

Using data linkage to better understand progress toward hepatitis elimination targets

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Acknowledgements

- Acknowledgement of Country
- Funding support from Royal Melbourne Hospital, Victorian Cancer Agency
- Our data linkage work is conducted in partnership with the Victorian Government Department of Health
- Project collaborators (Benjamin Cowie, Stacey Rowe, Nicole Allard) and team (Kathryn Snow, Chelsea Brown, George Mnatzaganian, Nicole Romero, Anna Deng)
- Work conducted by other research groups

Overview

- Overview of key indicators for evaluation of achieving targets
- Key global and Australian targets
- How data linkage can be used to monitor epidemiology, burden, and uptake
- Future data linkage for better surveillance of elimination progress
- Summary

The goal

GLOBAL VISION

A world where viral hepatitis transmission is halted and everyone living with viral hepatitis has access to safe, affordable and effective prevention, care and treatment services.

Key indicators

Service indicators



Treatment



*Care and
monitoring*

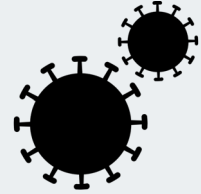


Immunisation



Diagnosis

Impact indicators







Reduce new infections

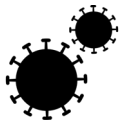




Reduce adverse outcomes

Key targets - service

	Measure/s	National target, 2022	Global target, 2030
 <i>Hepatitis B immunisation</i>	Infant coverage Birth dose coverage	95% -	90%
 <i>Diagnosis</i>	Proportion diagnosed HCV Proportion diagnosed HBV	90% 80%	90%
 <i>Care and monitoring</i>	Proportion in care HBV	50%	-
 <i>Treatment</i>	Proportion receiving treatment HBV Proportion cured HCV	20% 65%	80%

Key targets - impact

	Measure/s	National target, 2022	Global target, 2030
 <i>Incidence</i>	New cases of chronic infection B/C Newly acquired infection B/C	- 50% / 60%	90% -
 <i>Mortality</i>	Reduction in mortality hepatitis B Reduction in mortality hepatitis C	30% 65%	65%
 <i>Stigma</i>	Reported experience of stigma		-

Data linkage – overview

“The bringing together from two or more different sources, data that relate to the same individual, family, place or event”

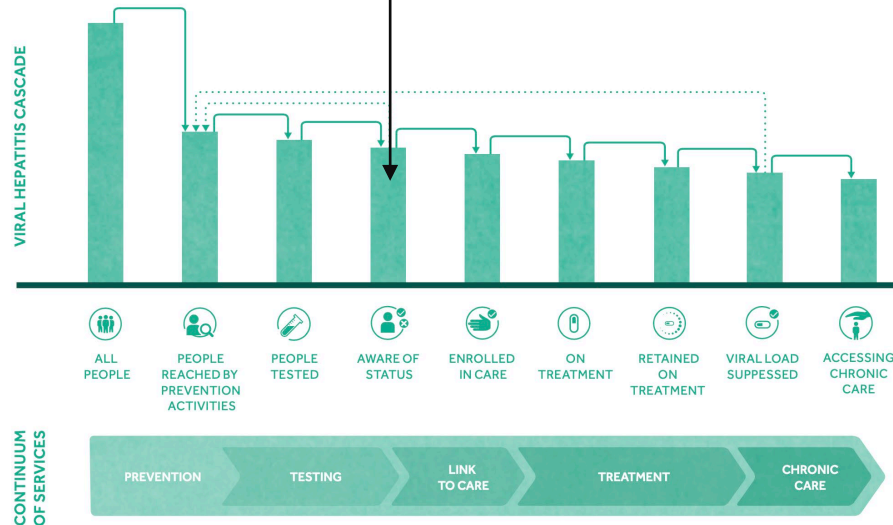
- Combining separately held datasets to increase the utility of each one
- Validation of accuracy of routinely collected datasets
- Provide a more complete picture of a person’s healthcare journey and the impacts of viral hepatitis on outcomes

Data linkage – sources

DIAGNOSIS

Positive test notified to health department
Notifiable diseases datasets

Figure 5. The continuum of viral hepatitis services and the retention cascade



Data linkage – sources

DIAGNOSIS

Positive test notified to health department

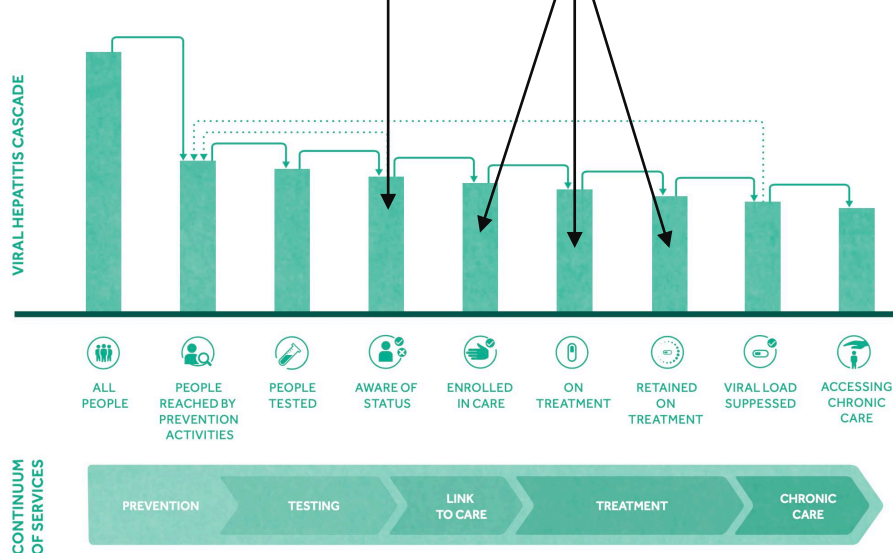
Notifiable diseases datasets

ENROLLED IN CARE / TREATMENT

Received subsidised items (testing, imaging, appointments, treatments)

