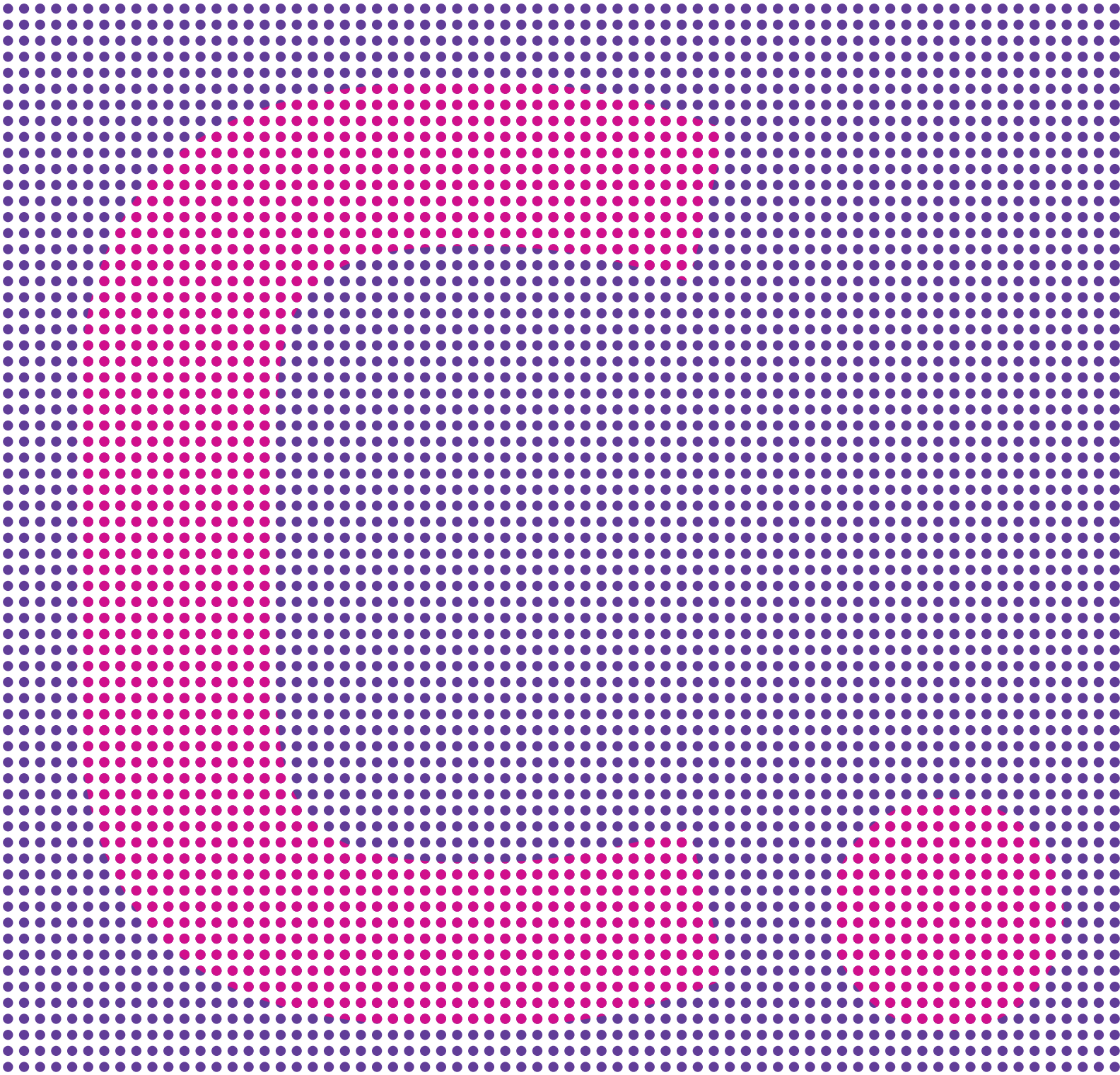
Hepatitis C Elimination in NSW:

Monitoring and Evaluation Report, 2019



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Hepatitis C Elimination in NSW:

Monitoring and Evaluation Report, 2019

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Figures

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Abbreviations

ABS	Australian Bureau of Statistics
ANSPS	Australian Needle and Syringe Program Survey
CEASE	Control and Elimination within AuStralia of Hepatitis C from people living with HIV
DAA	direct-acting antiviral
ETHOS Engage	Enhancing Treatment of Hepatitis C in Opioid Substitution Settings
KRC	The Kirketon Road Centre
NCIMS	NSW Notifiable Conditions Information Management System
NNEDC	NSW NSP Enhanced Data Collection
NSW	New South Wales
REACH-C	Real-world efficacy of antiviral therapy in chronic hepatitis C
WHO	World Health Organization

Preface

Hepatitis C is considered a global public health threat [1]. At the end of 2018, an estimated 128 970 people were living with chronic hepatitis C infection in Australia, 38% (48 381) of whom were estimated to be from New South Wales (NSW) [2]. Unrestricted access to government-reimbursed direct-acting antiviral (DAA) therapy for hepatitis C infected adults has considerably improved hepatitis C treatment access in Australia. As such, the NSW Ministry of Health has committed to eliminating hepatitis C as a public health threat in NSW by 2028.

This inaugural report, published annually, provides an account of progress towards hepatitis C elimination in NSW, as framed by the NSW Hepatitis C Strategy 2014–2020 [3], the National Hepatitis C Strategy 2018–2022 [4], and World Health Organization (WHO) Global Health Sector Strategy 2016–2021 [5]. At the state, national, and global levels, hepatitis C strategies have been developed to establish principles of a high-quality, evidence-based, and equitable response to hepatitis C elimination.

The targets and associated objectives of the NSW Hepatitis C Strategy, National Hepatitis C Strategy, and Global Health Sector Strategy are to improve testing, treatment, and uptake of preventative measures for hepatitis C, and to reduce the incidence, morbidity, and mortality associated with hepatitis C [3-5]. Each objective has a series of measurable indicators for monitoring progress, including a set of focused targets that evaluate service coverage and impact. Meeting international elimination targets is a critical part of Australia's hepatitis C elimination response. The aim of this report is to describe hepatitis C elimination targets, objectives, and indicators, and the level of progress made. Each of the indicators have several data considerations which are outlined in the relevant sections.

1. Summary data

Service coverage indicators

Harm reduction

- In 2018, 14 515 017 injecting units were distributed in NSW, an increase from 12 387 082 units distributed in 2014 (source: NSW Health NSP Minimum Data Set and ABS).
- In 2018, 20% of people attending needle syringe programs self-reported receptive syringe sharing in the last month, an increase from 14% in 2014 (source: NNEDC).
- In 2018, 52% of people attending needle syringe programs who had a history of injecting opioids, self-reported currently receiving opioid agonist therapy, similar to 53% in 2014 (source: ANSPS).

Service coverage indicators (continued)

Hepatitis C testing and diagnosis

- In 2018, 92% of people attending needle syringe programs who had current hepatitis C (hepatitis C RNA positive), self-reported a history of hepatitis C testing, similar to 90% in 2015 (source: ANSPS).
- In 2018, 63% of people attending needle syringe programs who had current hepatitis C and self-reported a history of hepatitis C testing, reported receiving a hepatitis C test in the past year, similar to 63% in 2014 (source: ANSPS).
- In 2018–2019, 89% and 67% of people attending drug treatment clinics and needle syringe programs who had current hepatitis C, self-reported a history of hepatitis C antibody and RNA testing, respectively (source: ETHOS Engage).
- In 2018–2019, 65% of people attending drug treatment clinics and needle syringe programs who had current hepatitis C and self-reported a history of hepatitis C testing, reported receiving a hepatitis C test in the past year (source: ETHOS Engage).

Hepatitis C treatment uptake

Overall

- In 2016–2018, 37% of people in NSW with chronic hepatitis C received treatment. Differences in treatment uptake were noted among people born before 1945 (21%), between 1945 and 1964 (39%), and after 1964 (36%); and among people born overseas (33%), compared to Australia (41%) (source: NSW data linkage).

People who inject drugs

- In 2016–2018, 47% of people in NSW with chronic hepatitis C and evidence of recent drug dependence received treatment. Differences in treatment uptake were noted among females (43%) and males (50%); people born before 1945 (24%), between 1945 and 1964 (49%), and after 1964 (47%); and Aboriginal and Torres Strait Islander peoples (42%) and non-Indigenous Australians (49%) (source: NSW data linkage).
- In 2018, 44% of people attending needle syringe programs who were treatment eligible self-reported initiating treatment in the past year, an increase from 3% in 2014. Treatment uptake was lower among females (39%), compared to males (45%) (source: ANSPS).
- In 2018, 53% of people attending needle syringe programs who were treatment eligible self-reported a history of DAA uptake. Disparities in DAA uptake were noted among females (46%) and males (58%); people younger than 44 years (47%) and older (61%); and Aboriginal and Torres Strait Islander peoples (48%) and non-Indigenous Australians (57%) (source: NNEDC).
- In 2018–2019, 68% of people attending drug treatment clinics and needle syringe programs who were treatment eligible self-reported a history of hepatitis C treatment uptake. Hepatitis C treatment uptake was lower among females (63%), compared to males (71%) (source: ETHOS Engage).

People who are incarcerated

- In 2016–2018, 47% of people in NSW with chronic hepatitis C who were recently incarcerated received treatment. Differences in treatment uptake were noted among females (40%) and males (48%); and Aboriginal and Torres Strait Islander peoples (42%) and non-Indigenous Australians (51%) (source: NSW data linkage).
- In 2018, 23% of people in NSW who were treated accessed treatment through Justice Health, an increase from 2% in 2016 (source: Health Protection NSW).

People living with HIV

- In 2016–2018, 60% of people in NSW with hepatitis C/HIV co-infection received treatment. Treatment uptake was lower among people born between 1945 and 1964 (56%), compared to after 1964 (62%) (source: NSW Data linkage).
- In 2018, 92% of people with hepatitis C/HIV co-infection who had evidence of ever chronic hepatitis C attending primary and tertiary clinics, had a history of hepatitis C treatment (source: CEASE).

Service coverage indicators (continued)

People with advanced liver disease

- In 2016–2018, 36% of people with a hepatitis C-related decompensated cirrhosis diagnosis received treatment. Disparities in treatment uptake were noted among females (32%) and males (37%); people born before 1945 (28%), between 1945 and 1964 (37%), and after 1964 (33%); Aboriginal and Torres Strait Islander peoples (30%) and non-Indigenous Australians (36%); and people born overseas (31%) and in Australia (37%) (source: NSW data linkage).
- In 2016–2018, 37% of people with a hepatitis C-related hepatocellular carcinoma diagnosis received treatment. Differences in treatment uptake were noted among people born before 1945 (29%), between 1945 and 1964 (39%), and after 1964 (32%); and people born overseas (32%) and in Australia (41%) (source: NSW data linkage).

Hepatitis C treatment outcomes

Treatment completion

- In 2016–2018, among people with chronic hepatitis C in NSW, 85% of courses of DAA treatment were dispensed the total prescribed course, indicative of treatment completion (source: NSW data linkage).
- In 2016–2018, among people in NSW with chronic hepatitis C and evidence of recent drug dependence, 83% of courses of DAA treatment were dispensed the total prescribed course, indicative of treatment completion (source: NSW data linkage).

Response to DAA therapy

- In 2016–2018, 96% of people who received DAA therapy in NSW were cured. Differences in sustained virological response were noted among people with cirrhosis (93%) and those without (97%); and treatment-experienced (93%) and treatment naïve individuals (97%) (source: REACH-C).

Hepatitis C retreatment

- In 2016–2018, 2% of people in NSW who received DAA therapy were retreated. The majority (58%) were due to virological failure (source: REACH-C).
- In 2016–2018, 4% of people in NSW who received DAA therapy and had evidence of recent injecting drug use were retreated. The majority (57%) were due to reinfection (source: REACH-C).

Stigma and discrimination

- In 2018, 84% of people attending Australian Injecting and Illicit Drug Users League member organisations self-reported recent (past year) experiences of stigma or discrimination in relation to their injecting drug use (source: Stigma Indicators Monitoring Project).
- In 2018, 38% of people attending Australian Injecting and Illicit Drug Users League member organisations self-reported recent (past year) experiences of stigma or discrimination in relation to their hepatitis C (source: Stigma Indicators Monitoring Project).

Impact indicators

People living with current hepatitis C infection

- By end of 2018, 48 381 people were estimated to be living with hepatitis C, a decline from 68 936 in 2015 (source: mathematical modelling).

Hepatitis C prevalence

People who inject drugs

- In 2018, 19% of people attending needle syringe programs with available RNA testing results had current hepatitis C (hepatitis C RNA positive), a decline from 51% in 2015. Prevalence of current infection was lower among non-Indigenous Australians (18%), compared to Aboriginal and Torres Strait Islander peoples (24%) (source: ANSPS).
- In 2018–2019, 24% of people attending drug treatment clinics and needle syringe programs with available RNA testing results had current hepatitis C. No major differences in prevalence of current infection was noted by sex, median age, Indigenous ethnicity and last/major drug injected (source: ETHOS Engage).

People living with HIV

- In May 2017-May 2018, 7% of people living with HIV who had positive anti-hepatitis C serology attending primary and tertiary clinics with available RNA testing results had current hepatitis C, a decline from 74% in July 2014-March 2017. No major differences in prevalence of current infection was noted by median age (source: CEASE).

Younger age (15–24 years) hepatitis C notifications

- In 2018, excluding Justice Health, there were 159 notifications in the 15–24 year age group, a decline from 212 in 2015. In 2018, in Justice Health settings, there were 173 notifications in this age group, an increase from 96 in 2015 (source: NCIMS).

Impact indicators (continued)

Incidence of infection among high risk populations

- In 2018, among people who inject drugs attending Kirketon Road Centre, hepatitis C incidence was 4.1 per 100 person-years (95% CI 1.3, 12.7), a decline from 13.2 per 100 person-years (95% CI 7.5, 23.3) in 2015 (source: Kirketon Road Centre).

Hepatitis C reinfection incidence among people living with HIV

- In 2016–2018, among people with hepatitis C/HIV co-infection attending primary and tertiary clinics who were retested after treatment-induced cure, hepatitis C incidence was 1.2 per 100 person-years (95% CI 0.4, 2.8) (source: CEASE).

Hepatitis C-related liver morbidity and mortality

Hepatitis C-related morbidity

- In 2018, 284 people in NSW had a hepatitis C-related decompensated cirrhosis diagnosis, a decline from 399 in 2015 (source: NSW data linkage). In 2018, 150 people in NSW had a hepatitis C-related hepatocellular carcinoma diagnosis, a decline from 168 in 2015 (source: NSW data linkage).

Hepatitis C-related liver mortality

- In 2018, 312 people in NSW died due to hepatitis C-related liver causes, a decline from 359 in 2015 (source: NSW data linkage)

2. Monitoring and evaluation indicators

2.1 NSW Hepatitis C Strategy 2014–2020 indicators

The NSW Hepatitis C Strategy 2014–2020 [3] continues the NSW Government's commitment to reduce hepatitis C infections and improve the health outcomes of people living with hepatitis C. The advent of DAA hepatitis C treatments in 2016, during the life of the Strategy, has increased the focus on improving access to treatment in key settings and populations.

The goals of the NSW Hepatitis C Strategy 2014–2020 are to:

- Reduce hepatitis C infections in NSW; and
- Improve the health outcomes of people living with hepatitis C in NSW.

To achieve these goals, efforts should focus on:

1. Reducing sharing of injecting equipment among people who inject drugs by 25%; and
2. Increasing the number of people accessing hepatitis C treatment in NSW by 100%.

2.2 National Hepatitis C Strategy 2018–2022 indicators

The National Hepatitis C Strategy 2018–2022 [4] has overarching goals, targets and priority areas which will guide Australia's response to hepatitis C.

The goals of the National Hepatitis C Strategy 2018–2022 are to:

- Make significant progress towards eliminating hepatitis C as a public health threat;
- Reduce mortality and morbidity related to hepatitis C;
- Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health; and
- Minimise the personal and social impact of hepatitis C.

By the end of 2022, targets of this Strategy are to:

1. Reduce the number of newly acquired hepatitis C infections, with a focus on priority populations, by 60%;
2. Increase the proportion of people living with hepatitis C who are diagnosed to 90%;
3. Increase the cumulative proportion of people living with chronic hepatitis C who have initiated direct-acting antiviral treatment to 65%;
4. Reduce hepatitis C attributable mortality overall by 65%; and
5. Reduce by 50% the reported experience of stigma among people living with hepatitis C, and the expression of stigma, in respect to hepatitis C status.

2.3 Global Health Sector Strategy 2016–2021 indicators

Methods used in the WHO 2015 Global reference list of 100 health indicators guided the process of selecting indicators for hepatitis C [6]. A minimum set of nine core indicators were selected to monitor and evaluate the health sector response to hepatitis C, including prevalence, infrastructure for testing, needle-syringe distribution, facility-level injection safety, people diagnosed, treatment coverage/initiation, hepatitis C cure, incidence, and attributable hepatocellular carcinoma, cirrhosis, and chronic liver disease mortality (Appendix A, Figure A1.) By 2020 and 2030, the Global health sector viral hepatitis strategy would be expected to deliver a 25% and 90% reduction in new HCV cases and a 10% and 65% reduction in the number of hepatitis C-related deaths, respectively. By 2020 and 2030, 8 million people and 80% of those eligible are expected to be treated, respectively [5, 7].

2.4 Indicator definitions and data sources

NSW Hepatitis C Strategy, National Hepatitis C Strategy, and Global Health Sector Strategy indicators including definitions and data sources for evaluation are outlined in Table 1 and Table 2.

