier (Illawarra Shoalhaven Local Health District), Cate Curran (Illawarra Shoalhaven Local Health District), Carina Burns (Southwest Sydney Local Health District), Ravina Raidu (Southwest Sydney Local Health District), Kylie Stolzenhein (Southwest Sydney Local Health District), Wanda Brabender (Southwest Sydney Local Health District), Kelly Somes (Southwest Sydney Local Health District), Nargis Abram (Nepean Blue Mountains Local Health District), Rick Turner (Nepean Blue Mountains Local Health District), Stuart Larter (Nepean Blue Mountains Local Health District), Fiona Goodberg (Nepean Blue Mountains Local Health District), Jennifer Luksza (Western Sydney Local Health District), Michelle Hall (Hunter New England Local Health District), Susan Hazelwood (Hunter New England Local Health District), Charlotte Ismay (Hunter New England Local Health District), Krista Zohrab (Mid North Coast Local Health District), Belinda McClurg (Mid North Coast Local Health District), Cherie Mincham (Mid North Coast Local Health District), Kali Barlow (Mid North Coast Local Health District), Anita Hoskins (Mid North Coast Local Health District), Kate Salisbury (Northern NSW Local Health District), Julie Markham (Queensland Injectors Health Network, Townsville), Jacky Talmet (Drug and Alcohol Services, South Australia), Sandy Dunn (Drug and Alcohol Services, South Australia), Amanda Mitchell (Drug and Alcohol Services, South Australia), Andrew McKinnon (Drug and Alcohol Services, South Australia), Fionnualh Smyth (Western Sydney Local Health District), Lisa Snell (Western Sydney Local Health District), Elizabeth Laing (Next Step, Perth) Martin Clark (Next Step, Perth), Justin Dorigo (Next Step, Perth), Louise Carman (Next Step Perth), Brent Fergusson (Townsville Hospital and Health Service), Bonny Puszka (Northern Sydney Local Health District), Gai Duncan (Northern Sydney Local Health District), Fiona Baker (Northern Sydney Local Health District), Jayde Walsh (Northern Sydney Local Health District), and Leeann Walsh (Northern Sydney Local Health District)

#### Gay community Periodic Survey

The Gay Community Periodic Surveys are funded by state and territory health departments and the Australian Government Department of Health.

#### Project team

Martin Holt, Benjamin Bavinton, Timothy Broady, Curtis Chan, Limin Mao, and Garrett Prestage.

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## **Data contributors**











**Canberra Health** Services



Health Justice Health and Forensic Mental Health Network











Government of Western Australia Department of Justice



Australia & New Zealand Liver and Intestinal Transplant Registry













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### Eliminating hepatitis C in Australia

# Where are we now **2022**



#### **KEY FINDINGS**

The rate of **new infections** has declined since 2016. This positive trend demonstrates Australia's progress towards reducing transmission.

#### **95,395 people** received direct-acting antiviral (DAA) treatment between March 2016 and the end of 2021.



#### Between the start of 2016 and the end of 2020,

#### 43%

of people living with hepatitis C had been **treated**.

Medicare data shows **declines in testing** since **2016**.

At the end of 2020, an estimated **117,800** 

people were still living with hepatitis C, highlighting the challenge remaining to eliminate hepatitis C in Australia. Challenges remain in ensuring equitable access to treatment across metropolitan, rural, and remote locations.

The **number treated** each year continues to **decline.** 

#### . . .

More investment is needed to tackle experiences of **stigma**, which have not improved between 2018 and 2021.



The COVID-19 pandemic increased challenges to accessing health care for people affected by hepatitis C.







Source: Burnet Institute and Kirby Institute. Australia's progress towards hepatitis C elimination: annual report 2022. Melbourne: Burnet Institute; 2022.