Medicare (MBS and PBS)

Figure 5. The continuum of viral hepatitis services and the retention cascade



Data linkage – sources

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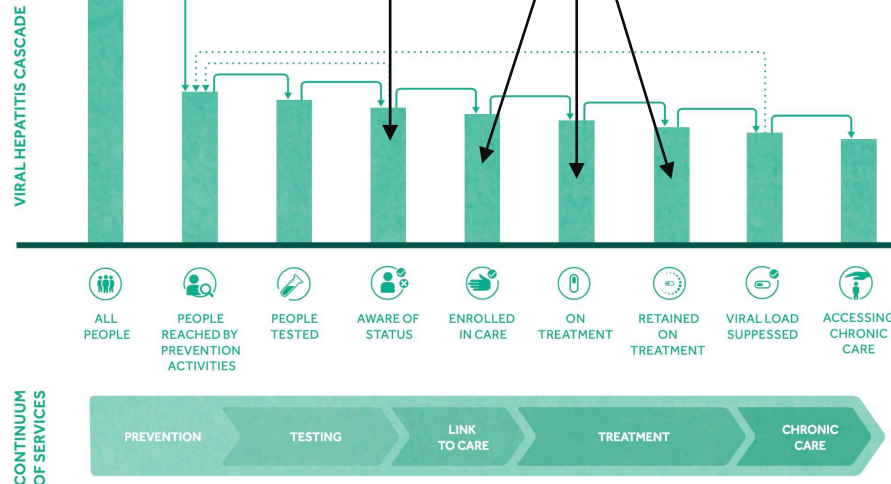
PRIORITY POPULATIONS

Receiving OAT
OAT registries

Born overseas, Aboriginal and/or Torres Strait Islander
Hospital presentations / admissions

History of incarceration
Corrections

Figure 5. The continuum of viral hepatitis services and the retention cascade



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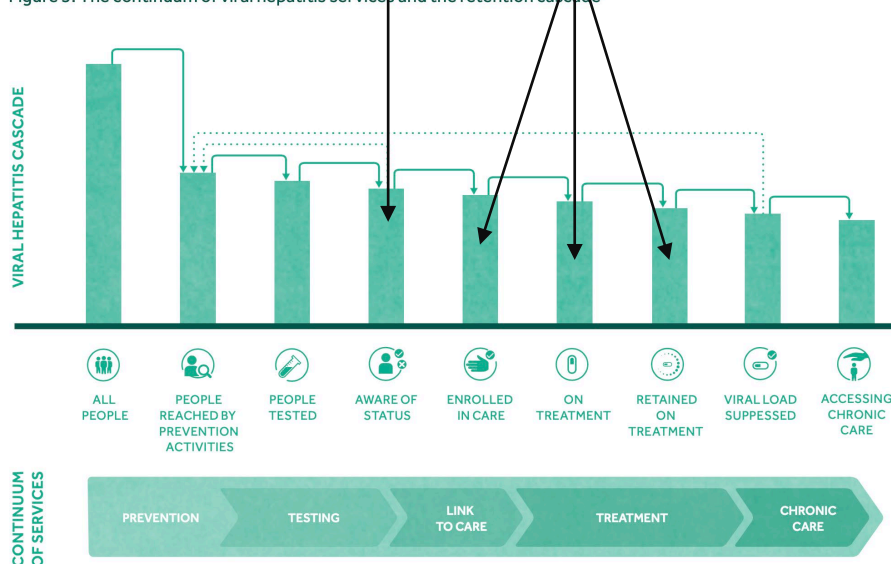
ADVERSE OUTCOMES

Diagnosed with liver cancer
Cancer registry

Hospitalised with complications
Hospital presentations / admissions

Died
Death registry

Figure 5. The continuum of viral hepatitis services and the retention cascade



Data linkage – sources

Overseen by human
research ethics
(national and local)

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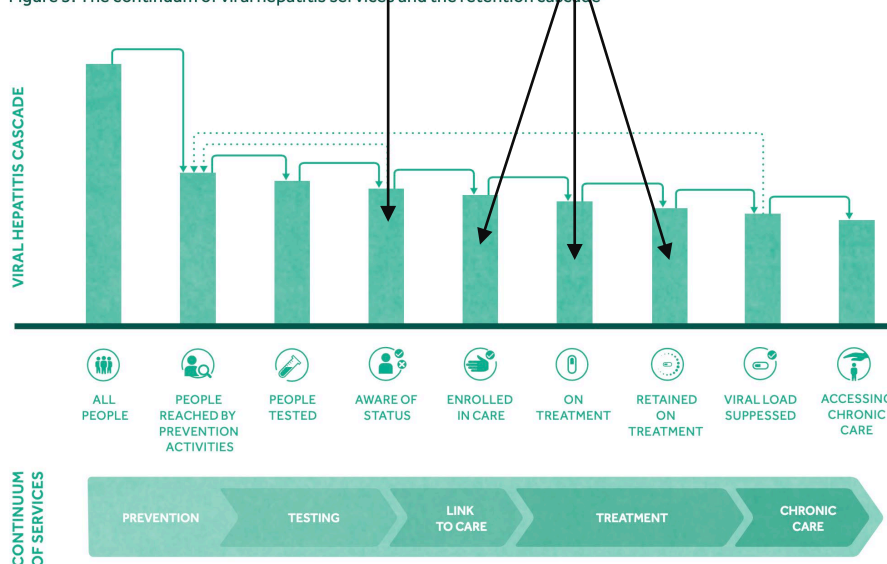
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Death registry

Figure 5. The continuum of viral hepatitis services and the retention cascade



Data linkage – what can it tell us?