Table 1. Hepatitis C indicators and data sources for monitoring service coverage

	Indicator	Definition	NSW indicator proposed	Pre-2015 estimate	2015 estimate	2018 estimate
 	Needle–syringe coverage	Number of needles/syringes distributed per person who injects drugs	Number of injecting units distributed within a one-year period	NSW Health NSP Minimum Data Set	NSW Health NSP Minimum Data Set	NSW Health NSP Minimum Data Set
			Proportion of people who inject drugs who report receptive syringe sharing in the past month (additional)	NNEDC	NNEDC	NNEDC
 	Opioid agonist therapy coverage	Proportion of people who have injected opioid drugs and are currently receiving opioid agonist therapy	Proportion of people attending NSPs and who have ever injected opioids who are currently receiving opioid agonist therapy (additional)	-	-	ANSPS
 	People living with hepatitis C who have been diagnosed	Proportion of people living with current hepatitis C infection who have been diagnosed	Proportion of people who inject drugs living with current hepatitis C who ever received hepatitis C testing and those who received testing in the past year	ANSPS	ANSPS	ANSPS & ETHOS Engage

	Indicator	Definition	NSW indicator proposed	Pre-2015 estimate	2015 estimate	2018 estimate
  	Treatment initiation for hepatitis C	Proportion of people with a hepatitis C diagnosis who started on treatment during a specified time frame (e.g. DAA era, 2016–2018)	Proportion of people who received hepatitis C treatment, in 2016–2018	Data Linkage	Data Linkage	Data Linkage
			Proportion of people who inject drugs who received hepatitis C treatment, ever, recently, and in 2016–2018	Data Linkage	Data Linkage & ANSPS	Data Linkage & ANSPS & NNEDC & ETHOS Engage
			Proportion of incarcerated people who received hepatitis C treatment, recently and in 2016–2018	Data Linkage & Justice Health	Data Linkage & Justice Health	Data Linkage & Justice Health
			Proportion of people living with HIV who received hepatitis C treatment in 2016–2018	Data Linkage	Data Linkage & CEASE	Data Linkage & CEASE
			Proportion of people with advanced liver disease who received hepatitis C treatment in 2016–2018	Data Linkage	Data Linkage	Data Linkage
			Proportion of people who completed hepatitis C antiviral treatment in 2016–2018 (additional)	-	-	Data Linkage
			Proportion of people who achieved sustained virological response in 2016–2018 (additional)	-	-	REACH-C
			Proportion of people who were retreated in 2016–2018 (additional)	-	-	REACH-C
 	Experience of stigma and discrimination	Impact of stigma and discrimination on health of people at risk of or living with hepatitis C	Number of people with a history of injecting drug use who experienced stigma in relation to injection drug use	-	-	Stigma Indicators Monitoring Project
			Number of people who had a hepatitis C diagnosis and experienced stigma in relation to hepatitis C infection	-	-	Stigma Indicators Monitoring Project

2.4 Indicator definitions and data sources (continued)

Table 2. Hepatitis C indicators and data sources for monitoring impact targets

	Indicator	Definition	NSW indicator proposed	Pre-2015 estimate	2015 estimate	2018 estimate
	Prevalence of chronic hepatitis C infection	Number and proportion of people living with current hepatitis C infection (hepatitis C RNA positive)	Number of people living with current hepatitis C infection	Mathematical modelling	Mathematical modelling	Mathematical modelling
			Prevalence of current hepatitis C infection among people who inject drugs	-	ANSPS	ANSPS & ETHOS Engage
			Prevalence of current hepatitis C infection among people living with HIV	-	CEASE	CEASE
	Incidence of hepatitis C infection	Number and rate of new hepatitis C infections	Number of younger age (15–24 years) hepatitis C notifications, excluding Justice Health	NCIMS	NCIMS	NCIMS
			Number of younger age (15–24 years) hepatitis C notifications in Justice Health	NCIMS	NCIMS	NCIMS
			Incidence of hepatitis C infection among people who inject drugs	KRC	KRC	KRC
			Incidence of hepatitis C reinfection among people living with HIV (additional)	-	CEASE	CEASE
	Deaths attributable to hepatitis C infection	Deaths from hepatocellular carcinoma, cirrhosis and chronic liver diseases attributable to hepatitis C	Number of hepatitis C-related decompensated cirrhosis diagnoses (additional)	Data Linkage	Data Linkage	Data Linkage
			Number of hepatitis C-related hepatocellular carcinoma diagnoses (additional)	Data Linkage	Data Linkage	Data Linkage
			Number of deaths related to hepatitis C-related liver disease	Data Linkage	Data Linkage	Data Linkage

2.5 Data sources

Australian Needle and Syringe Program Survey (ANSPS)

The ANSPS commenced in 1995 and is conducted annually over a one- or two-week period in October at selected needle syringe programs in NSW (~20 sites from 9 Local Health Districts) and Australia. Eligible participants include all people attending participating centres. At enrolment, participants are invited to complete a brief, anonymous questionnaire, providing information on drug use, self-reported hepatitis C testing, hepatitis C infection, and hepatitis C treatment uptake. Participants provide a capillary dried blood spot for hepatitis C antibody and RNA testing (since 2015).

Data from NSW sites of ANSPS was used to evaluate progress with four indicators, including opioid agonist therapy coverage; people living with current hepatitis C who have been diagnosed; treatment initiation for hepatitis C; and prevalence of chronic hepatitis C infection.

Control and Elimination within Australia of Hepatitis C from people living with HIV (CEASE)

CEASE is an observational cohort study with the aim of evaluating the impact of DAA scale-up on HCV disease burden among people living with hepatitis C/HIV co-infection in NSW and Australia attending high caseload sites in primary care and tertiary centres (11 sites in NSW). Eligible participants are HIV antibody and hepatitis C antibody positive. At enrolment (31 July 2014–22 March 2017), participants were invited to complete a questionnaire, providing information on drug use and hepatitis C treatment uptake. Further, participants provided a capillary dried blood spot for hepatitis C RNA testing. First period of follow-up CEASE assessment was undertaken between 26 May 2017–31 May 2018. At follow-up, participants completed a brief questionnaire and had a capillary dried blood spot sample collected. Second period of follow-up CEASE assessment is commencing 2019–2020.

Enrolment and (first) follow-up data from NSW sites of CEASE were used to evaluate progress with three indicators, including treatment initiation for hepatitis C; prevalence of chronic hepatitis C infection; and incidence of hepatitis C infection.

ETHOS Engage: Enhancing Treatment of Hepatitis C in Opioid Substitution Settings

ETHOS Engage is an observational cohort study evaluating testing, treatment, and hepatitis C prevalence among people attending drug treatment clinics and needle syringe programs (17 sites in NSW). Eligible participants are people with a history of injecting drug use, either in the last 6 months, or currently receiving opioid agonist therapy. At enrolment, participants were invited to complete a questionnaire, providing information on drug use, self-reported hepatitis C testing, hepatitis C infection, and hepatitis C treatment uptake. Further, participants provided a finger-stick capillary blood sample for hepatitis C RNA testing using the point-of-care Xpert Viral Load Fingerstick assay. The first wave of ETHOS Engage enrolment was 28 May 2018–06 September 2019. A second wave of recruitment commenced in November 2019.

2018–2019 enrolment data from NSW sites of ETHOS Engage was used to evaluate progress with three indicators, including people living with hepatitis C who have been diagnosed; treatment initiation for hepatitis C; and prevalence of chronic hepatitis C infection.

Justice Health and Forensic Mental Health Network

Justice Health and Forensic Mental Health Network is a Statutory Health Corporation established under the Health Services Act (NSW) 1997, reporting to the Minister for Health through the Network Board and the Secretary, NSW Health. The Network delivers health care to adults and young people in contact with the forensic mental health and criminal justice systems, across community, inpatient and custodial settings.

Data from Justice Health and Forensic Mental Health Network was used to evaluate progress with one indicator; treatment initiation for hepatitis C.

The Kirketon Road Centre (KRC)

Established in 1987, KRC is a targeted primary health care facility in inner Sydney, focused on the prevention, treatment and care of HIV, viral hepatitis and sexually transmissible infections among people who inject drugs, sex workers, and 'at-risk' young people. It provides a comprehensive range of medical, nursing, and social care, free of charge and anonymously. Every year, approximately 4000 people attend KRC. All people attending KRC undertake a standardised intake questionnaire, providing information on drug use, and undergo blood borne virus testing.

Data from KRC was used to evaluate progress with one indicator; incidence of hepatitis C infection.

Mathematical modelling

Data from National Notifiable Diseases Surveillance System and Pharmaceutical Benefits Scheme were used to produce the model estimates for the number of people living with current hepatitis C in NSW and the resulting time trends. A specific estimate for the year 2015 was produced nationally using cumulative hepatitis C notifications, adjusted for duplicate notifications, spontaneous clearance, mortality, migration, and treatment uptake and cure numbers. Subsequently, a mathematical model of hepatitis C transmission, developed by Centre for Disease Analysis (centerforda.com), was used to fit to the 2015 estimate and the following years.

Mathematical modelling was used to evaluate progress with one indicator; prevalence of chronic hepatitis C infection.

NSW data linkage

Since 2003, well-established population-level data linkage mechanisms have been used to link hepatitis C notifications (positive hepatitis C serology) to a range of administrative data sets, including hospital admissions, incarceration, opioid agonist therapy, HIV diagnosis, hepatitis C treatment, cancer registry, and deaths in NSW. Linked data were utilised to characterise populations living with hepatitis C, including people with evidence of recent drug dependence, people who are/were incarcerated, individuals with hepatitis C/HIV co-infection, and those with advanced liver disease. Since 2003, subsequent rounds of data linkages were conducted in 2007, 2015, and 2019.

Linked data from the 2019 round was used to evaluate progress with two indicators, including treatment initiation for hepatitis C and deaths attributable to hepatitis C infection.

NSW Health Needle and Syringe Program Minimum Data Set

NSW Health Needle and Syringe Program Minimum Data Set is a state-wide standardised data collection system that provides core data about program activities. Each Local Health District report needle-syringe program data to NSW Health on a quarterly basis.

Data from the NSW Health Needle and Syringe Program Minimum Data Set was used to evaluate progress with one indicator; needle-syringe coverage.

NSW Notifiable Conditions Information Management System (NCIMS)

The NSW NCIMS is a register of diagnoses of infectious diseases and adverse events following immunisation, notified to NSW Health by laboratories, hospitals, and medical practitioners. Since 1991, the NSW NCIMS holds records of all individuals with positive hepatitis C serology who were NSW residents at the time of diagnosis, notified of diagnoses via mandatory notification procedures.

Data from NCIMS was used to evaluate progress with one indicator; incidence of hepatitis C infection.

NSW NSP Enhanced Data Collection (NNEDC)

The NNEDC provides a systematic snapshot of people attending all primary and some secondary needle syringe programs in all local health districts in NSW. Eligible participants include all people attending participating centres. At enrolment, participants are invited to complete a brief anonymous questionnaire, including drug use information. Since 2018, additional questions were included to collect data on participants' lifetime history of hepatitis C diagnosis and treatment uptake.

Data from NNEDC was used to evaluate progress with two indicators, including needle-syringe coverage and treatment initiation for hepatitis C.

2.5 Data sources (continued)

Real-world efficacy of antiviral therapy in chronic hepatitis C (REACH-C)

The REACH-C project comprises an observational cohort of people with chronic hepatitis C who have initiated treatment in the DAA era (from March 2016, through Pharmaceutical Benefits Scheme). Participants are recruited from a national network of diverse clinical services (18 in NSW), including specialist liver clinics, drug and alcohol services, sexual health clinics, general practice, community health clinics, and prisons. The study evaluates patterns of treatment uptake and treatment response rates to DAA therapies, including the reasons for treatment failure, since March 2016..

Data from NSW sites of REACH-C March 2016–December 2018 was used to evaluate progress with one indicator; treatment initiation for hepatitis C.

Stigma Indicators Monitoring Project

The aim of the Stigma Indicators Monitoring Project is to measure experiences of stigma and discrimination among priority groups identified by the five national strategies addressing blood borne viruses and sexually transmissible infections. These include men who have sex with men, people who inject drugs, people living with HIV, people living with viral hepatitis (B and C) and people who engage in sex work. In 2018, people who inject drugs were recruited through Australian Injecting and Illicit Drug Users League member organisations in each Australian state and territory (1 site in NSW). Participants were invited to complete a questionnaire, providing information on their experiences of stigma or discrimination within the past 12 months in relation to their injecting drug use. Those who reported ever being diagnosed with hepatitis C were also asked about their experiences of stigma or discrimination within the past 12 months in relation to hepatitis C.

Data from the NSW site of Stigma Indicators Monitoring Project was used to evaluate progress with one indicator; experience of stigma and discrimination.

3. Main Findings

3.1 Monitoring service coverage

3.1.1 Harm Reduction

Background

Injecting drug use is the major risk factor for hepatitis C infection in Australia. High coverage of harm reduction interventions for people who inject drugs, including access to sterile injecting equipment and opioid agonist therapy is critical for reducing harms, including hepatitis C infection. Individual-level access to harm reduction interventions and recent injecting behaviours are used to monitor successful implementation of these interventions.

Key Indicators

a.1 Provision of injecting equipment per capita
a.2 Frequency of receptive needle and syringe sharing among people who inject drugs
b. Coverage of opioid agonist therapy among people who inject opioids

3.1 Monitoring service coverage

3.1.1 Harm reduction

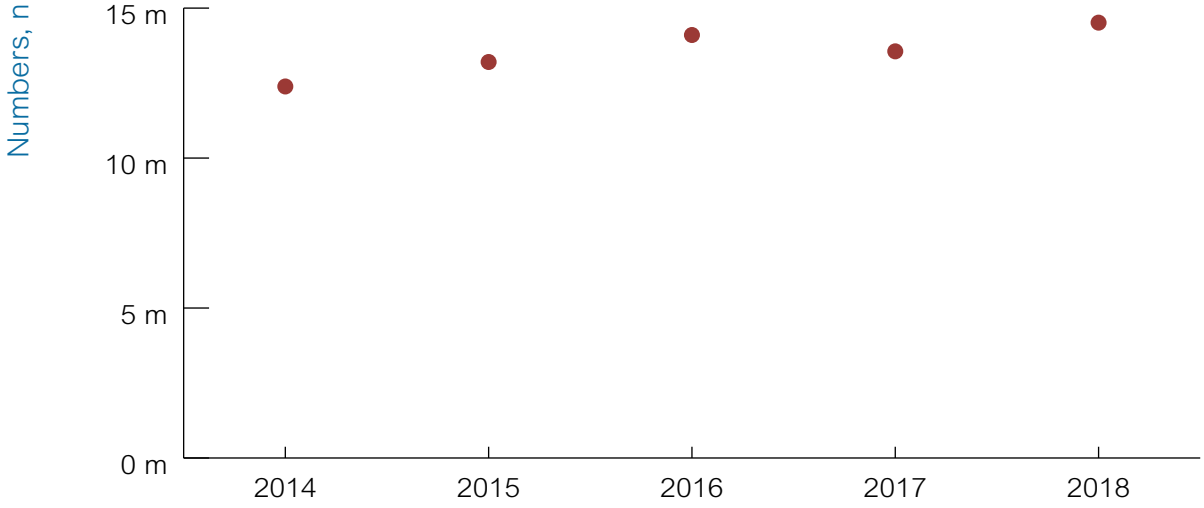
a.1 Provision of injecting equipment per capita

Indicator definition

Number of injecting units distributed within a one-year period

Results: In 2018, 14 515 017 injecting units were distributed in NSW, an increase from 12 387 082 units distributed in 2014 (Figure 1).

Figure 1. Provision of sterile injecting units in NSW, 2014–2018



Indicator Key

Study & Design: **NSW Health Needle and Syringe Program Minimum Data Set, annual report**

3.1 Monitoring service coverage

3.1.1 Harm reduction

a.2 Frequency of receptive syringe sharing among people who inject drugs

Indicator definition

Numerator

NNEDC participants who self-reported receptive syringe sharing in the month preceding the survey

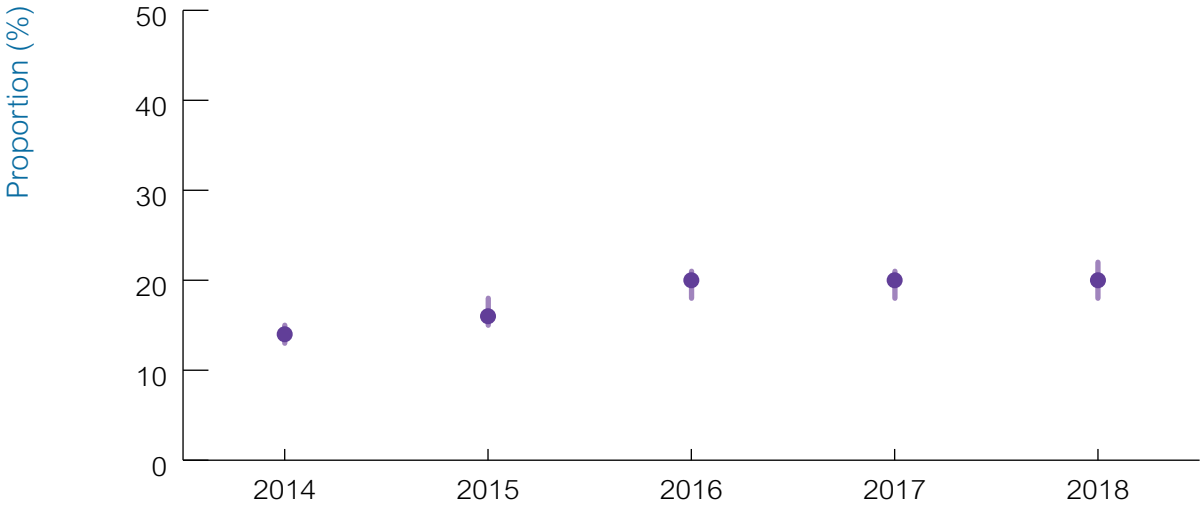
Denominator

NNEDC participants who reported injecting in the month proceeding the survey

Results: In 2018, among 3264 NNEDC participants, 2256 reported injecting in the month preceding the survey, of whom 20% (n=451) self-reported at least one occasion of receptive syringe sharing in the last month. Between 2014 and 2018, the proportion of people who self-reported receptive syringe sharing increased (14% and 20%, respectively) (Figure 2).

In 2018, among people who self-reported receptive syringe sharing, the majority (78%, n=351) reported more than one occasion, including 34% (n=152) who had more than five occasions. A minority (22%, n=100) self-reported receptive syringe sharing only once.