- Establish burden attributable to viral hepatitis and disparities according to priority population
- Validation of modelling and other methodologies
- Tracking individual-level cascades of care and trends over time
- Identification of missed opportunities
- Measure impacts on attributable morbidity and mortality

Establishing burden and disparities

- Linkage of notified cases of hepatitis B and C to cancer registry and death records in NSW

Cancer incidence in people with hepatitis B or C infection: A large community-based linkage study

Janaki Amin^{1,*}, Gregory J. Dore¹, Dianne L. O'Connell², Mark Bartlett³,
Elizabeth Tracey⁴, John M. Kaldor¹, Matthew G. Law¹
Journal of Hepatology 45 (2006) 197–203

Causes of death after diagnosis of hepatitis B or hepatitis C infection: a large community-based linkage study

Janaki Amin, Matthew G Law, Mark Bartlett, John M Kaldor, Gregory J Dore

Lancet 2006; 368: 938–45

- Demonstrating people with hepatitis B and C have substantially higher risks of liver-related death and liver cancer

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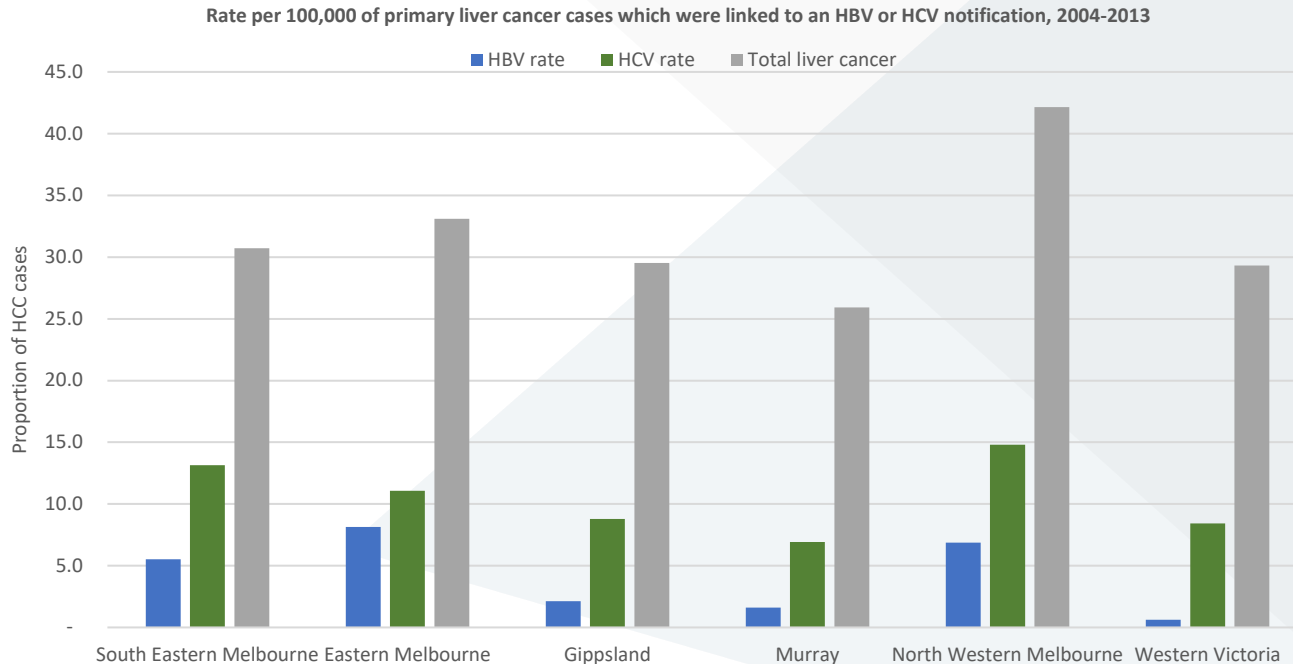
- Demonstrating people with hepatitis B and C have substantially higher risks of liver-related death and liver cancer

Table 1: Region of birth* for hepatocellular carcinomas (ICD 22.0) reported to the NSW Central Cancer Registry and by hepatitis linkage status, 1990–2002.

	n=2072	All HCC Crude rate/ 100,000	RR	95% CI	HBV n=323	%	HCV n=267	%	HBV+HCV n=18	%	Unlinked n=1,464	%
Australia	983	1.61	1.00		20	6.2	62	23.2	3	16.7	898	61.3
Other Oceania	40	2.09	1.30	0.95–1.78	15	4.6	2	0.7	1	5.6	22	1.5
New Zealand	15	1.15	0.71	0.43–1.19	2	0.6	2	0.7	1	5.6	10	0.7
Europe	407	4.37	2.72	2.42–3.05	43	13.3	85	31.8	4	22.2	275	18.8
Italy	104	11.19	6.96	5.69–8.52	14	4.3	30	11.2	2	11.1	58	4.0
United Kingdom	101	2.43	1.51	1.23–1.85	1	0.3	13	4.9	–	–	87	5.9
Former Yugoslavia	35	3.89	2.42	1.73–3.39	9	2.8	7	2.6	–	–	19	1.3
Greece	33	5.56	3.46	2.45–4.89	6	1.9	4	1.5	–	–	23	1.6
Germany	16	3.48	2.17	1.32–3.55	1	0.3	3	1.1	–	–	12	0.8
Hungary	13	9.48	5.90	3.41–10.19	2	0.6	6	2.2	–	–	5	0.3
Romania	11	21.86	13.60	7.51–24.64	1	0.3	4	1.5	1	5.6	5	0.3
Poland	10	3.83	2.38	1.28–4.44	1	0.3	3	1.1	–	–	6	0.4
Middle East/Nth Africa	50	2.87	1.78	1.34–2.37	7	2.2	10	3.7	–	–	33	2.3
Egypt	30	11.87	7.38	5.13–10.62	2	0.6	9	3.4	–	–	19	1.3
Lebanon	10	1.31	0.81	0.44–1.52	4	1.2	1	0.4	–	–	5	0.3
Asia	518	9.93	6.18	5.55–6.87	222	68.7	95	35.6	8	44.4	193	13.2
Vietnam	151	18.61	11.58	9.75–13.74	59	18.3	41	15.4	4	22.2	47	3.2
China and Taiwan	161	16.01	9.96	8.43–11.76	81	25.1	19	7.1	–	–	61	4.2
Korea	36	11.63	7.24	5.19–10.09	18	5.6	6	2.2	–	–	12	0.8
Hong Kong	26	4.93	3.07	2.08–4.53	17	5.3	–	–	–	–	9	0.6
Indonesia	25	9.93	6.17	4.15–9.18	3	0.9	10	3.7	–	–	12	0.8
Cambodia	20	15.63	9.72	6.25–15.14	10	3.1	2	0.7	1	5.6	7	0.5
Philippines	19	2.92	1.82	1.15–2.86	4	1.2	5	1.9	1	5.6	9	0.6
India	15	3.65	2.27	1.36–3.78	5	1.5	3	1.1	–	–	7	0.5
Malaysia	14	4.69	2.92	1.72–4.94	11	3.4	6	2.2	–	–	3	0.2
Sri Lanka	10	5.02	3.12	1.68–5.82	–	–	–	–	–	–	10	0.7
Thailand	10	9.16	5.70	3.06–10.62	7	2.2	1	0.4	1	5.6	1	0.1
Americas	15	1.58	0.98	0.59–1.64	1	0.3	2	0.7	–	–	12	0.8
Other Africa	9	1.68	1.05	0.54–2.02	1	0.3	1	0.4	–	–	7	0.5

Establishing burden and disparities

- Linkage of notified cases of hepatitis B and C to cancer registry and death records in VIC
- Burden of attributable liver cancer not evenly distributed according to region