Figure 2. Recent (last month) receptive syringe sharing among NNEDC participants, 2014–2018



Indicator Key

Study & Design: **NNEDC, annual survey**
Sample size in 2018: **3264**
Number of sites in 2018: **50**

3.1 Monitoring service coverage

3.1.1 Harm reduction

b. Coverage of opioid agonist therapy among people who inject opioids

Indicator definition

Numerator

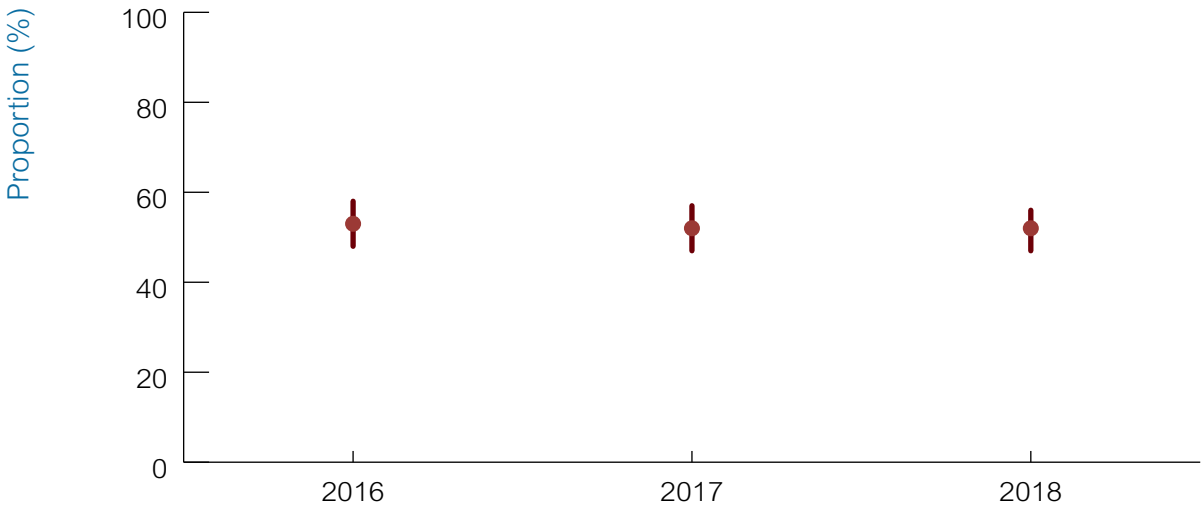
ANSPS participants who self-reported currently receiving opioid agonist therapy

Denominator

ANSPS participants who self-reported a history of injecting opioids

Results: In 2018, among 574 ANSPS participants in NSW, 436 self-reported ever injecting opioids, of whom 52% (n=225) self-reported currently receiving opioid agonist therapy. Between 2016 and 2018, the proportion of people who had ever injected opioids currently receiving opioid agonist therapy remained stable (53% and 52%, respectively) (Figure 3).

Figure 3. Current opioid agonist therapy among ANSPS participants in NSW, 2016–2018



Indicator Key

Study & Design: **ANSPS, annual survey**
Sample size in NSW in 2018: **574**
Number of sites in NSW in 2018: **19**

3.1 Monitoring Service Coverage

3.1.2 Hepatitis C Testing and Diagnosis

Background

Testing for current hepatitis C infection is a prerequisite for treatment. Uptake of testing for hepatitis C infection among populations of people who inject drugs is essential for linkage to care with treatment which reduces the risk of further transmission of hepatitis C virus.

Key Indicators

a.1 and a.2 Hepatitis C testing and diagnosis among people who inject drugs

3.1 Monitoring service coverage

3.1.2 Hepatitis C testing and diagnosis

a.1 Hepatitis C testing and diagnosis among people who inject drugs

Indicator definition

Numerator

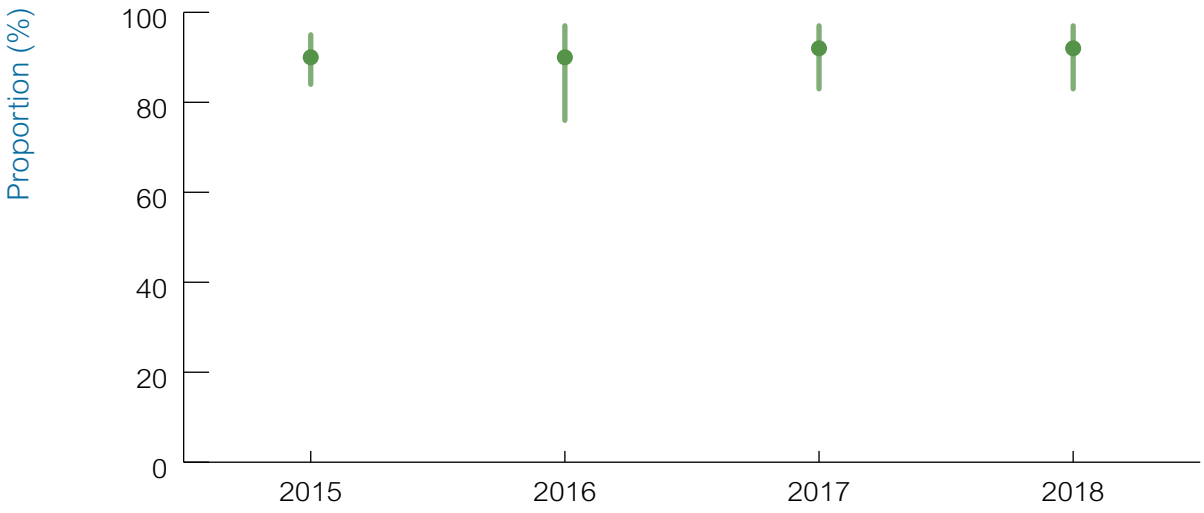
ANSPS participants who self-reported a history of hepatitis C testing

Denominator

ANSPS participants who tested positive for hepatitis C RNA

Results: In 2018, among 574 ANSPS participants in NSW, 374 had sufficient dried blood samples for hepatitis C RNA testing, of whom 19% (n=71) had current hepatitis C infection (i.e. hepatitis C RNA positive, tested on dried blood spot samples).* Among people who had current hepatitis C (n=71), 92% (n=65) had a self-reported history of hepatitis C testing (including antibody and/or RNA testing). Among those with a history of testing (n=65), 63% (n=41) self-reported hepatitis C testing in the 12 months preceding the survey. Between 2015 and 2018, the proportion of people with a history of hepatitis C testing remained stable (90% and 92%, respectively) (Figure 4); similarly, the proportion of those who received testing in the past 12 months did not change (63% and 63%, respectively).

Figure 4. History of hepatitis C testing among ANSPS participants in NSW, 2015–2018



Indicator Key

Study & Design: **ANSPS, annual survey**
Sample size in NSW in 2018: **574**
Number of sites in NSW in 2018: **19**

* weighted for sex and hepatitis C antibody status.

3.1 Monitoring service coverage

3.1.2 Hepatitis C testing and diagnosis

a.2 Hepatitis C testing and diagnosis among people who inject drugs

Indicator definition

Numerator

ETHOS Engage participants who self-reported hepatitis C testing

Denominator

All ETHOS Engage participants

Results: In 2018–2019, among 1015 ETHOS Engage participants, 975 had available point-of-care hepatitis C RNA testing data, of whom 24% (n=233) had current hepatitis C infection (i.e. hepatitis C RNA positive, tested by Xpert HCV Viral Load Fingerstick Point-of-Care Assay). Among people who had current hepatitis C (n=233), 89% (n=208) had a self-reported history of hepatitis C antibody testing, and 67% (n=156) had a history of RNA testing. Among those with a history of testing (n=208), 65% (n=136) self-reported hepatitis C testing in the 12 months preceding the survey.

Indicator Key

Study & Design: **ETHOS Engage, observational cohort**
Sample size in NSW: **1015**
Number of sites in NSW: **17**

3.1.3 Hepatitis C Treatment Uptake and Outcomes

Background

The advent of DAA therapy has increased population-level hepatitis C treatment uptake; however, it is essential to monitor treatment uptake among key populations, including people who inject drugs, people who have been incarcerated or are currently in a custodial setting, people with hepatitis C/HIV co-infection, and those with advanced liver disease. Along with treatment uptake, it is also important to monitor treatment completion, treatment outcomes, and retreatment due to virological failure or hepatitis C reinfection.

Key Indicators

a. Hepatitis C treatment uptake among those with hepatitis C notification
b.1, b.2, b.3, and b.4 Hepatitis C treatment uptake among people who inject drugs
c.1 Hepatitis C treatment uptake among people who have been incarcerated
c.2 Hepatitis C treatment uptake among people who are incarcerated
d.1 and d.2 Hepatitis C treatment uptake among people living with HIV
e. Hepatitis C treatment uptake among people with advanced liver disease
f. Hepatitis C treatment completion
g. Hepatitis C treatment outcomes
h. Hepatitis C retreatment

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

a. Hepatitis C treatment uptake

Indicator definition

Numerator

People with a hepatitis C notification who received hepatitis C treatment

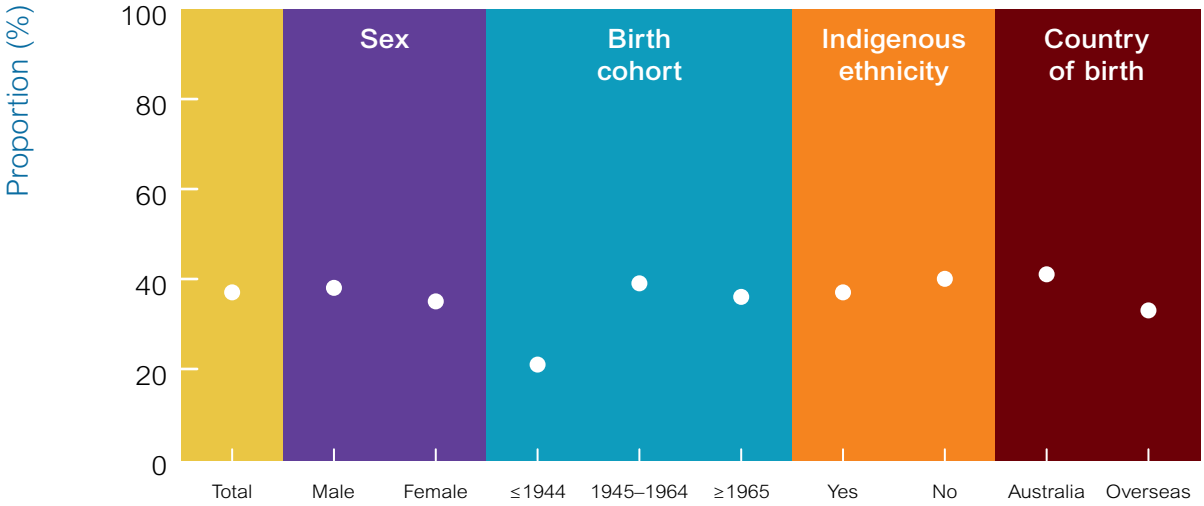
Denominator

People with a hepatitis C notification estimated to have chronic hepatitis C infection

Results: Among 66 821 people with a hepatitis C notification 1995–2017 and estimated chronic hepatitis C (i.e. treatment eligible), 37% (n=24 451) had a history of hepatitis C treatment 2010–2018, including 21 675 people who received treatment in 2016–2018 (37% of the treatment eligible population in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 35% among females (7139/20 454) and 38% (14 445/38 060) among males.* Among people born before 1945, between 1945 and 1964, and after 1964, treatment uptake was 21% (429/2013), 39% (9142/23 708), and 36% (12 050/33 274), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 37% (2815/7646) and 40% (16 250/40 797), respectively. Among people with unknown ethnicity, treatment uptake was 24% (2558/10 564). ** Among people born overseas and in Australia, treatment uptake was 33% (3451/10 583) and 41% (16 202/39 205), respectively.*** Treatment uptake among overseas-born people was highest among those born in Europe, New Zealand, and Americas (37%, 1955/5262); but lower among individuals born in Western and Southern Asia (29%, 364/1252), and among people born in Oceania and Eastern Asia (27%, 932/3417) (Figure 5).

Figure 5. Hepatitis C treatment uptake among people with a hepatitis C notification in NSW, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

* sex-specific weights were applied to account for higher spontaneous clearance among women; therefore, number of treatment eligible males and females is different, compared to the overall treatment eligible population in 2016–2018.

** 18% of the treatment eligible population in 2016–2018 had unknown ethnicity.

*** 19% of the treatment eligible population in 2016–2018 had unknown country of birth. Countries with highest number of treatment uptake in 2016–2018 were England (n=485), New Zealand (n=473), Vietnam (n=358), Italy (n=159), and Egypt (n=103).

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

b.1 Hepatitis C treatment uptake among people who inject drugs

Indicator definition

Numerator

People with a hepatitis C notification and evidence of recent drug dependence who received hepatitis C treatment

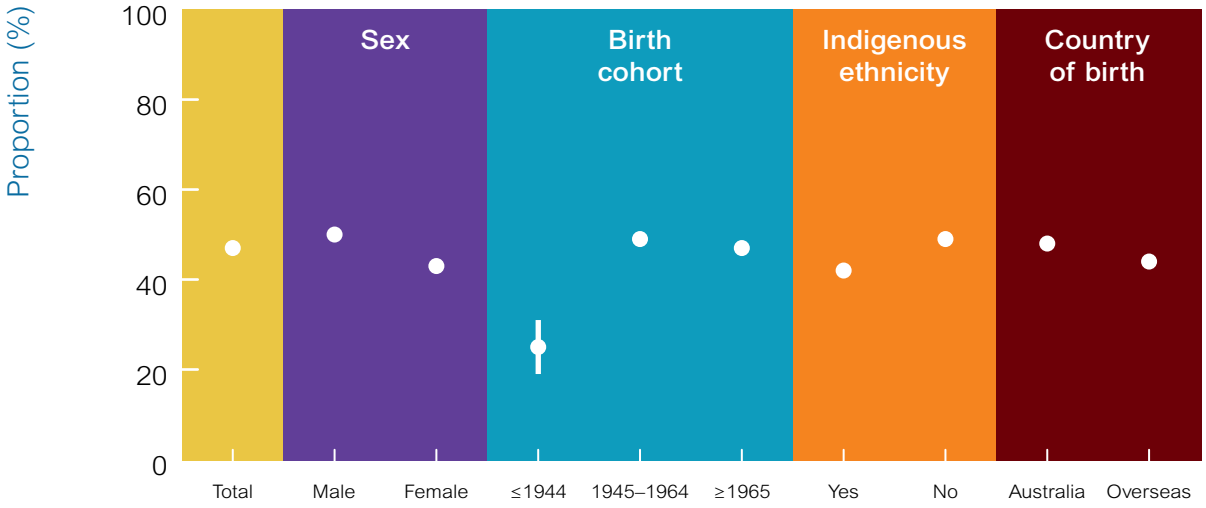
Denominator

People with a hepatitis C notification estimated to have chronic hepatitis C infection and evidence of recent drug dependence

Results: In 2015–2018, 15 966 people with a hepatitis C notification 1995–2017 and estimated chronic hepatitis C (i.e. treatment eligible) had evidence of recent drug dependence. Recent drug dependence was characterised by indicators of injecting drug use, including at least one hospital admission due to injection drug use-related complications, and/or receipt of opioid agonist therapy in 2015–2018. Among people with recent drug dependence, 51% (n=8166) had a history of hepatitis C treatment 2010–2018, including 7560 people who received treatment in 2016–2018 (47% of the treatment eligible population in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 43% (2126/4992) among females and 50% (5416/10 918) among males.* Among people born before 1945, between 1945 and 1964, and after 1964, treatment uptake was 24% (61/247), 49% (1989/4024), and 47% (5502/11 693), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 42% (1600/3822) and 49% (5750/11 640), respectively. Among people born overseas and in Australia, treatment uptake was 44% (940/2231) and 48% (6578/13 746), respectively (Figure 6).

Figure 6. Hepatitis C treatment uptake among people with a hepatitis C notification and evidence of recent drug dependence in NSW, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

* sex-specific weights were applied to account for higher spontaneous clearance among women; therefore, number of treatment eligible males and females is different, compared to the overall treatment eligible population in 2016–2018.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

b.2 Hepatitis C treatment uptake among people who inject drugs

Indicator definition

Numerator

ANSPS participants who self-reported receiving hepatitis C treatment

Denominator

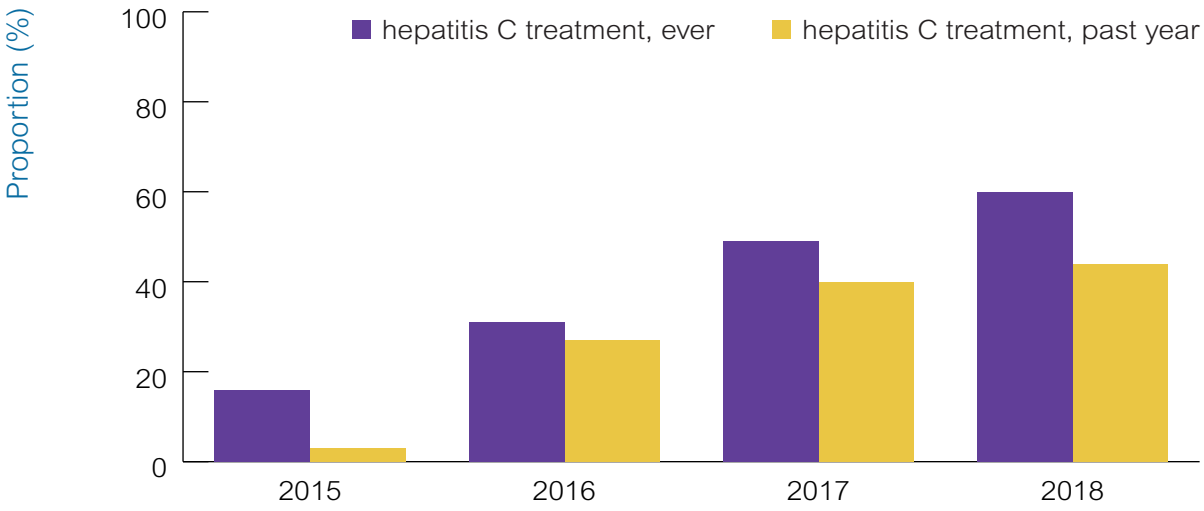
ANSPS participants with positive hepatitis C antibody and no history of spontaneous clearance

Results: In 2018, among 574 ANSPS participants in NSW, 163 had a positive hepatitis C antibody test and no self-reported history of spontaneous clearance, of whom 60% (n=97) self-reported ever receiving hepatitis C treatment. During 2015–2018, the proportion of people who self-reported ever receiving hepatitis C treatment increased from 16% to 60%.