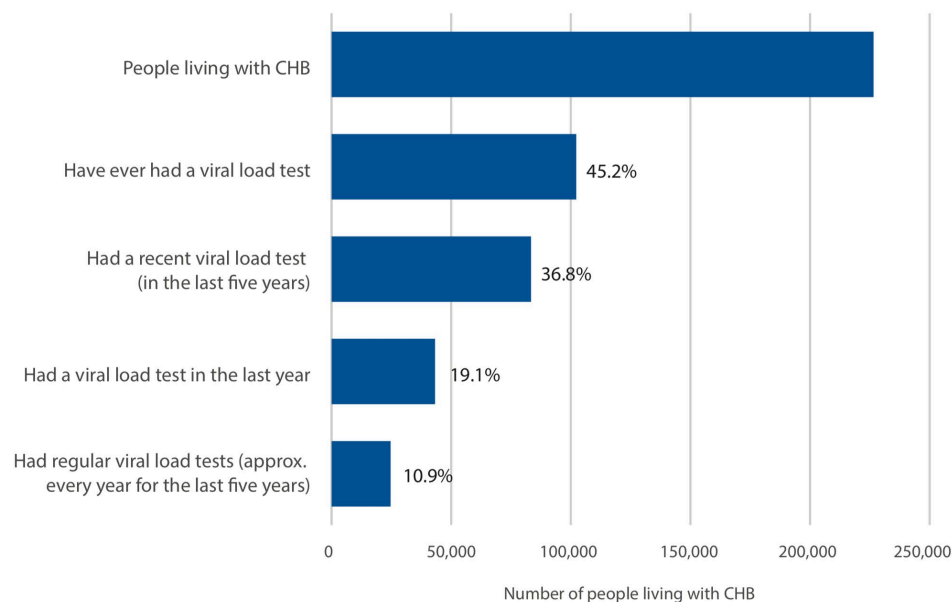


Cascades of care and trends

- Internal linkage of MBS and PBS data, and unique identifiers for individuals

TARGET:
Increase
hepatitis
B care

Figure A.2: CHB monitoring in Australia, 2018

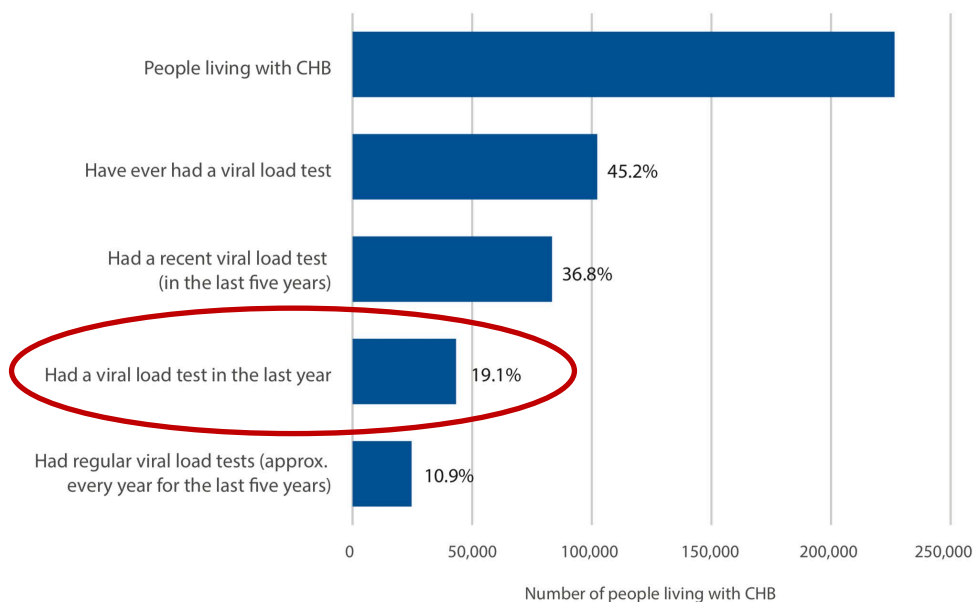


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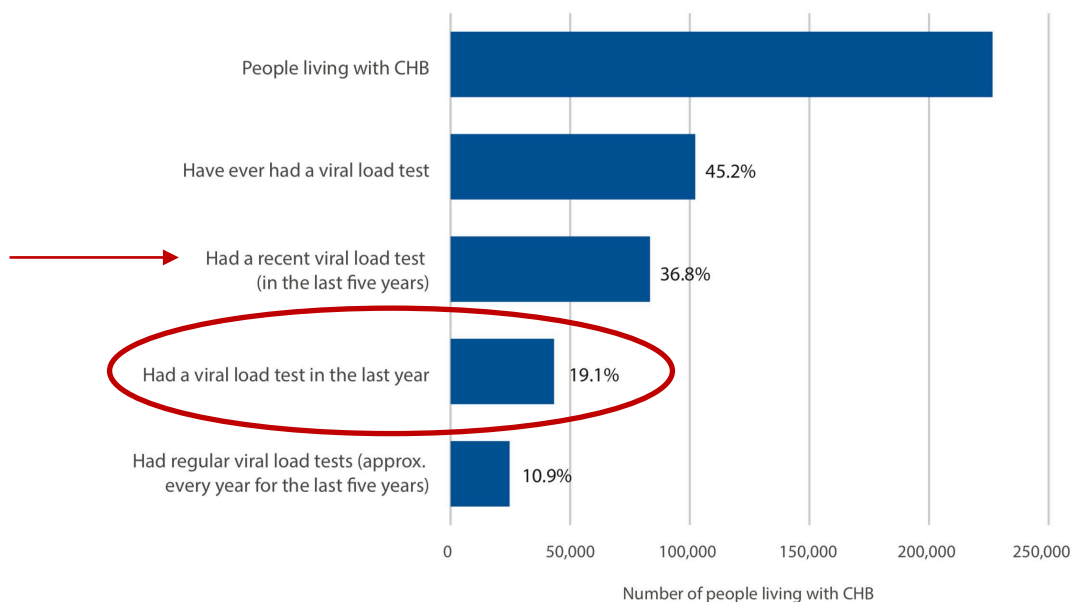


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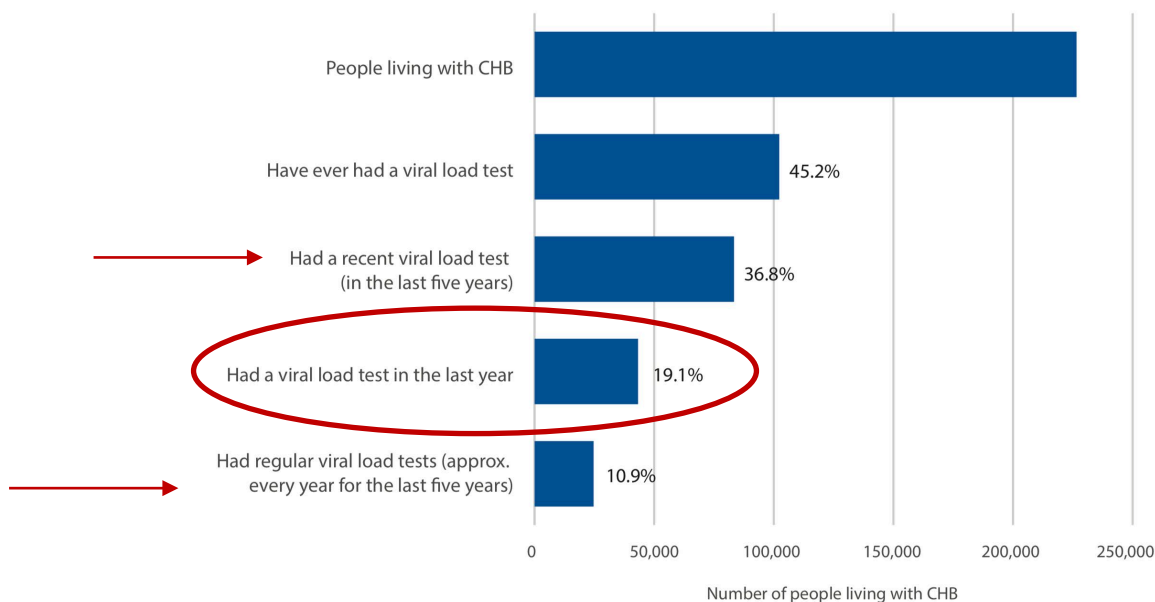


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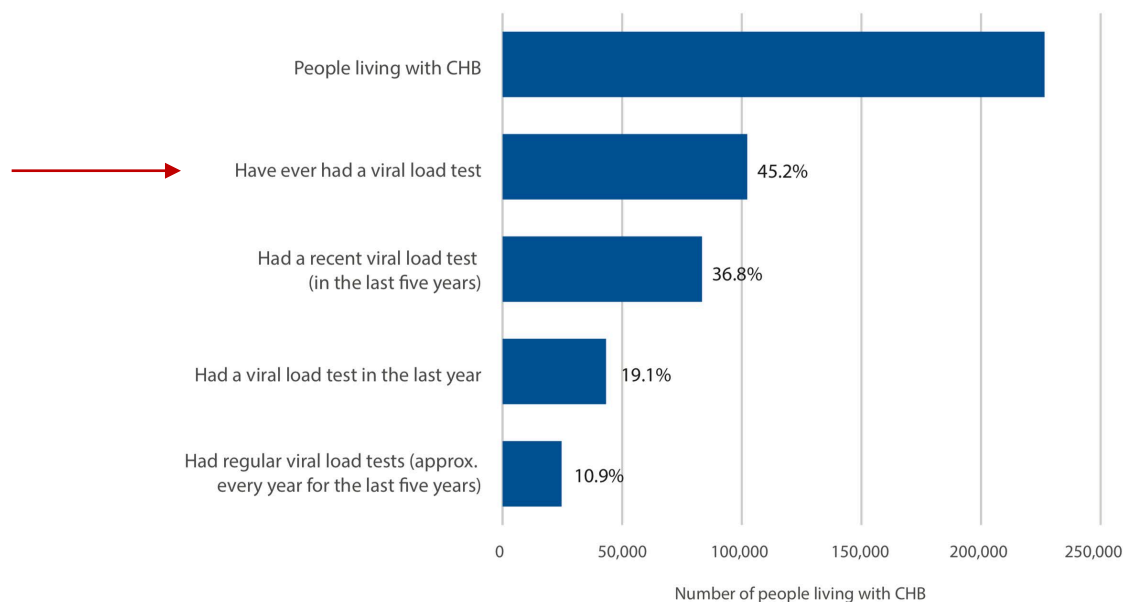


Cascades of care and trends

- Linkage of notifications with MBS and PBS, deaths

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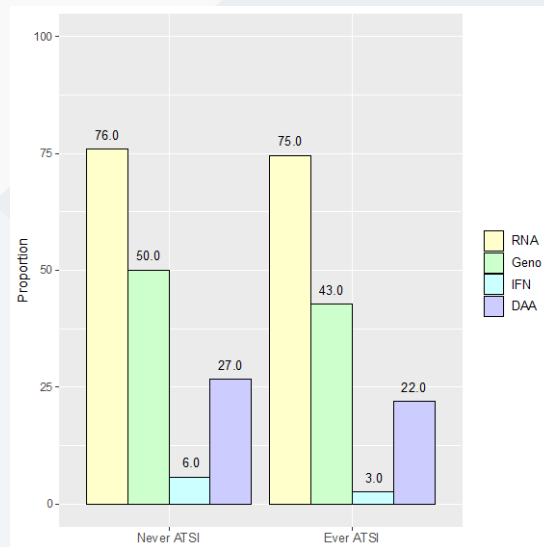
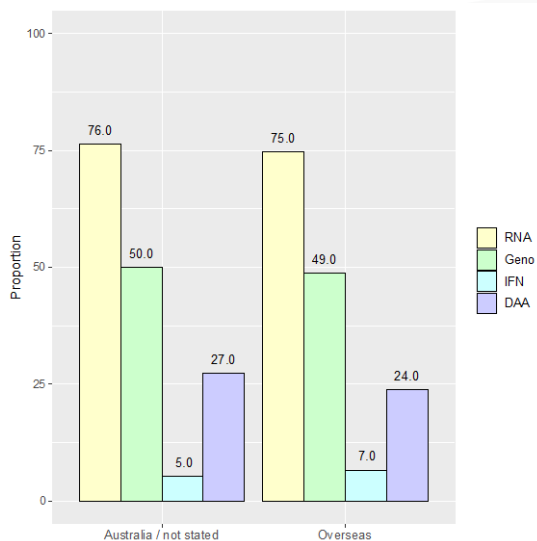
Figure A.2: CHB monitoring in Australia, 2018



Cascades of care and trends

- Linkage of notifications with MBS and PBS, deaths
- Priority gaps in cascade; variations according to priority populations

TARGET:
Increase
hepatitis
C
treatment



*Doherty Institute /
DH Victoria
Linkage project*

Missed opportunities for care

- Among people diagnosed with viral hepatitis too late to intervene (<2 years prior to a liver cancer or death), most had health care

Missed opportunity	HBV late diagnosis	%	HCV late diagnosis	%
<i>GP consultations</i>	142	88%	302	95%
<i>Specialist consultations</i>	100	62%	185	58%
<i>Blood draws</i>	114	70%	233	73%
<i>ED presentations</i>	85	52%	216	68%
<i>Hospital admissions</i>	95	59%	208	65%
<i>Any missed opportunity</i>	146	90%	306	96%

TARGET:
Increase
hepatitis C
treatment,
Increase
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care

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HBV

Missed opportunity	Mean	Median	IQR	Range
GP consultations	54.63	33	14-82	1-321
Specialist consultations	14.15	6	2-19.5	1-80
Blood draws	11.85	6	3-14	1-103
ED presentations	5.18	3	1-5	1-107
Hospital admissions	6.82	3	2-7	1-97