In 2018, among 131 participants who were treatment eligible, 44% (n=57) self-reported initiating hepatitis C treatment in the 12 months preceding the survey*. During 2015–2018, the proportion of people who self-reported initiating hepatitis C treatment in the past 12 months increased from 3% to 44% (Figure 7).

In 2018, recent (last year) hepatitis C treatment uptake was 39% (12/31) among females and 45% (45/100) among males. Among people older and younger than 45 years (median age), treatment uptake was 44% (30/68) and 43% (27/63), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 56% (14/25) and 42% (42/101), respectively. Among people who mainly injected stimulants and opioids in the month preceding the survey, treatment uptake was 41% (19/46) and 44% (32/72), respectively (Figure 8).

Figure 7. Lifetime and recent (last year) hepatitis C treatment uptake among ANSPS participants in NSW, 2015–2018



* It is likely that self-reported treatment in past year represents a longer period than 12 months.

Figure 8. Recent (last year) hepatitis C treatment uptake among ANSPS participants in NSW, 2018, by sex, median age, Indigenous ethnicity, and last drug injected

Indicator Key

Study & Design: **ANSPS, annual survey**
Sample size in NSW in 2018: **574**
Number of sites in NSW in 2018: **19**

* among 163 ANSPS participants originally eligible for treatment, 32 were excluded due to self-reported HCV treatment-induced cure before 2018.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

b.3 Hepatitis C treatment uptake among people who inject drugs

Indicator definition

Numerator

NNEDC participants who self-reported receiving hepatitis C treatment

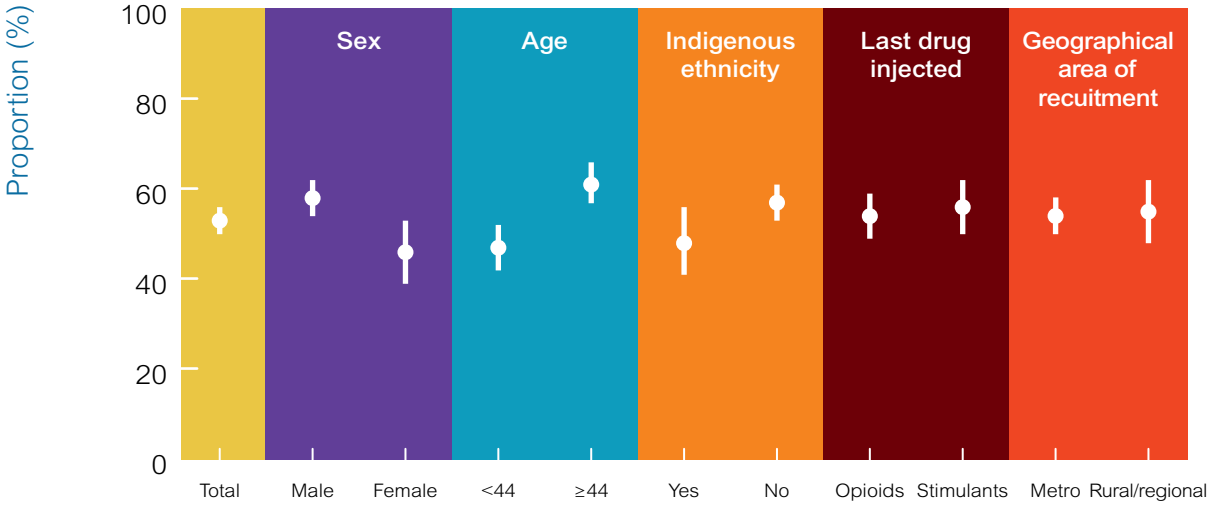
Denominator

NNEDC participants with a hepatitis C diagnosis and no history of spontaneous clearance

Results: In 2018, among 3264 NNEDC participants, 947 self-reported hepatitis C diagnosis and did not self-report spontaneous clearance, of whom 13% (n=125) self-reported a history of interferon-based hepatitis C treatment. In 2018, among 848 people who were treatment eligible, * 53% (n=449) had a history of DAA treatment uptake.

In 2018, history of DAA treatment uptake was 46% (100/219) among females and 58% (347/597) among males. Among people older and younger than 44 years (median age), treatment uptake was 61% (260/423) and 47% (185/392), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 48% (89/185) and 57% (358/632), respectively. Among people who mainly injected stimulants and opioids in the month preceding the survey, treatment uptake was 56% (160/284) and 54% (257/476), respectively. Among people who were recruited in metropolitan areas and those in rural and regional NSW, ** treatment uptake was 54% (333/612) and 55% (116/210), respectively (Figure 9).

Figure 9. Lifetime direct-acting antiviral treatment uptake among NNEDC participants in NSW, 2018, by sex, median age, Indigenous ethnicity, last drug injected, and geographical area of recruitment



Indicator Key

Study & Design: **NNEDC, annual survey**
Sample size in 2018: **3264**
Number of sites in 2018: **50**

* among 947 NNEDC participants originally eligible for treatment, 99 were excluded due to missing hepatitis C treatment information (n=30) and 55% cure assumed among individuals with a history of interferon-based treatment (n=69).

** metropolitan areas comprised 8 Local Health Districts, including Central Coast, Illawarra Shoalhaven, Nepean Blue Mountains, Northern Sydney, South Eastern Sydney, South Western Sydney, and Western Sydney. Rural and regional areas comprised 7 Local Health Districts, including Far West, Hunter New England, Mid North Coast, Murrumbidgee, Northern NSW, Southern NSW, and Western NSW.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

b.4 Hepatitis C treatment uptake among people who inject drugs

Indicator definition

Numerator

ETHOS Engage participants who self-reported receiving hepatitis C treatment

Denominator

ETHOS Engage participants with a hepatitis C diagnosis and no history of spontaneous clearance

Results: In 2018–2019, among 1015 ETHOS Engage participants, 580 had previous chronic or current hepatitis C (ever treatment eligible),* of whom 68% (n=395) self-reported a history of hepatitis C treatment. Most treated people (69%, 272 of 395) self-reported initiating DAA treatment in the 12 months preceding the survey.

In 2018–2019, among people who had evidence of hepatitis C infection (hepatitis C RNA positive, n=474), 57% had received hepatitis C treatment in the 12 months preceding the survey.

In 2018–2019, history of hepatitis C treatment was 63% (112/178) among females and 71% (282/399) among males. Among people older and younger than 45 years (median age), treatment uptake was 74% (222/302) and 62% (179/278), respectively. Treatment uptake among females and males was similar for those aged 45 years or older (73% vs. 74%, respectively); however, a difference in treatment uptake was noted among females and males who were aged less than 45 years (54% vs. 67%, respectively). Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 66% (96/146) and 69% (299/434), respectively. Among people who had injected drugs in the last month (n=332), treatment among those who mainly injected stimulants and opioids was 63% (98/155) and 68% (117/173), respectively (Figure 10).

Figure 10. Lifetime hepatitis C treatment uptake among ETHOS Engage participants in NSW, 2018, by sex, median age, Indigenous ethnicity, and major drug injected

Indicator Key

Study & Design: **ETHOS Engage, observational cohort**
Sample size in NSW: **1015**
Number of sites in NSW: **17**

* in 2018–2019, among 1051 enrolled participants, 580 were identified as having evidence of previous chronic or current hepatitis C infection, including people who self-reported previous infection who had received treatment (n=332) and those who tested positive on ETHOS Engage campaign days (n=248), using the Cepheid GeneXpert fingerstick test for hepatitis C viral load.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

c.1 Hepatitis C treatment uptake among people who are incarcerated

Indicator definition

Numerator

People with a hepatitis C notification who were recently incarcerated who received hepatitis C treatment

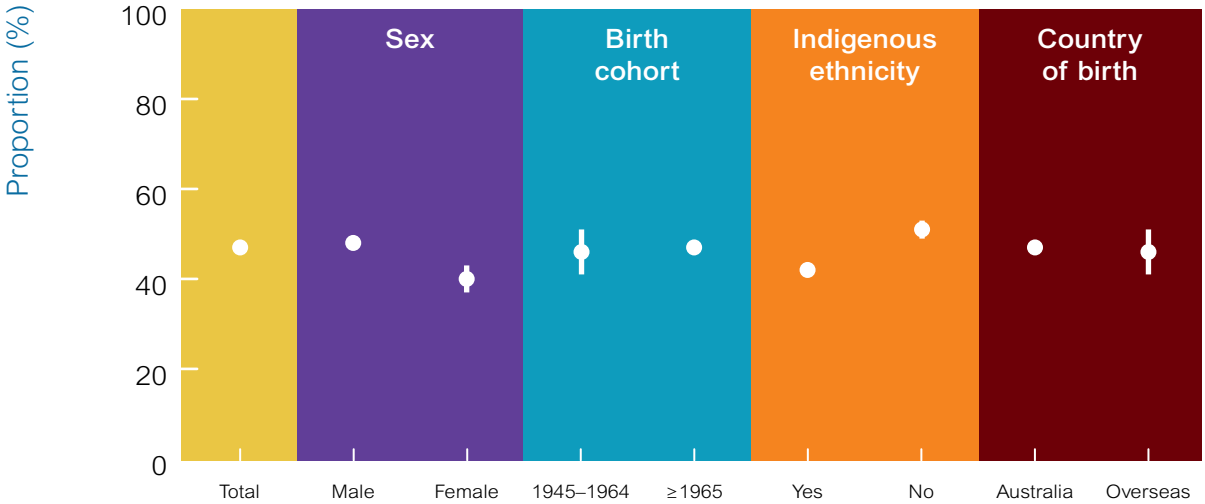
Denominator

People with a hepatitis C notification estimated to have chronic hepatitis C infection who were recently incarcerated

Results: In 2016–2018, 5582 people with a hepatitis C notification 1995–2017 and estimated chronic hepatitis C (i.e. treatment eligible) were incarcerated. Incarceration was characterised by having at least one episode of imprisonment 2016–2018 (i.e. recently incarcerated). Among people who were recently incarcerated, 50% (n=2814) had a history of hepatitis C treatment 2010–2018, including 2652 people who received treatment in 2016–2018 (47% of the treatment eligible population in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 40% (451/1118) among females and 48% (2169/4505) among males.* Among people born between 1945 and 1964, and after 1964, treatment uptake was 46% (204/444) and 47% (2419/5114), respectively.** Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 42% (921/2213) and 51% (1653/3247), respectively.*** Among people born overseas and in Australia, treatment uptake was 46% (212/462) and 47% (2386/5034), respectively (Figure 11).

Figure 11. Hepatitis C treatment uptake among people with a hepatitis C notification in NSW who were incarcerated, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

* sex-specific weights were applied to account for higher spontaneous clearance among women; therefore, number of treatment eligible males and females is different, compared to the overall treatment eligible population in 2016–2018.

** treatment uptake in one category (birth before 1945) is not displayed, due to small numbers.

*** in 2016–2018, in NSW, hepatitis C treatment uptake was 31% among the treatment eligible population without recent incarceration, characterised by no episodes of incarceration 2016–2018. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians without recent incarceration, treatment uptake was 35% and 39%, respectively. Among people with unknown ethnicity, treatment uptake was 24%.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

c.2 Hepatitis C treatment uptake among people who are incarcerated

Indicator definition

Numerator

People who received hepatitis C treatment during incarceration

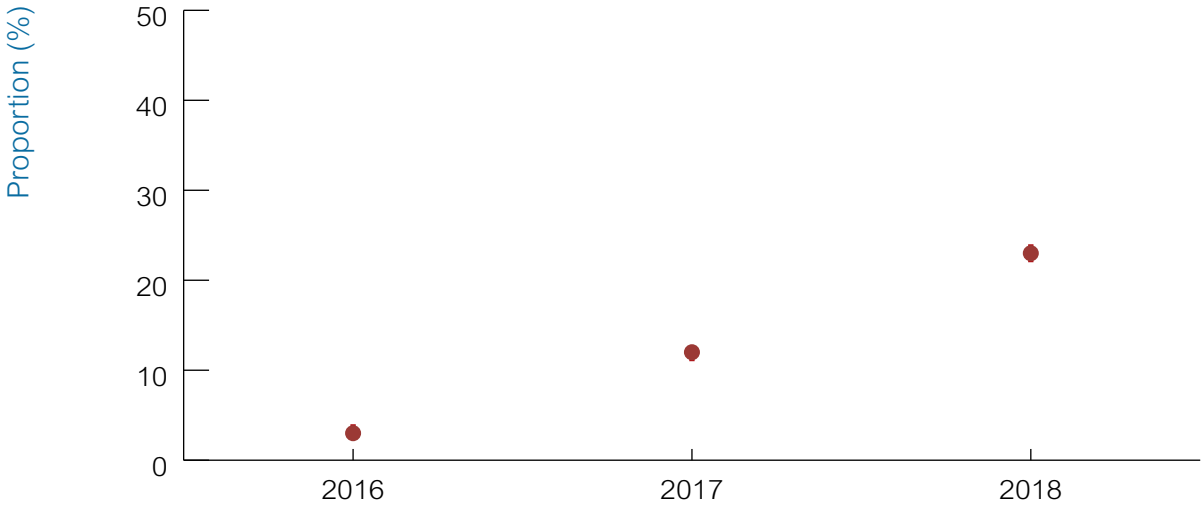
Denominator

People who received hepatitis C treatment in NSW

Results: In 2018, among 5232 people who received hepatitis C treatment in NSW, 23% (n=1191) accessed treatment through Justice Health. Between 2016 and 2018, the proportion of people who received hepatitis C treatment in Justice Health settings increased from 2% to 23% (Figure 12).

Between 2016 and 2018, among people who accessed hepatitis C treatment through Justice Health, the proportion who were Aboriginal and Torres Strait Islander peoples increased from 32% to 42%, respectively.

Figure 12. Annual hepatitis C treatment in Justice Health as a proportion of total hepatitis C treatment, 2016–2018



Indicator Key

Study & Design: **Annual Data report by NSW Health**

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

d.1 Hepatitis C treatment uptake among people living with HIV

Indicator definition

Numerator

People with a hepatitis C notification who were living with HIV who received hepatitis C treatment

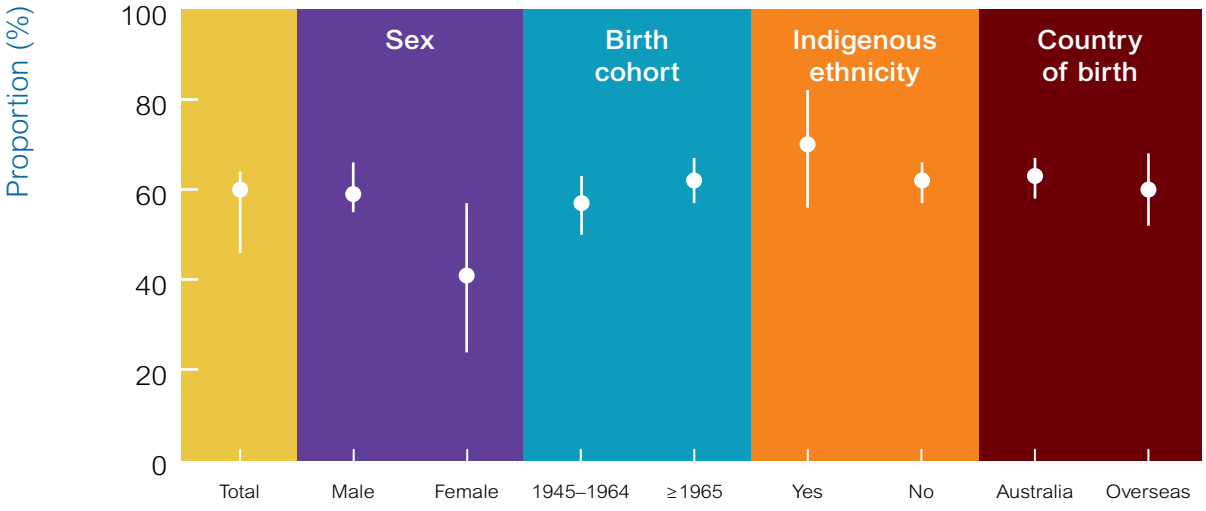
Denominator

People with a hepatitis C notification estimated to have chronic hepatitis C who were living with HIV

Results: In 1985–2017, 803 people with a hepatitis C notification 1995–2017 and estimated chronic hepatitis C were living with HIV. Hepatitis C/HIV co-infection was characterised by having an HIV diagnosis date. Among people who were living with HIV and HCV, 55% (n=439) had a history of hepatitis C treatment 2010–2018, including 403 people who received treatment in 2016–2018 (60% of the treatment eligible population in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 42% (19/46) among females and 59% (382/649) among males.* Among people born between 1945 and 1964 and after 1964, treatment uptake was 56% (152/269) and 62% (249/400), respectively.** Among non-Indigenous Australians and Aboriginal and Torres Strait Islander peoples, treatment uptake was 62% (339/551) and 70% (37/53), respectively. Among people born overseas and in Australia, treatment uptake was 60% (93/154) and 63% (291/462), respectively (Figure 13).

Figure 13. Hepatitis C treatment uptake among people with a hepatitis C notification in NSW who were living with HIV, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

* sex-specific weights were applied to account for higher spontaneous clearance among women; therefore, number of treatment eligible males and females is different, compared to the overall treatment eligible population in 2016–2018.

** treatment uptake in one category (birth in or before 1944) is not displayed, due to small numbers.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

d.2 Hepatitis C treatment uptake among people living with HIV

Indicator definition

Numerator

CEASE participants who received hepatitis C treatment

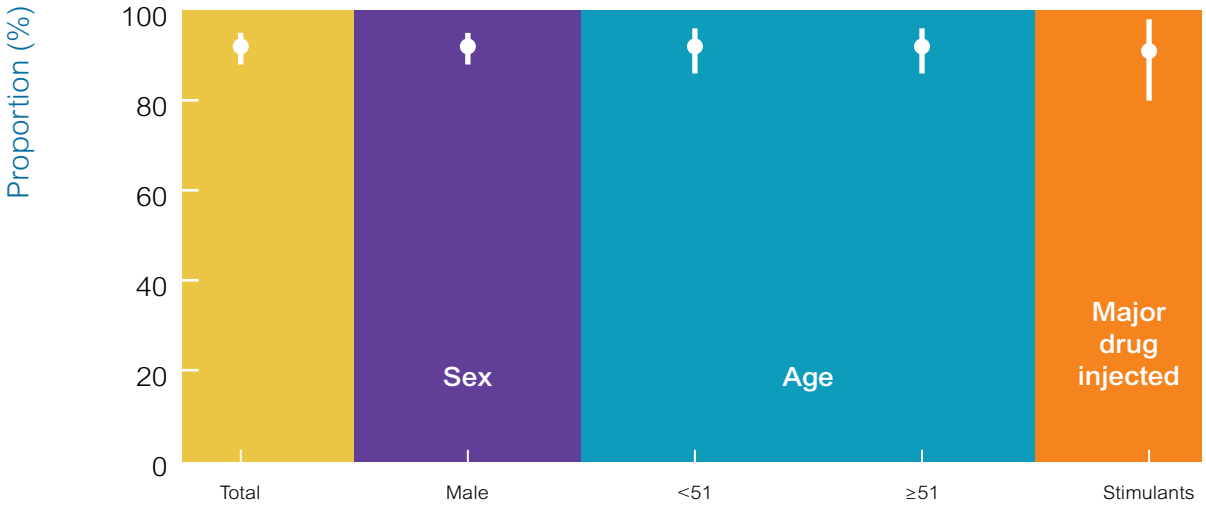
Denominator

CEASE participants with chronic hepatitis C

Results: In 2018, among 339 enrolled participants, 245 had available data on previous hepatitis C exposure (antibody positive at enrolment) or current hepatitis C, of whom 92% (n=226) had a life-time history of hepatitis C treatment, including 142 people who received hepatitis C treatment in 2016–2018.

In 2018, history of hepatitis C treatment was 92% (218/236) among males.* Among people older and younger than 51 years (median age), treatment uptake was 92% (120/130) and 92% (106/115), respectively. Among people who had injected drugs in the last month (n=57), treatment uptake among those who mainly injected stimulants was 91% (43/47)* (Figure 14).

Figure 14. Life-time history of hepatitis C treatment among CEASE participants in NSW, 2018, by sex, median age, and major drug injected



Indicator Key

Study & Design: **CEASE, observational cohort**
Sample size in NSW: **339**
Number of sites in NSW: **11**

* treatment uptake among females and people who mainly injected opioids is not displayed, due to small numbers.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

e. Hepatitis C treatment uptake among people with advanced liver disease

Indicator definition

Numerator

People with a hepatitis C notification who had an advanced liver disease diagnosis who received hepatitis C treatment

Denominator

People with a hepatitis C notification who had an advanced liver disease diagnosis

Results: In 2001–2018, 5614 people with a hepatitis C notification 1995–2017 had an advanced liver disease diagnosis, characterised by decompensated cirrhosis and/or hepatocellular carcinoma diagnosis. Decompensated cirrhosis diagnosis was defined by a first-time hospital admission and hepatocellular carcinoma was defined by a first-time hospital admission and/or diagnosis through cancer registry during 2001–2018.

Decompensated cirrhosis

Among 4747 people with a decompensated cirrhosis diagnosis 2001–2018, 17% (n=810) had a history of hepatitis C treatment 2010–2018, including 722 who received treatment in 2016–2018 (36% of people with chronic hepatitis C in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 32% (177/553) among females and 37% (536/1455) among males. Among people born before 1945, between 1945 and 1964, and after 1964, treatment uptake was 28% (26/93), 37% (482/1302), and 33% (207/618), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 30% (92/302) and 36% (610/1678), respectively. Among people born overseas and in Australia, treatment uptake was 31% (130/426) and 37% (585/1584), respectively (Figure 15).

Hepatocellular carcinoma

Among 1944 people with a hepatocellular carcinoma diagnosis 2001–2018, 19% (n=365) had a history of hepatitis C treatment 2010–2018, including 316 who received treatment in 2016–2018 (37% of people with chronic hepatitis C in 2016–2018).

In 2016–2018, hepatitis C treatment uptake was 39% (62/160) among females and 37% (253/691) among males. Among people born before 1945, between 1945 and 1964, and after 1964, treatment uptake was 29% (29/101), 39% (262/673), and 32% (25/79), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, treatment uptake was 40% (23/57) and 37% (288/777), respectively. Among people born overseas and in Australia, treatment uptake was 32% (104/328) and 41% (213/523), respectively (Figure 16).

Figure 15. Hepatitis C treatment uptake among people with a hepatitis C notification in NSW who had a decompensated cirrhosis diagnosis, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth

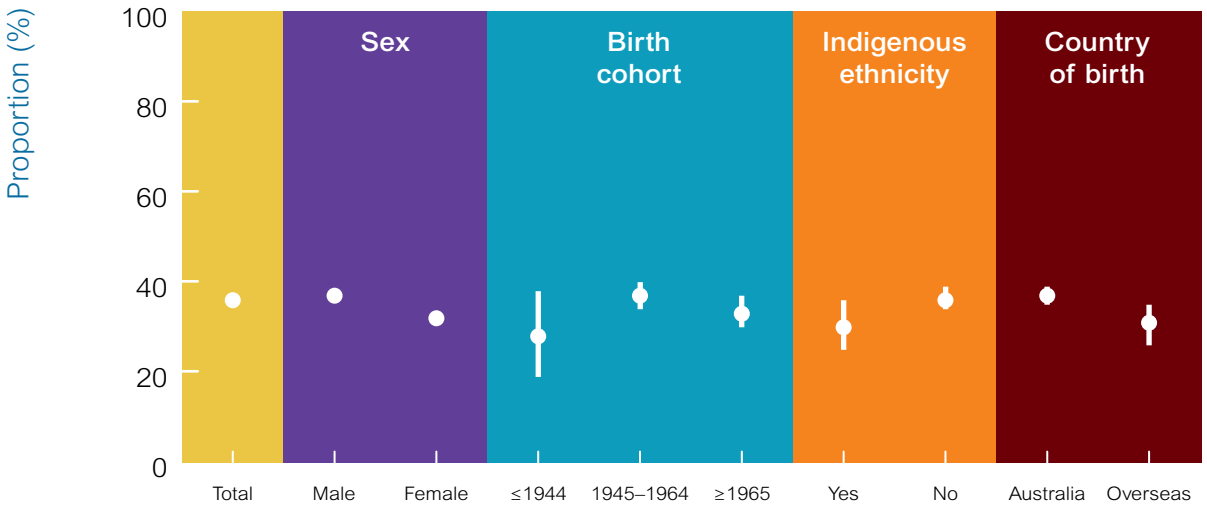
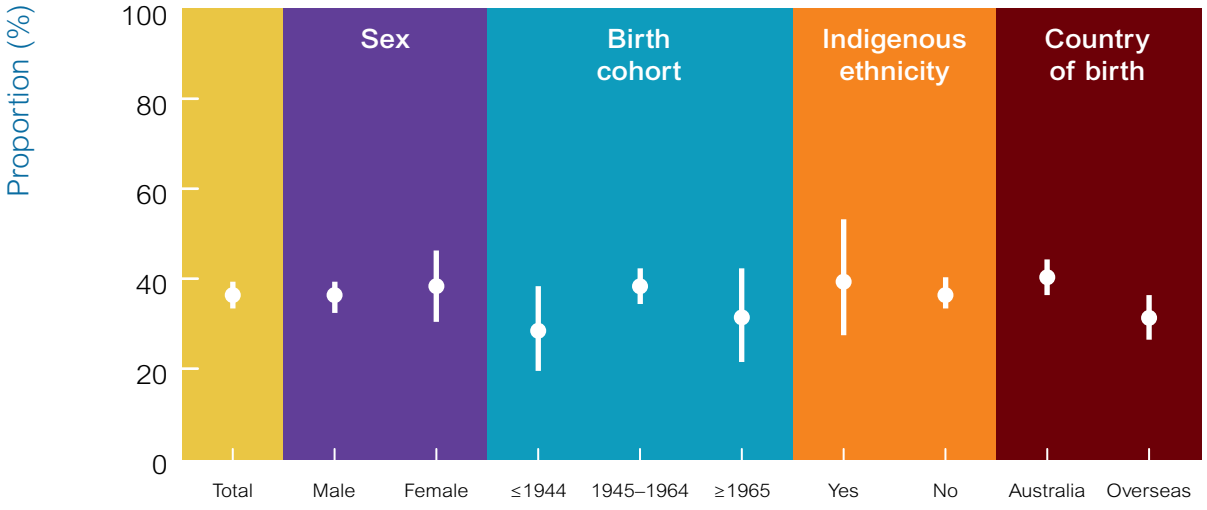


Figure 16. Hepatitis C treatment uptake among people with a hepatitis C notification in NSW who had a hepatocellular carcinoma diagnosis, 2016–2018, by sex, birth cohort, Indigenous ethnicity, and country of birth



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

f. Hepatitis C treatment completion

Indicator definition

Numerator

People with a hepatitis C notification who initiated hepatitis C treatment and were dispensed all their prescribed medication

Denominator

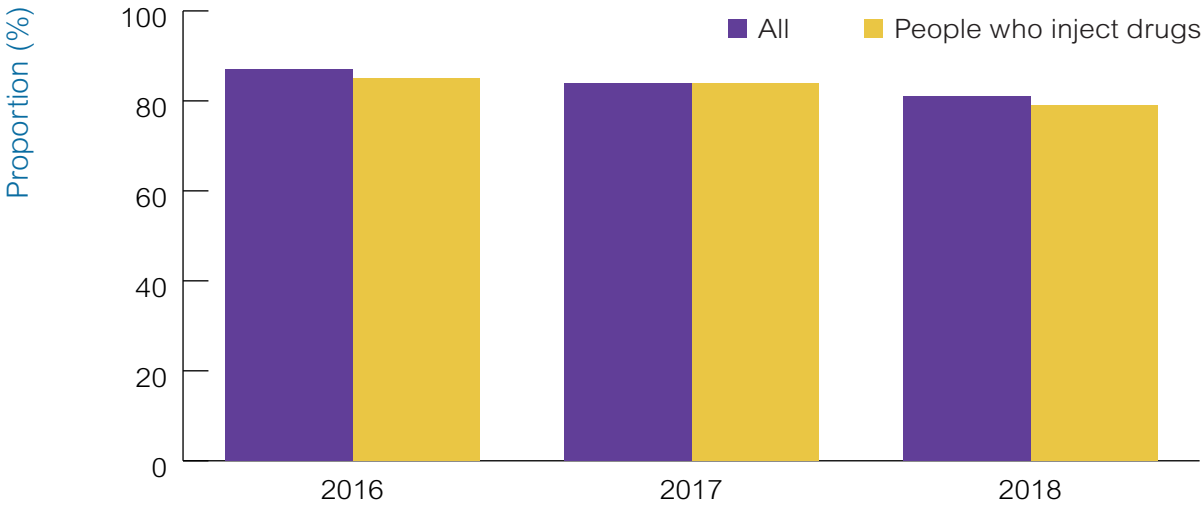
People with a hepatitis C notification who initiated hepatitis C treatment

Background: Completion of the course of hepatitis C treatment is associated with improved response to therapy. Numbers of dispensed medications (generally dispensed monthly), compared to the full course prescribed, is used as an indicator of treatment completion* among all treated individuals and people with evidence of recent drug dependence.**

Results: In 2016–2018, 26 069 courses of DAA treatment were dispensed to NSW residents. The majority (85%, n=22 084) were dispensed the total prescribed course, indicative of treatment completion. Between 2016 and 2018,*** the number of completed courses of DAA treatment declined slightly (87% and 81%, respectively) (Figure 17).

In 2016–2018, 8002 courses of DAA treatment were dispensed to people with evidence of recent drug dependence.** The majority (83%, n=6662) were dispensed all their prescribed course, indicative of treatment completion. Between 2016 and 2018, the number of completed courses of DAA treatment declined slightly (85% and 79%, respectively) (Figure 17).

Figure 17. Direct-acting antiviral treatment completion among people with a hepatitis C notification in NSW, by injecting drug use, 2016–2018



Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **92 807 people with a hepatitis C notification 1995–2017, of whom an estimated 66 821 had chronic hepatitis C**

* treatment completion is defined by the total number of dispensed medications. Compliance and adherence to treatment cannot be determined from NSW data linkage.

** characterised by having indicators of injecting drug use, including at least one hospital admission due to injection drug use-related complications and/or receipt of opioid agonist therapy 2015–2018.

*** courses commenced in 2018 with insufficient follow up time for treatment completion not accounted for.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

g. Hepatitis C treatment outcomes

Indicator definition

Numerator

REACH-C participants who received hepatitis C treatment and achieved sustained virological response

Denominator

REACH-C participants who received hepatitis C treatment and had data on sustained virological response

Background: Most people treated with DAA therapy achieve virological cure, defined by sustained virological response: no detectable hepatitis C RNA 12 weeks after treatment completion. A minority of individuals, however, have virological failure despite treatment completion or discontinue therapy early.

Results: In 2016–2018, among 2987 REACH-C participants who had received DAA treatment, 2498 had data on sustained virological response, of whom 96% (n=2398) achieved sustained virological response.* Between 2016 and 2018, the proportion of people who were cured was stable (96% and 96%) (Figure 18). In 2016–2018, 4% of people with available data on sustained virological response were not cured (n=88). Between 2016 and 2018, the proportion of people who did not achieve sustained virological response was stable (4% and 4%).

In 2016–2018, hepatitis C cure was 98% (732/744) among females and 96% (1658/1734) among males. Among people older than 51 years and younger (median age), 95% (1313/1378) and 98% (1085/1108) achieved virological cure, respectively. Among people with and without cirrhosis, cure was 93% (463/500) and 97% (1929/1979), respectively. Among treatment-experienced and treatment naïve individuals cure was 93% (330/353) and 97% (2042/2100), respectively. Among people living with hepatitis C mono- and hepatitis C/HIV co-infection, 96% (2109/2191) and 98% (218/223) were cured, respectively. Among people who had and had not injected drugs in the 6 months preceding treatment initiation, 96% (440/456) and 96% (1662/1727) achieved virological cure, respectively (Figure 19).

Figure 18. Sustained virological response among REACH-C participants in NSW, 2016–2018

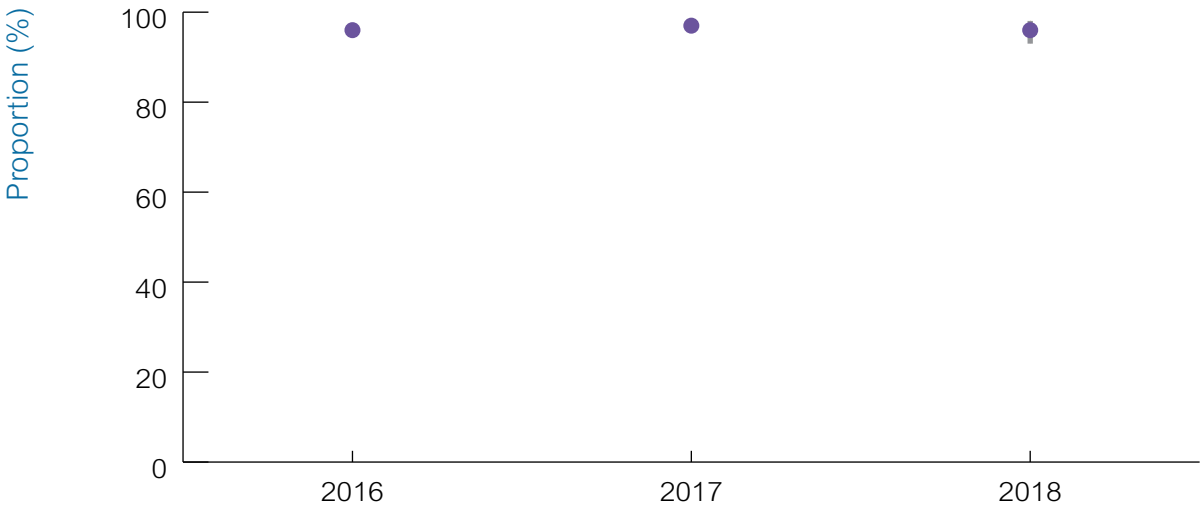
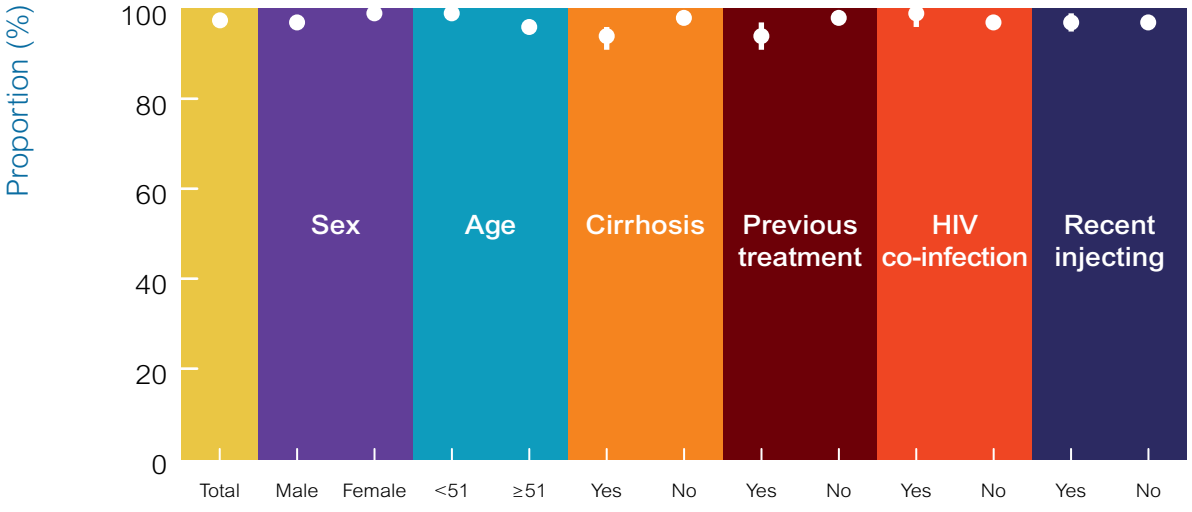


Figure 19. Sustained virological response among REACH-C participants in NSW, 2016–2018, by sex, median age, cirrhosis status, history of hepatitis C treatment, hepatitis C/HIV co-infection, and recent (past 6 months) injecting drug use



Indicator Key

Study & Design: **REACH-C, observational cohort**
Sample size in NSW: **3068**
Number of sites in NSW: **18**

* individuals with unknown sustained virological response were not included in this analysis.