HCV

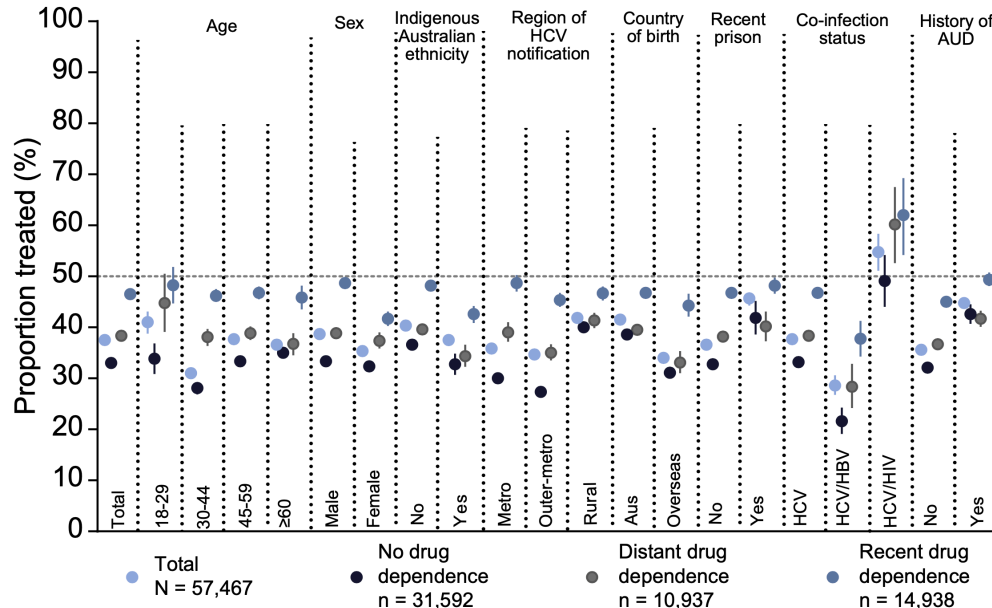
Missed opportunity	Mean	Median	IQR	Range
GP consultations	51.88	33	14-67	1-585
Specialist consultations	9.68	4	1-11	1-169
Blood draws	9.53	4	2-10	1-214
ED presentations	7.03	3	1-6	1-318
Hospital admissions	12.68	3	1-6	1-1212

Doherty Institute /
DH Victoria
Linkage project

Focus on priority populations

- Linkage of notifications with hospital admissions, deaths, incarceration, HIV notifications, PBS, and OAT authority data

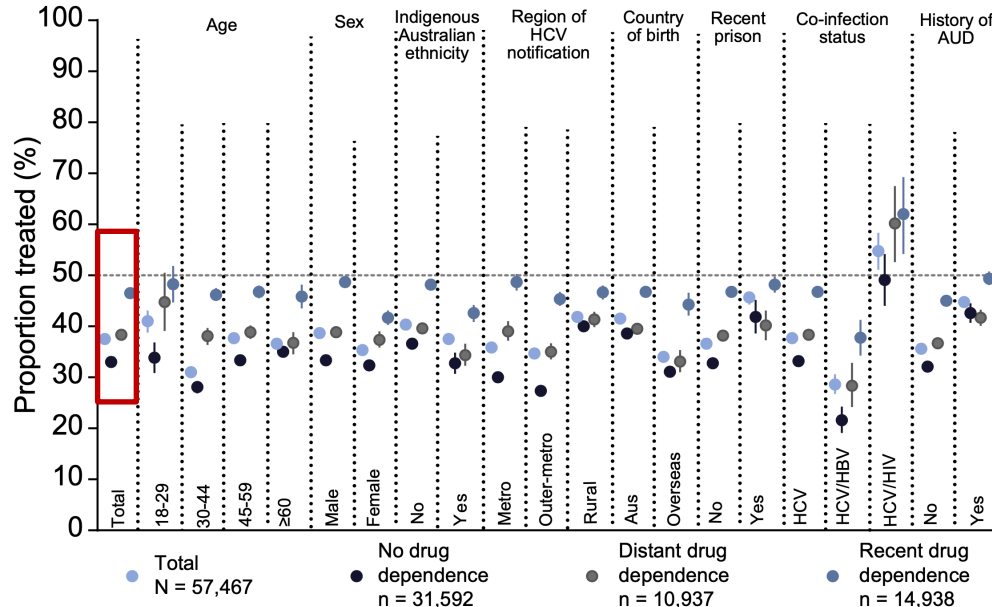
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Reductions in attributable mortality