3.1 Monitoring service coverage

3.1.3 Hepatitis C treatment uptake and outcomes

h. Hepatitis C retreatment

Indicator definition

Numerator

REACH-C participants who received hepatitis C treatment and were subsequently retreated

Denominator

REACH-C participants who received hepatitis C treatment

Background: People who receive DAA treatment may be retreated due to virological failure or reinfection. Hepatitis C retreatment is used to monitor virological failure and hepatitis C reinfection.

Results: In 2016–2018, among 2987 REACH-C participants who had received DAA treatment, 2% (n=72) were retreated.* Reasons for retreatment included virological failure (58%, n=42), reinfection (29%, n=21), and unknown (13%, n=9).

In 2016–2018, among 627 people with recent injecting drug use (past 6 months) who had received DAA treatment, 4% (n=28) were retreated.* Reasons for retreatment included virological failure (18%, n=5), reinfection (57%, n=16), and unknown (25%, n=7).

Indicator Key

Study & Design: **REACH-C, observational cohort**
Sample size in NSW: **3068**
Number of sites in NSW: **18**

* hepatitis C retreatment was evaluated during the follow-up period 2016–2019.

3.1 Monitoring service coverage

3.1.4 Stigma and Discrimination

Background

Among people who inject drugs and people with hepatitis C, experience of stigma has a major impact on health seeking behaviour and health outcomes. In the context of hepatitis C, perceptions of stigma and discrimination may impact a person's willingness to engage with testing and treatment. Monitoring experiences of stigma and discrimination helps to understand the broader picture behind engagement with harm reduction, testing, and treatment uptake.

Key Indicators

a. Stigma and discrimination due to injection drug use
b. Stigma and discrimination due to hepatitis C infection

3.1 Monitoring service coverage

3.1.4 Stigma and Discrimination

a. Stigma and discrimination due to injection drug use

Indicator definition

Numerator

Stigma Indicators Monitoring Project participants who inject drugs who self-reported experiencing stigma and discrimination

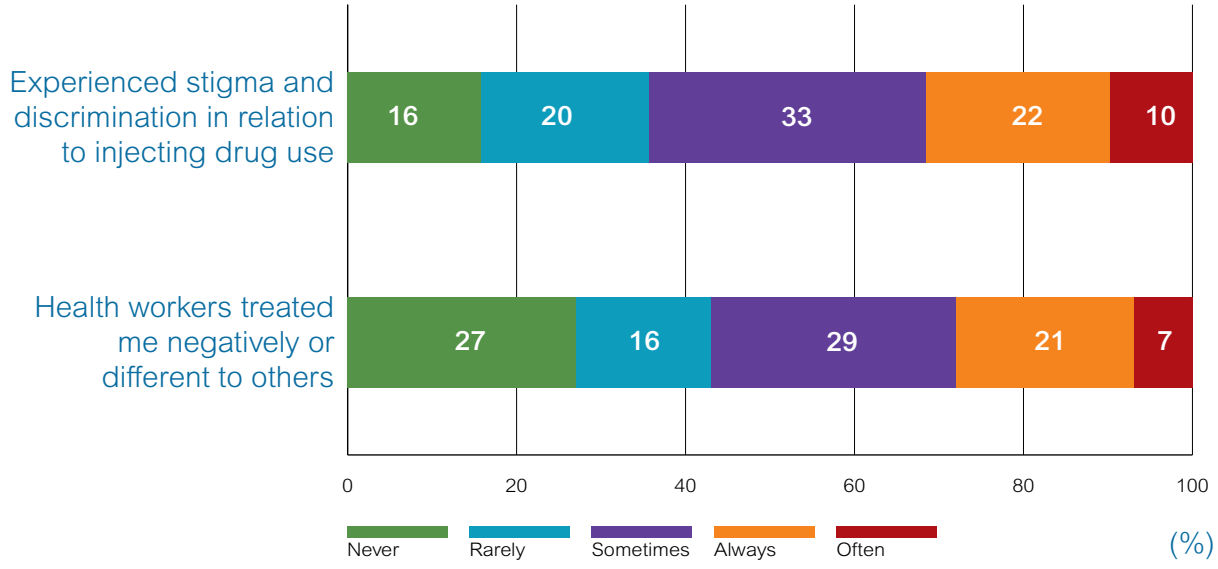
Denominator

Stigma Indicators Monitoring Project participants who inject drugs

Results: In 2018, among 82 people who had a history of injecting drug use, 84% (69/82) self-reported experiencing stigma or discrimination in relation to their injection drug use in the 12 months preceding the survey, including 32% reporting that they 'often' or 'always' experienced stigma.

In 2018, among 82 people who had a history of injecting drug use, 73% (60/82) self-reported being treated negatively or differently by health workers in the 12 months preceding the survey, including 28% reporting that they 'often' or 'always' experienced being treated negatively or differently compared to other people (Figure 20).

Figure 20. Experience of stigma and discrimination in relation to injecting drug use among Stigma Indicators Monitoring Project participants in NSW, 2018



Indicator Key

Study & Design: **Stigma Indicators Monitoring Project, survey every two years**
Sample size in NSW: **84**
Number of sites in NSW: **1**

3.1 Monitoring service coverage

3.1.4 Stigma and Discrimination

b. Stigma and discrimination due to hepatitis C infection

Indicator definition

Numerator

Stigma Indicators Monitoring Project participants who had a history of hepatitis C diagnosis who self-reported experiencing stigma and discrimination

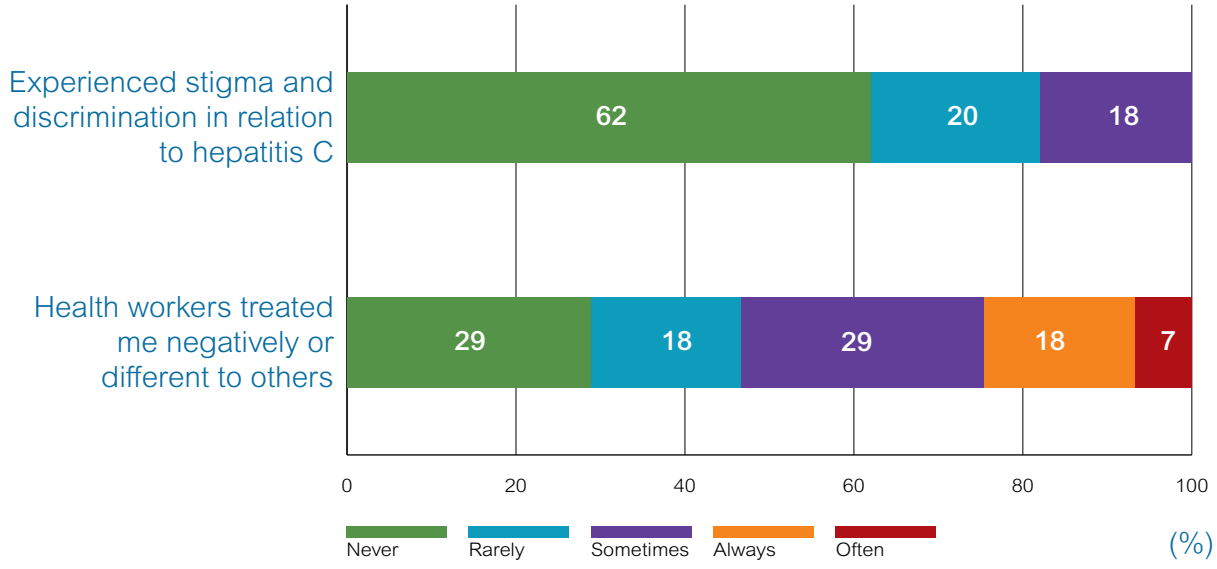
Denominator

Stigma Indicators Monitoring Project participants who had a history of hepatitis C diagnosis

Results: In 2018, among 45 people who had a history of hepatitis C diagnosis, 38% (17/45) self-reported experiencing stigma or discrimination in relation to their hepatitis C in the 12 months preceding the survey; however, no participants reported 'often' or 'always' experiencing stigma.

In 2018, among 45 people who had a history of hepatitis C diagnosis, 71% (32/45) reported being treated negatively or differently by health workers, including 25% reporting that they 'often' or 'always' experienced being treated negatively or differently compared to other people (Figure 21).

Figure 21. Experience of stigma and discrimination in relation to injecting drug use among Stigma Indicators Monitoring Project participants in NSW, 2018



Indicator Key

Study & Design: **Stigma Indicators Monitoring Project, survey every two years**
Sample size in NSW: **47**
Number of sites in NSW: **1**

3.2.1 People living with current hepatitis C

Background

Population-level DAA treatment scale-up is expected to reduce current hepatitis C infection (hepatitis C RNA prevalence). Numbers of people who are living with hepatitis C is used to monitor the impact of treatment scale-up on overall hepatitis C infection and in different populations, including people who inject drugs and people living with HIV.

Key Indicators

a.	People living with current hepatitis C infection
b.1 and b.2	Hepatitis C RNA prevalence among people who inject drugs
c.	Hepatitis C RNA prevalence among people living with HIV

3.2 Monitoring impact

3.2.1 People living with current hepatitis C infection

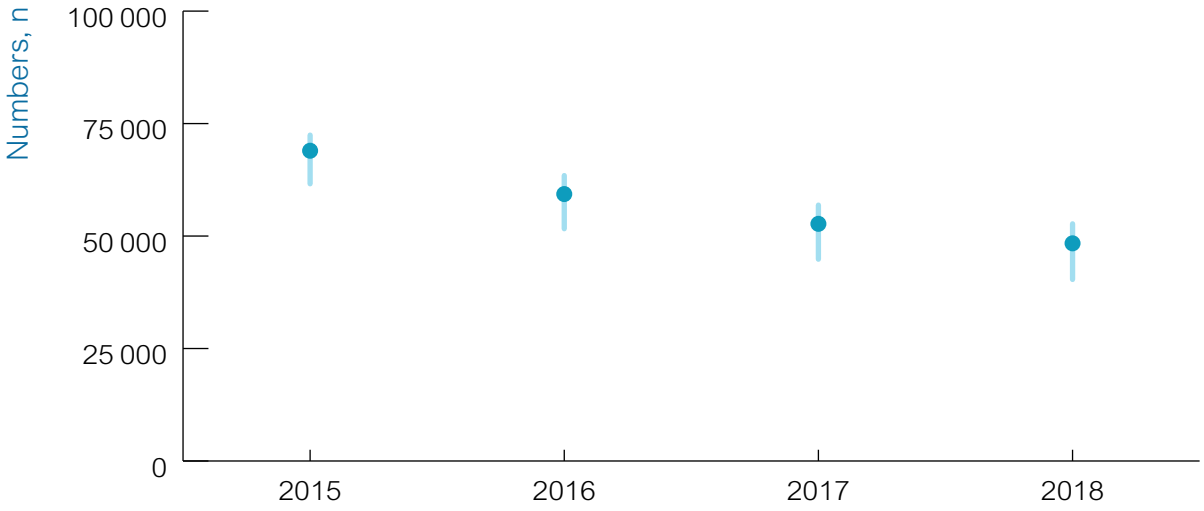
a. People living with current hepatitis C infection

Indicator definition

People living with current hepatitis C infection, adjusted for spontaneous hepatitis C clearance, mortality, hepatitis C cure through treatment, undiagnosed hepatitis C, and new hepatitis C infections

Results: In 2018, 48 381 people were estimated to be living with hepatitis C in NSW. Between 2015 and 2018, number of people living with hepatitis C decreased (68 963 and 48 381, respectively) (Figure 22).

Figure 22. People living with current hepatitis C infection in NSW, 2015–2018



Indicator Key

Study & Design: **Mathematical modelling**

3.2 Monitoring impact

3.2.1 Prevalence of current hepatitis C infection among high-risk populations

b.1 Hepatitis C RNA prevalence among people who inject drugs

Indicator definition

Numerator

ANSPS participants who had current hepatitis C infection

Denominator

ANSPS participants with hepatitis C RNA testing results

Results: In 2018, among 574 ANSPS participants in NSW, 373 had enough dried blood spot sample for hepatitis C RNA testing, of whom 19% (n=71) had current hepatitis C infection (i.e. hepatitis C RNA positive). Between 2015 and 2018, proportion of people with current hepatitis decreased (51% and 19%, respectively) (Figure 23).

In 2018, prevalence of current hepatitis C infection was 19% (50/270) among males and 20% (20/98) among females. Among people older than 45 years and younger (median age), prevalence was 18% (35/193) and 22% (39/180), respectively. Among non-Indigenous Australians and Aboriginal and Torres Strait Islander peoples, prevalence was 18% (53/299) and 24% (15/63), respectively. Among people who mainly injected opioids and stimulants in the month preceding the survey, prevalence was 21% (34/164) and 23% (31/135), respectively (Figure 24).

Figure 23. Prevalence of current hepatitis C infection among ANSPS participants in NSW, 2015–2018

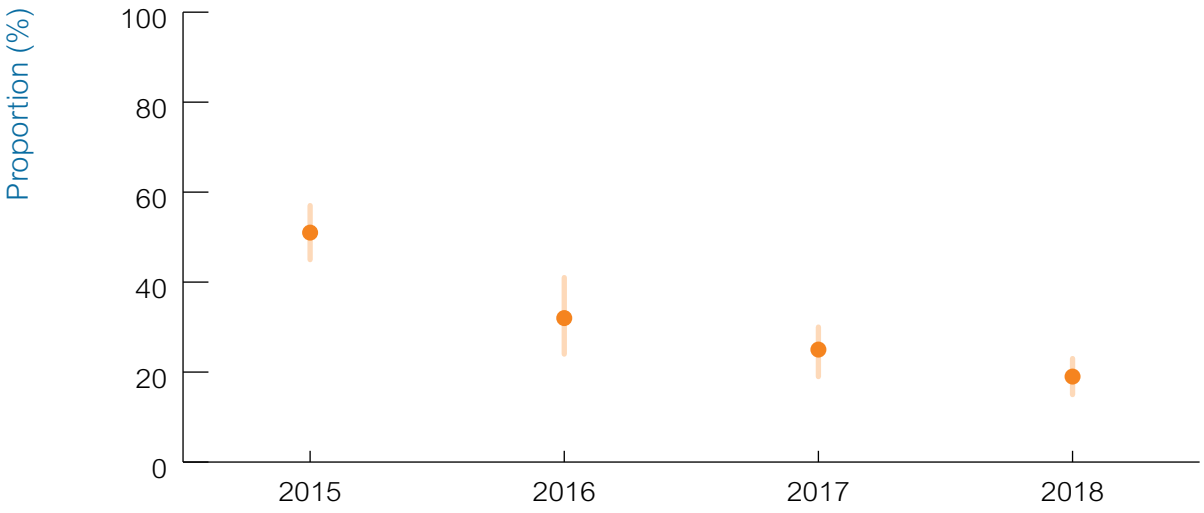


Figure 24. Prevalence of current hepatitis C infection among ANSPS participants in NSW, 2018, by sex, median age, Indigenous ethnicity, and last drug injected

Indicator Key

Study & Design: **ANSPS, annual survey**
Sample size in NSW in 2018: **574**
Number of sites in NSW in 2018: **19**

3.2 Monitoring impact

3.2.1 Prevalence of current hepatitis C infection among high-risk populations

b.2 Hepatitis C RNA prevalence among people who inject drugs

Indicator definition

Numerator

ETHOS Engage participants who had current hepatitis C infection

Denominator

ETHOS Engage participants with hepatitis C RNA testing results

Results: In 2018–2019, among 1051 ETHOS Engage participants, 975 had available point-of-care hepatitis C RNA testing results,* of whom 24% (n=233) had current hepatitis C infection (hepatitis C RNA positive).

In 2018–2019, prevalence of current hepatitis C infection was 23% (81/352) among females and 24% (150/620) among males. Among people younger and older than 45 years (median age), prevalence was 25% (129/515) and 23% (104/460), respectively. Among Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians, prevalence was 24% (62/257) and 24% (171/718), respectively. Among people who mainly injected stimulants and opioids in the month preceding the survey, prevalence was 27% (72/270) and 26% (72/273), respectively (Figure 25).

Figure 25. Prevalence of current hepatitis C infection among ETHOS Engage participants in NSW in 2018, by sex, median age, Indigenous ethnicity, and major drug injected

Indicator Key

Study & Design: **ETHOS Engage, observational cohort**
Sample size in NSW: **1051**
Number of sites in NSW: **17**

* Xpert HCV Viral Load Fingerstick Point-of-Care Assay were used for hepatitis C RNA testing.

3.2 Monitoring impact

3.2.1 Prevalence of current hepatitis C infection among high-risk populations

c. Hepatitis C RNA prevalence among people living with HIV

Indicator definition

Numerator

CEASE participants who had current hepatitis C infection

Denominator

All CEASE participants

Results: In the enrolment period July 2014-March 2017, among 339 CEASE participants, 336 had available data on hepatitis C RNA testing, of whom 74% (n=247) had current hepatitis C infection (i.e. hepatitis C RNA positive). During the follow-up period May 2017-May 2018, proportion of people with current hepatitis C infection decreased to 7% (17/241).

In 2018, prevalence of current hepatitis C infection was 7% (17/233) among males.* Among people older and younger than 51 years (median age), prevalence was 6% (7/128) and 9% (10/113), respectively.*

Indicator Key

Study & Design: **CEASE, observational cohort**
Sample size in NSW: **339**
Number of sites in NSW: **11**

* prevalence of current hepatitis C among females and people with recent injecting drug use is not displayed, due to small numbers.