- Linkage of notifications with hospital admissions and deaths

TARGET:
Reduce mortality attributable to hepatitis C

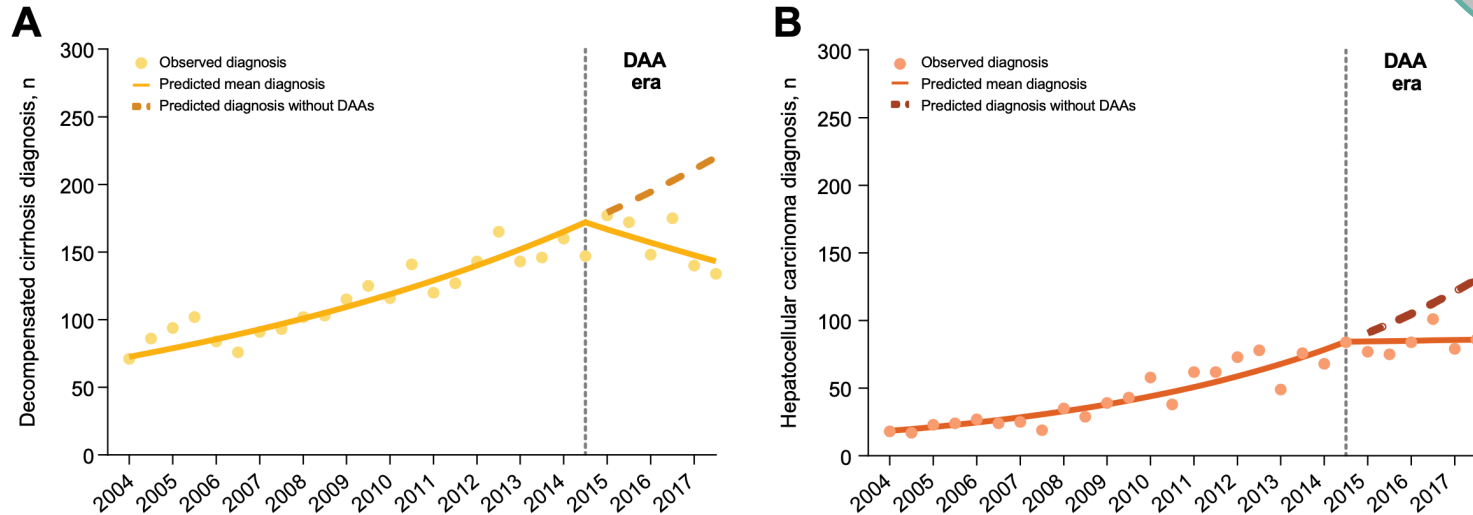


Fig. 4. Impact of direct-acting antiviral therapy on numbers of decompensated cirrhosis and hepatocellular carcinoma diagnoses. Data from individuals with an HCV notification in New South Wales, 2001–2017 ($n = 99,910$). (A) Decompensated cirrhosis diagnoses and (B) hepatocellular carcinoma diagnoses. Segmented Poisson regression models, fitting a second time trend parameter using splines, were used to evaluate the effect of the DAA therapy era on the numbers of decompensated cirrhosis and hepatocellular carcinoma diagnoses. DAA, direct-acting antiviral; HCV, hepatitis C virus. (This figure appears in colour on the web.)

Future data linkage

- Addition of further datasets – particularly primary care
- Expansion to other jurisdictions to broaden view of population – ensure coverage of all people living with viral hepatitis
- More responsive, rapid processes – living linked datasets allowing for more rapid evaluation of progress

Take home messages

- Data linkage provides essential additional information to assess progress toward targets:
 - Identifying disparities in access and progress
 - Informing about potential intervention points to address gaps in indicators
- Expanding coverage and more responsive processes will be essential to support the move toward elimination of viral hepatitis as a public health concern

Data linkage at AVHC 2021

Virtual on demand session: *Using data linkage to better understand progress towards viral elimination targets*

Maryam Alavi, UNSW; Stephen Lambert, University of QLD; Kelly Hosking, Menzies NT

Virtual on demand abstracts:

#102 Evaluation of the HCV Cascade of Care Among People with HIV/Hepatitis C Co-Infection in New South Wales, Australia: A Data Linkage Study

Samira Hosseini-Hooshyar, The Kirby Institute, UNSW Sydney, NSW

#112 Opportunities to Enhance Linkage to Hepatitis C Care Among Hospitalised People with Recent Drug Dependence in New South Wales, Australia: A Population-Based Linkage Study

Speaker: Heather Valerio, The Kirby Institute, UNSW Sydney

Live (this afternoon): *Data Linkage for Surveillance of Newly Acquired Hepatitis C Infections in Queensland: Early Findings and Implications for Policy and Practice*

Speaker: Damin Si, Queensland Department Of Health, QLD

With thanks

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WHO Collaborating Centre
for Viral Hepatitis

WHO

Vale Professor Monica Robotin



VIEWPOINT

Preventing primary liver cancer: how well are we faring towards a national hepatitis B strategy?

Monica C Robotin, Jacob George, Rajah Supramaniam, Freddy Sitas and Andrew G Penman

Worldwide, primary liver cancer is the fifth most common cancer and the third most common cause of cancer-related death. In Australia, it is relatively uncommon, ranking 15th in males and 20th in females.¹ However, the incidence and mortality of primary liver cancer have risen progressively over the past two decades; in New South Wales, primary liver cancer incidence rates have been rising faster than incidence rates of any other internal cancer.²

The Cancer Council NSW's report *Cancer incidence in New South Wales migrants 1991 to 2001* stated that, although immigrants had an overall incidence of cancer commensurate with their proportional representation in the NSW population (24.5%), their rate of primary liver cancer was substantially higher, with 46% of all diagnoses occurring in overseas-born people.³ Standardised incidence ratios for primary liver cancer in men born in Vietnam, Hong Kong and Macau, Korea, Indonesia and China, and in women born in Vietnam and China, were at least six times those in Australian-born people³ (Box 1). In NSW, liver cancer shows geographic clustering, with rates in western Sydney far exceeding the NSW average (12.1 versus 4.8 cases per 100 000 population).⁴

Over 80% of primary liver cancer worldwide is attributable to the effects of chronic infection with hepatitis B or C virus (HBV or HCV).⁵ People with chronic HBV or HCV infection have a 20-fold to 200-fold greater risk than those not infected of developing hepatocellular carcinoma (HCC)^{6,7} (the most common form of primary liver cancer).

ABSTRACT

- Worldwide, over 80% of primary liver cancers are attributable to chronic infection with hepatitis B or C virus.
- Over the past two decades, primary liver cancer incidence rates have been consistently rising in Australia.
- In New South Wales, the standardised incidence ratios for primary liver cancer in males born in Vietnam, Hong Kong and Macau, Korea, Indonesia and China and in females born in Vietnam and China are 6–12 times those in Australian-born populations.
- The incidence of liver cancer is likely to continue to increase unless a coordinated approach to disease control can be developed.
- Effective programs for chronic hepatitis B management need to link prevention, treatment and care, and enhance opportunities for research and surveillance activities.
- The evidence that suppression of hepatitis B virus replication could limit disease progression needs to inform the development of a public health response.
- Lessons learned in the development of the National Hepatitis C Strategy and the experience of international hepatitis B control programs need to inform this process.

MJA 2008; 136: 363–365

Indicator: attributable mortality

- Positive impact of antiviral therapy on adverse outcomes for hepatitis B – but still room to improve