3.2.2 Younger age (15–24 years) hepatitis C notifications

Background

Primary route of transmission of hepatitis C is sharing injecting equipment and injecting drug use typically starts in late adolescence or early adulthood. Numbers of newly diagnosed hepatitis C infections among individuals aged between 15 and 24 years is used as an indicator to monitor the impact of DAA scale-up on recent hepatitis C transmission. This indicator, however, is subject to the impact of change in hepatitis C testing practice. For example, since 2016, there has been a marked increase in hepatitis C testing in the Justice Health system.

Key Indicators

a.1 Younger age hepatitis C notifications, excluding Justice Health
a.2 Younger age hepatitis C notifications in Justice Health

3.2 Monitoring impact

3.2.2 Younger age (15–24 years) hepatitis C notifications

a.1 Younger age hepatitis C notifications, excluding Justice Health

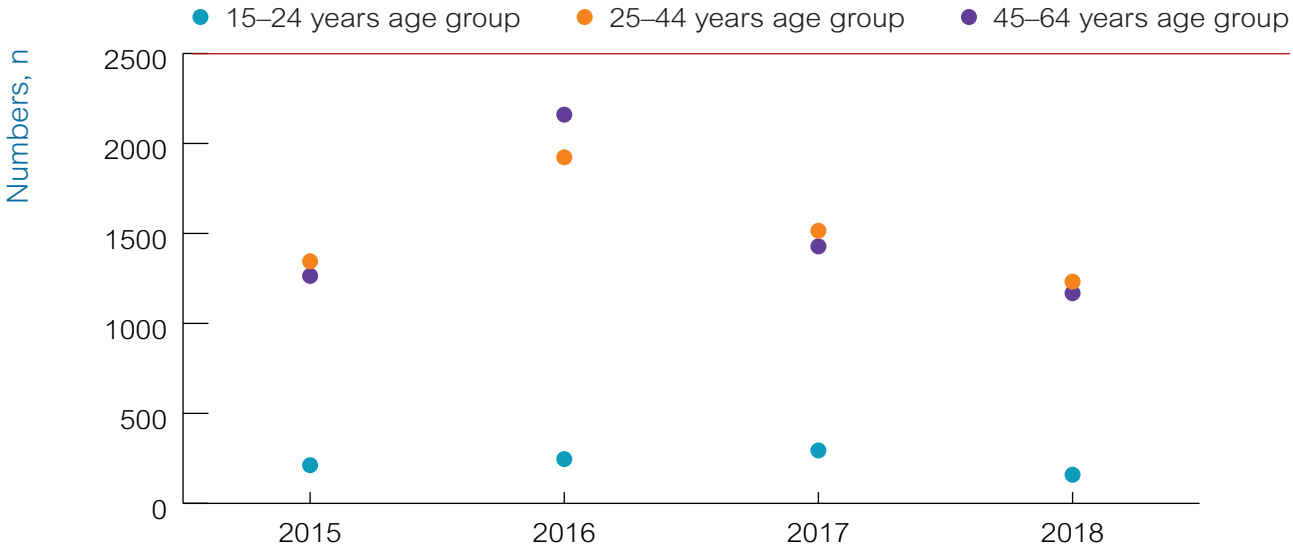
Indicator definition

Hepatitis C notifications among people aged 15–24 years, excluding Justice Health settings

Results: In 2018, excluding Justice Health, there were 159 notifications among people in the 15–24 years age group. Between 2015 and 2018, number of notifications excluding Justice Health in this age group decreased (212 and 159, respectively) (Figure 26).

Among males, in 2018, there were 96 notifications in the 15–24 years age group. Between 2015 and 2018, number of notifications among males in this age group declined (109 and 96, respectively). Among females, in 2018, there were 62 notifications in the 15–24 years age group. Between 2015 and 2018, number of notifications among females in this age group declined (103 and 62, respectively).

Figure 26. Hepatitis C notifications, excluding Justice Health, 2015–2018, by age group



Indicator Key

Study & Design: **NCIMS database, register of diagnoses of notifiable infectious diseases**

3.2 Monitoring impact

3.2.2 Younger age (15–24 years) hepatitis C notifications

a.2 Younger age hepatitis C notifications in Justice Health settings

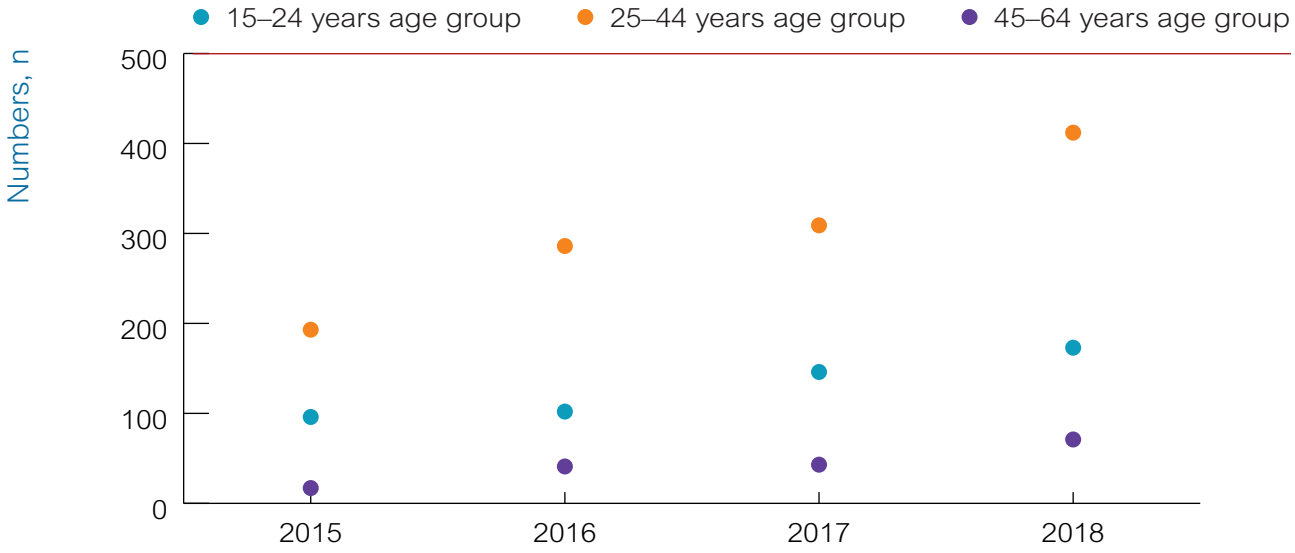
Indicator definition

Hepatitis C notifications among people aged 15–24 years in Justice Health settings

Results: In 2018, in Justice Health settings, there were 173 notifications among people in the 15–24 years age group. Between 2015 and 2018, number of notifications in this age group increased (96 and 173, respectively) (Figure 27).

Among males, in 2018, there were 159 notifications in the 15–24 years age group. Between 2015 and 2018, number of notifications among males in this age group increased (89 and 159, respectively). Among females, in 2018, there were 13 notifications in the 15–24 years age group. Between 2015 and 2018, number of notifications among females in this age group increased (7 and 13, respectively).

Figure 27. Hepatitis C notifications in Justice Health, 2015–2018, by age group



Indicator Key

Study & Design: **NCIMS database, register of diagnoses of notifiable infectious diseases**

3.2.3 Incidence of infection among high risk populations

Background

In the DAA era, higher numbers of people who are at risk of transmitting hepatitis C, are receiving treatment. Numbers of newly acquired hepatitis C infections among different populations is used to monitor the impact of DAA scale-up, including community-based cohorts, people who inject drugs who have been re-tested in the context of sentinel surveillance, and people who have received prior hepatitis C treatment.

Key Indicators

a Hepatitis C incidence among people who inject drugs
b. Hepatitis C reinfection incidence among people living with HIV

3.2 Monitoring impact

3.2.3 Incidence of hepatitis C infection among high risk populations

a. Hepatitis C incidence among people who inject drugs

Indicator definition

Numerator

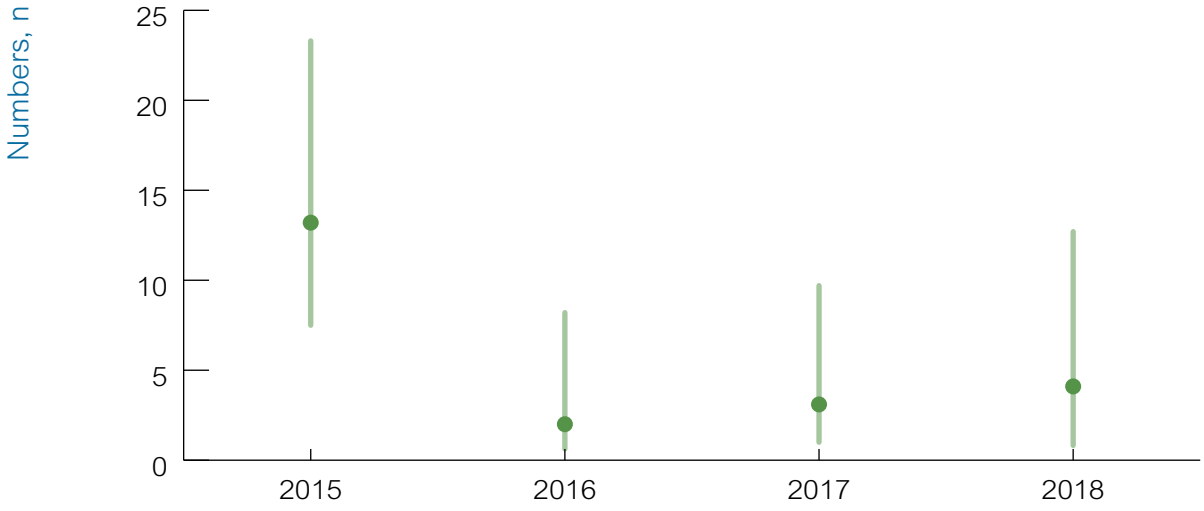
People attending KRC who had newly acquired hepatitis C infection

Denominator

People attending KRC who were hepatitis C antibody negative and retested

Results: In 2018, hepatitis C incidence was 4.1 per 100 person-years (3 cases in 73.3 person-years of follow-up, 95% CI 1.3, 12.7) among people who inject drugs attending KRC who were retested following a negative test for hepatitis C antibody.* Between 2015 and 2018, hepatitis C incidence among people who inject drugs decreased (13.2 per 100 person-years and 4.1 per 100 person-years, respectively) (Figure 28).

Figure 28. Hepatitis C incidence among people who inject drugs attending KRC, 2015–2018



Indicator Key

Study & Design: **KRC, primary care clinic in central Sydney**

* repeat hepatitis C antibody testing was carried out based on assessment of risk behaviour for hepatitis.

3.2 Monitoring impact

3.2.3 Incidence of hepatitis C reinfection among high risk populations

b. Hepatitis C reinfection incidence among people living with HIV

Indicator definition

Numerator

CEASE participants who had newly acquired hepatitis C infection after treatment-induced cure

Denominator

CEASE participants who were retested for hepatitis C after treatment-induced cure

Results: In 2016–2018, among 244 CEASE participants who received DAA treatment and were retested after treatment-induced cure,* hepatitis C incidence was 1.2 per 100 person-years (95% CI 0.4, 2.8).

Indicator Key

Study & Design: **CEASE, observational cohort**
Sample size in NSW: **339**
Number of sites in NSW: **11**

* repeat hepatitis C antibody testing varied across clinics; mostly, testing was carried out based on assessment of risk behaviour for hepatitis C.

3.2 Monitoring Impact;

3.2.4 Hepatitis C-related liver mortality

Background: In the era of interferon-based therapies, suboptimal treatment uptake and outcomes contributed to the rising liver disease burden of hepatitis C. Increased uptake of DAA treatment is expected to lower hepatitis C liver-related morbidity and mortality at the population level. Hepatitis C-related liver morbidity and mortality are used to monitor the impact of DAA treatment scale-up.

Key Indicators:

a. Hepatitis C-related decompensated cirrhosis diagnosis
b. Hepatitis C-related hepatocellular carcinoma diagnosis
c. Hepatitis C-related liver mortality

3.2 Monitoring impact

3.2.4 Morbidity and mortality

a. Hepatitis C-related decompensated cirrhosis diagnosis

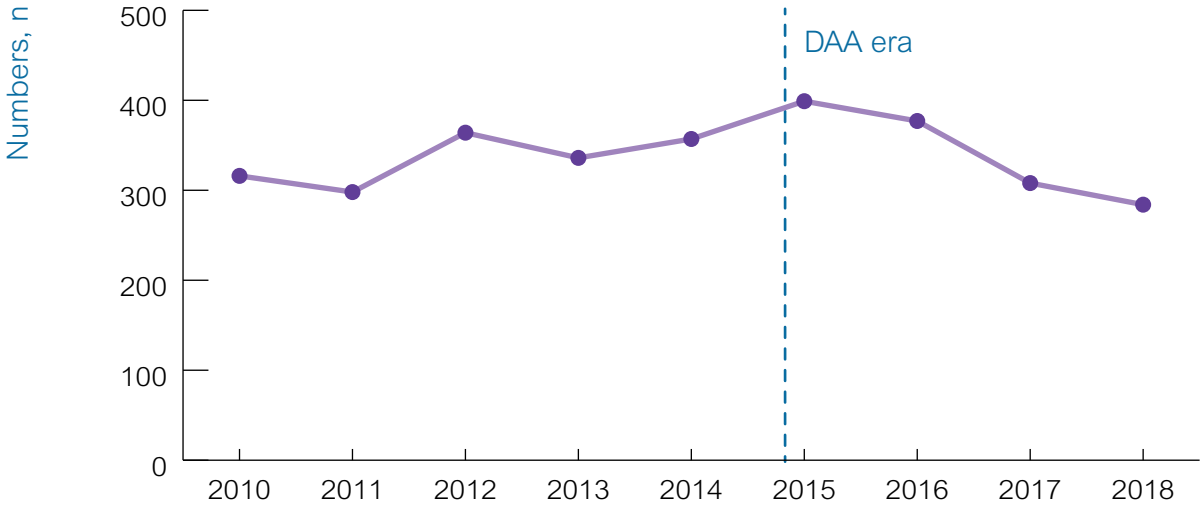
Indicator definition

Numerator

People with a hepatitis C notification who had a decompensated cirrhosis diagnosis

Results: In 2001–2018, 4850 people with a hepatitis C notification 1995–2017 had a decompensated cirrhosis diagnosis, characterised by a first-time hospital admission. Between 2015 and 2018, the number of people with a new decompensated cirrhosis diagnosis decreased (399 and 284, respectively) (Figure 29).

Figure 29. Decompensated cirrhosis diagnosis among people with a hepatitis C notification in NSW, 2010–2018



DAA era commences in late 2014 when compassionate access programs for patients with cirrhosis were initiated.

Indicator Key

Study & Design: **Population-level data linkage**
Sample size: **103 350 people with a hepatitis C notification 1995–2017**

3.2 Monitoring impact

3.2.4 Morbidity and mortality

b. Hepatitis C-related hepatocellular carcinoma diagnosis

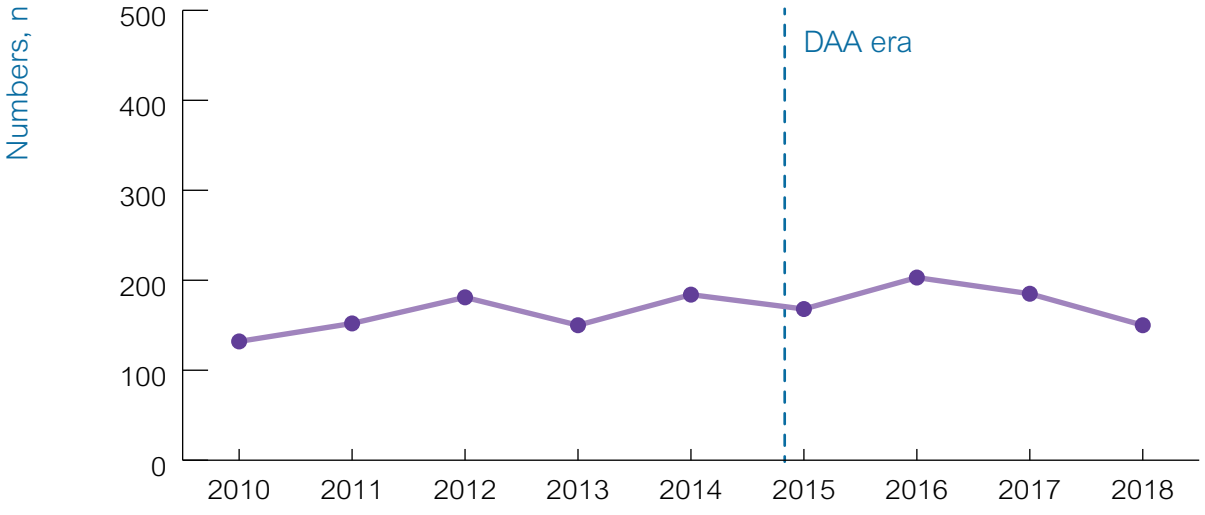
Indicator definition

Numerator

People with a hepatitis C notification who had a hepatocellular carcinoma diagnosis

Results: In 2001–2018, 1979 people with a hepatitis C notification 1995–2017 had a hepatocellular carcinoma diagnosis, characterised by a first-time hospital admission and/or diagnosis through cancer registry. Between 2015 and 2018, numbers of people with a hepatocellular carcinoma diagnosis decreased (168 and 150, respectively) (Figure 30).

Figure 30. Hepatocellular carcinoma diagnosis among people with a hepatitis C notification in NSW, 2010–2018



DAA era commences in late 2014 when compassionate access programs for patients with cirrhosis were initiated.

Indicator Key

Study & Design: **Population-level data linkage**
Sample size: **103 350 people with a hepatitis C notification 1995–2017**

3.2 Monitoring impact

3.2.4 Morbidity and mortality

c. Hepatitis C-related liver mortality

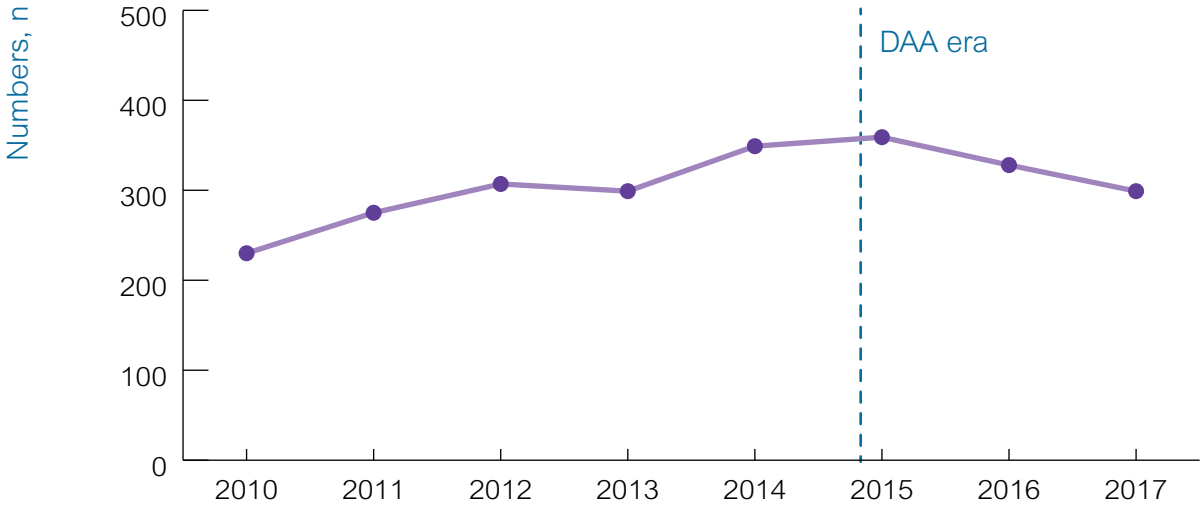
Indicator definition

Numerator

People with a hepatitis C notification who died due to liver-related causes

Results: In 2001–2018, 3854 people with a hepatitis C notification 1995–2017 had died due to liver-related causes, characterised by deaths following a decompensated cirrhosis and/or hepatocellular carcinoma diagnosis*. Between 2015 and 2017, numbers of people who died due to liver-related causes decreased (359 and 312, respectively) (Figure 31).

Figure 31. Liver-related mortality among people with a hepatitis C notification in NSW, 2010–2018



DAA era commences in late 2014 when compassionate access programs for patients with cirrhosis were initiated.

Indicator Key

Study & Design: **Population-level data linkage**

Sample size: **103 350 people with a hepatitis C notification 1995–2017**

* Decompensated cirrhosis diagnosis was defined by a first-time hospital admission and hepatocellular carcinoma was defined by a first-time hospital admission and/or diagnosis through cancer registry.

4. Discussion

The initial years of the DAA era in NSW have provided considerable impetus towards achievement of hepatitis C elimination goals of reducing hepatitis C incident infections and hepatitis C-related mortality. There are several areas that demonstrate highly encouraging service and impact outputs. Despite some concerns that the advent of highly curative DAA therapy would lead to increases in hepatitis C risk behaviour, available evidence indicates unchanged risk behaviour. Needle syringe coverage among people who inject drugs is high and the around one in five who report a recent sharing event has remained stable in recent years. Among people with hepatitis C/HIV co-infection, hepatitis C reinfection risk has been low during the DAA era.

Hepatitis C testing levels have remained high, supporting the high proportion of people living with infection that are diagnosed. There has also been enhanced efforts for screening within the Justice Health setting. Unrestricted access to DAA therapy has provided remarkably equitable uptake, with indications that higher-risk (generally more marginalised) populations in fact have had higher uptake than the broader hepatitis C population. More than one third of those with hepatitis C who would have been treatment eligible within the DAA era (i.e. were 18 years and older and had chronic infection) have been treated, but among those with evidence of recent drug dependence (recent injecting drug use or on opioid agonist therapy) one half or more have been treated. The strength of the evidence for the latter is that it comes from several different sources: 1) NSW data linkage between hepatitis C notifications, hospitalisations, opioid agonist therapy, and Pharmaceutical Benefits Scheme treatment; 2) two surveys conducted among people attending needle syringe services; and 3) a longitudinal cohort of people recruited largely through drug treatment services. Hepatitis C treatment uptake has been even higher among people with HIV co-infection, and DAA delivery has continued to increase within the prison setting. In terms of equity of treatment uptake, of particular note is the similar uptake among Indigenous and non-Indigenous populations.

There is early evidence that stable hepatitis C risk behaviour and high initial DAA uptake is leading to reductions in new hepatitis C infections. Younger age hepatitis C notifications (outside of Justice Health) are continuing to trend downwards, suggestive of reduced transmission. Enhanced screening within Justice Health may have masked even greater declines. There is clear evidence that advanced liver disease burden, which had been progressively rising in the pre-DAA era, is now in decline. Reductions in liver-related mortality are likely to be a combination of reduced cases of decompensated cirrhosis, a plateauing of hepatocellular carcinoma, and improved survival following both of these advanced liver disease complications.

Despite these encouraging findings, there are relative gaps for some hepatitis C sub-populations in service and impact measures. Stigma and discrimination levels would appear to remain incredibly high, although expanded data is required to further characterise this crucial strategic element of hepatitis C elimination. Treatment uptake is lower among females than males within several data sources. This disparity appears to be particularly evident in child-bearing aged females and requires further evaluation. Treatment uptake is also lower among people born overseas, a population that is generally not involved in the targeted programs within drug treatment and other harm reduction services. Although overall treatment uptake is similar in Indigenous and non-Indigenous populations, it is lower among Indigenous populations with recent drug dependence and recent incarceration. Despite slightly lower relative uptake among Indigenous people who are incarcerated, the disturbingly high rate of incarceration means that a much higher proportion of Indigenous people with hepatitis C have received their treatment within the prison setting.

This inaugural report does have some key limitations, and areas that can be enhanced or included within subsequent reports. There is no evaluation of either prevention or treatment service provision or their impacts by geographical area or local health district. This is clearly an area for focus in the next report. The report also does not include qualitative evaluation and has limited measures of stigma and discrimination. Finally, there is no incorporation of mathematical modelling to guide levels of prevention and treatment provision required over coming years to achieve hepatitis C elimination targets.

In conclusion, this report outlines considerable success in regard to implementation of strategies to achieve the New South Wales Government's goal of eliminating hepatitis C. The framework for evaluation has been established through a very active process led by the Kirby Institute – New South Wales Health Working Group that includes membership from many stakeholder groups and provides the foundation to provide policy direction over the coming years.

Methodological notes

NSW Health Needle and Syringe Program Minimum Data Set

Data from NSW Health Needle and Syringe Program Minimum Data Set was used to evaluate progress with one indicator; needle-syringe coverage.

Distribution of injecting units was evaluated among public outlets and individual pharmacies [8]. In 2018, the public NSW Needle and Syringe Program had 30 primary outlets, 316 secondary outlets, 178 automatic dispensing machines and 77 internal dispensing chutes.

Australian Needle and Syringe Program Survey (ANSPS)

Data from NSW sites of ANSPS (n=19; 574 participants) was used to evaluate progress with four indicators, including opioid agonist therapy coverage; people living with current hepatitis C who have been diagnosed; hepatitis C treatment uptake; and prevalence of current hepatitis C infection.

ANSPS participants include people attending Needle Syringe Programs, who may not represent the broader population of people who inject drugs in NSW, including those who are less engaged with healthcare. In 2015, the ANSPS commenced hepatitis C RNA testing, in addition to antibody testing. Methods for detection of hepatitis C antibody and RNA have been described in detail elsewhere [9]. Since 2015, only a sub-sample of participants have had enough dried blood spot samples for RNA testing. Weightings were applied to account for potential sample bias among participants eligible for RNA testing with respect to sex (given higher rates of spontaneous clearance among women) and hepatitis C antibody status. Number of participants who self-reported hepatitis C testing and hepatitis C treatment uptake in the past 12 months may be overestimated, due to recall bias.

Control and Elimination within AuStralia of Hepatitis C from people living with HIV (CEASE)

Enrolment and follow-up data from NSW sites of CEASE (n=11; 339 participants) was used to evaluate progress with three indicators, including hepatitis C treatment uptake; prevalence of current hepatitis C infection; and incidence of hepatitis C reinfection.

The CEASE cohort may not represent the broader population of people with hepatitis C/HIV co-infection in NSW. CEASE was designed to include HIV antibody and hepatitis C antibody positive individuals, to reduce bias towards enrolling participants only if they were interested in hepatitis C treatment and to ensure follow-up for evaluation of hepatitis C reinfection is among all at-risk individuals. However, it is possible that the study population comprised a higher number of people who were more likely to initiate treatment. Further, CEASE study sites included high caseload services in urban centres, limiting generalisability of findings among clinical practices outside urban areas or among individuals who are less engaged with healthcare systems.

ETHOS Engage: Enhancing Treatment of Hepatitis C in Opioid Substitution Settings

Enrolment data from NSW sites of ETHOS Engage (n=17; 1015 participants) was used to evaluate progress with three indicators, including people living with current hepatitis C who have been diagnosed; hepatitis C treatment uptake; and prevalence of current hepatitis C infection.

ETHOS Engage cohort may not represent the broader population of people who inject drugs in NSW, including those who are less engaged with healthcare. Number of participants who self-reported hepatitis C testing and hepatitis C treatment uptake in the past 12 months may be overestimated, due to recall bias.

The Kirketon Road Centre (KRC)

Data from KRC was used to evaluate progress with one indicator; incidence of hepatitis C infection.

Hepatitis C incidence rates through KRC should be interpreted with caution, given relatively low numbers of people who inject drugs attending KRC. Further, these data do not reflect hepatitis C diagnoses elsewhere.

Mathematical modelling

Mathematical modelling was used to evaluate progress with one indicator; chronic hepatitis C infection.

The national number of people living with current hepatitis C who are previously diagnosed were derived from totalling all hepatitis C notifications from 1991 to 2018, adjusted for duplicate notifications, spontaneous clearance, mortality, migration, and treatment uptake and cure numbers. Following data sources and assumptions were used:

- The model used annual notifications from the National Notifiable Diseases Surveillance System and a 10% sample of treatment uptake numbers, by Pharmaceutical Benefits Scheme [10]
- The proportion who spontaneously cleared hepatitis C was estimated at 28% [11]
- Recent data linkage studies in NSW and Victoria estimated 7% to 11% of hepatitis C notifications are duplicates; 9% (range: 7–11%) of all notifications were assumed to be duplicates nationally (expert opinion)
- The annual proportion of people living with hepatitis C who die each year (all-cause) was estimated using data from the NSW linkage study over 1993–2013 [12]
- The estimated number of individuals cured of hepatitis C was estimated using available clinical data. A 95% sustained virological response rate (range: 90–97%) for therapies in F0–F3 fibrosis stages and a 90% rate were used for people in the F4 fibrosis stage (cirrhosis), with decompensated cirrhosis, and with hepatocellular carcinoma [13-16]
- A small amount of emigration was assumed, similar to the rate of permanent departure for the general population (ABS series 340102) [17]

Number of people living with current hepatitis C in NSW was evaluated by multiplying the national estimates and the proportion of cumulative hepatitis C notifications from 1995 to 2018 in NSW (estimates to be 36.5% of the national number) [18]. Previous studies have validated the model's demographic, epidemiological, and clinical outputs for the Australia population. This model also provides annual hepatitis C estimates for the HIV, Viral Hepatitis and Sexually Transmitted Infections in Australia [19, 20].

NSW data linkage

NSW data linkage (n=92 807 people) was used to evaluate progress with two indicators, including hepatitis C treatment uptake and deaths attributable to hepatitis C infection.

Hepatitis C notifications in NSW are largely laboratory-based following anti-hepatitis C antibody diagnosis. To estimate the number of people with chronic hepatitis C, weightings were applied to account for sex-specific spontaneous clearance (higher rates among women). International Classification of Diseases, 10th revision was used for characterisation of key populations, including people with evidence of recent drug dependence and those with an advanced liver disease diagnosis, predisposing these definitions to misclassification bias. From late 2014 (prior to The Australian Government-funded DAA program launch in March 2016), access to DAAs was provided through pharmaceutical company compassionate access programs, clinical trials, and generic importation [10]. Data on treatment uptake through compassionate access is not collected by the Pharmaceutical Benefits Scheme; therefore, DAA uptake among people with advanced liver disease is underestimated in this report. Data on decompensated cirrhosis and hepatocellular carcinoma diagnosis and liver-related mortality were available until mid-2018; event numbers in 2018 were doubled for inclusion in liver-related mortality indicators.

NSW Notifiable Conditions Information Management System (NCIMS)

Data from NCIMS was used to evaluate progress with one indicator; incidence of hepatitis C infection.

Hepatitis C notifications through NCIMS may not reflect the true incidence and prevalence of hepatitis C in Australia, as a proportion of persons with hepatitis C remains undiagnosed. In addition, it should be noted that time and place of notification is not equivalent to time and place of disease acquisition.

NSW NSP Enhanced Data Collection (NNEDC)

Data from NNEDC (n=50 sites; 3264 participants) was used to evaluate progress with two indicators, including receptive syringe sharing and hepatitis C treatment uptake among people who inject drugs.

NNEDC participants include people attending Needle Syringe Programs, who may not represent the broader population of people who inject drugs in NSW, including those who are less engaged with healthcare. Receptive needle/syringe sharing is a highly stigmatised behaviour and might have been underreported, due to social desirability bias.

Stigma Indicators Monitoring Project

Data from 2018 surveys among people who inject drugs and people living with hepatitis C in NSW were used to evaluate progress with one indicator; experience of stigma and discrimination within the past 12 months.

Development of stigma indicators for bloodborne viruses and sexually transmissible infections has been described in detail elsewhere [21]. Indicators described in this report are broad in wording and scope, in order to capture all stigmatising experiences. However, using simplified indicators may limit our understanding of the more complex aspects of experiencing stigma.

Real-world efficacy of antiviral therapy in chronic hepatitis C (REACH-C)

Data from NSW sites of REACH-C (n=18, 3068 participants) was used to evaluate progress with one indicator; hepatitis C treatment uptake.

The REACH-C cohort is generally representative of the overall Australian population treated with DAAs through the Pharmaceutical Benefits scheme. Data collection for the REACH-C study is ongoing a proportion of missing data may be retrievable from clinics in the future.

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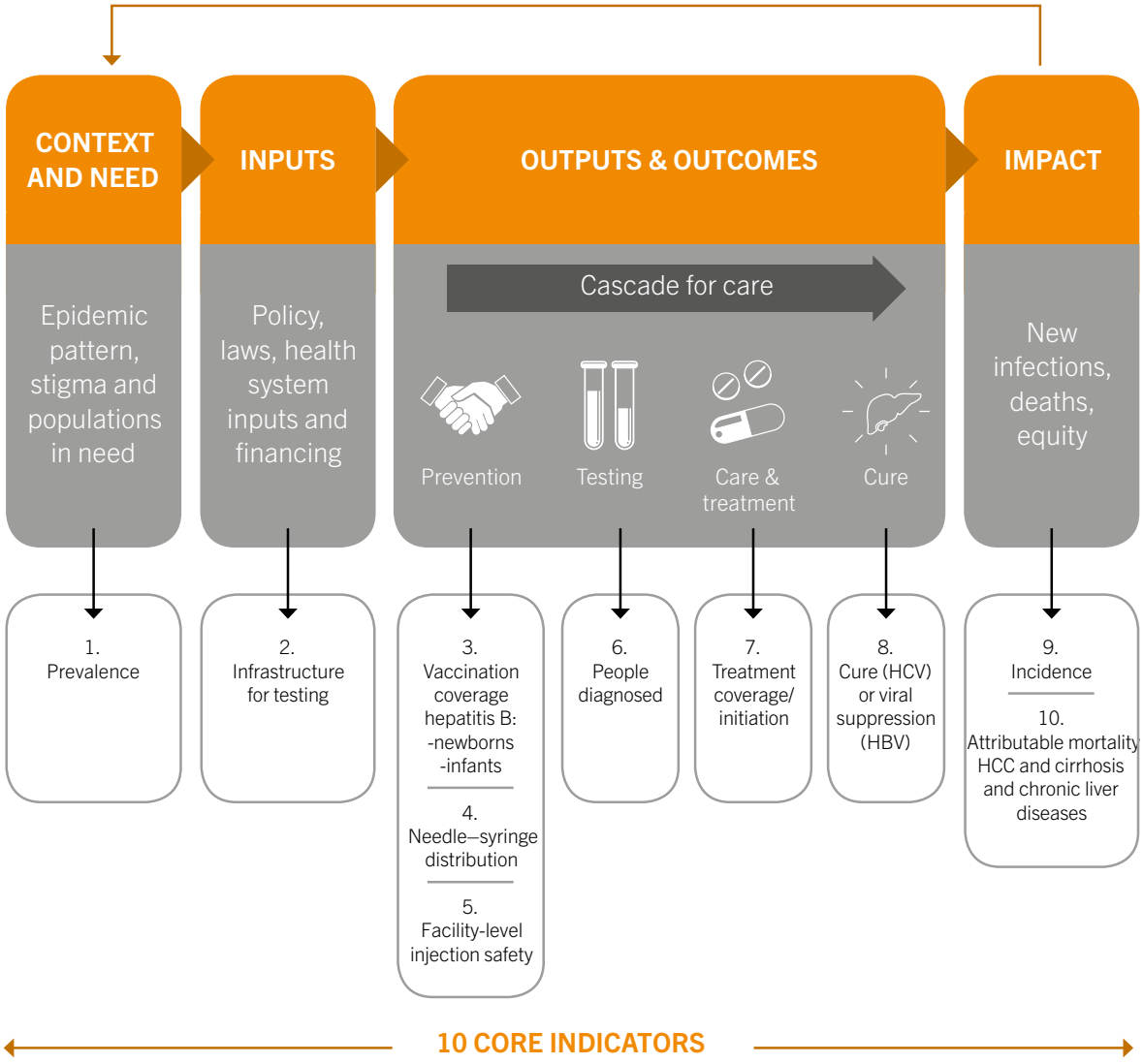
Appendix A

Figure A1. Monitoring and evaluation framework: minimum set of 10 core indicators to monitor and evaluate the health sector response to viral hepatitis B and C along the result chain in countries



Reprinted from "Monitoring and evaluation for viral hepatitis B and C: recommended indicators and framework, page 9. World Health Organization 2016" [7]

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