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Enhanced surveillance for hepatitis B and C: insights into clinical care after diagnosis

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Abstract

Background

There are known gaps in care uptake for hepatitis B virus (HBV) and hepatitis C virus (HCV) infection, and public health surveillance represents an opportunity to support health service engagement for cases; however, specific data are lacking regarding follow-up after diagnosis. We assessed outcomes of a Victorian initiative to enhance data availability and to support linkage to care.

Methods

Notified cases of HBV and HCV within Victoria during 2023–2024 were analysed to determine post-diagnosis follow-up, including variation by demographics and setting, and reported reasons for lack of linkage to care.

Results

Information was available for two-thirds of cases. For HBV, 37.7% reported current treatment or management, while 53.6% reported referral or assessment in progress; for HCV, these proportions were 33.3% and 54.7%. Reasons for gaps included loss to follow-up, cost barriers, and misapplication of HBV treatment criteria.

Discussion

Cascade of care information can be effectively collected via public health surveillance, and these systems represent an opportunity to support prioritisation of public health follow-up.

Keywords: hepatitis B; hepatitis C; linkage to care; surveillance; antiviral treatment

Introduction

Chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) infection cause a substantial ongoing burden of disease in Australia, resulting in an estimated 1,000 deaths per year due to advanced liver disease and liver cancer.[1,2] These outcomes can be largely avoided by the timely delivery of guideline-based care, including follow-up testing and monitoring after diagnosis and antiviral treatment where indicated.[3,4] However, there are identified gaps in care,[2,5] and improved uptake is needed to reduce avoidable morbidity and mortality.[1,2,6,7]

HBV and HCV infection are notifiable conditions in all Australian states and territories.[8] Victorian public health units play a role in both data collection for newly diagnosed cases, and increasingly are actively supporting primary care providers (who provide the majority of testing and diagnosis for these conditions)[9,10] to facilitate management of diagnosed individuals.[11,12] Improved and enhanced data collection would support public health actions and would identify gaps in care, especially among individuals from marginalised populations who have a greater risk of not being reached by health care services.

In the state of Victoria, newly acquired cases have been routinely subject to enhanced surveillance, while historically more limited data were available for unspecified (usually chronic) cases. Initial work to improve the surveillance system has been successful in improving completeness of key variables such as country of birth and injecting drug use history.[13] Further enhanced surveillance, which includes the collection of additional data regarding follow-up care such as polymerase chain reaction (PCR) testing and treatment prescription, has also been trialled and has been shown to facilitate care engagement for HCV.[11] Following this work, new fields for HBV and HCV care engagement have been added to existing routine case data collection mechanisms[14,15] and paired with work in local public health units to develop response protocols to increase support for diagnosing clinicians.

This paper assesses completeness of these new enhanced data collection fields; addresses the reported care provision for newly diagnosed HBV and HCV in Victoria (including variation by population group and barriers to care); and explores the utility of this system to support enhanced engagement in care.

Methods

We analysed all newly diagnosed cases of unspecified HBV and HCV infection notified to the Victorian Government Department of Health from 1 January 2023 to 31 December 2024, after the three new fields for HBV and HCV care engagement were added to the existing case report form. Data were extracted in August 2025, to allow sufficient time for ascertaining clinical follow-up. 'Unspecified' cases are those acquired more than 24 months prior to diagnosis or of unspecified period of infection, in accordance with national case definitions,[8] and represent the vast majority of cases of both HBV and HCV. A case is notifiable on the basis of laboratory evidence for infection with HBV or HCV, based on either diagnostic serology or follow-up PCR testing. The notification represents the first report of the case in Victoria, usually at the time of diagnosis but also including those previously diagnosed outside Victoria.

Information regarding case characteristics and care provision is ascertained directly from the diagnosing clinician by staff at Victoria's Local Public Health Units (LPHUs). Optimally this is collected for all unspecified cases; however, capacity varies by LPHU, and prioritisation may be applied based on factors such as risk of onward transmission (for example, diagnosis during pregnancy). Follow-up incorporates a time delay to allow for the care provision to occur prior to contact.

Summary demographics (proportion according to sex, and median and interquartile range (IQR) of age at time of notification) were generated. Data were extracted for the new care provision variables, which assess whether the case has had follow-up PCR testing; the result of this test (positive or negative); whether the case had been offered treatment by the diagnosing clinician; and if not, why (both pre-specified options and free text parsed for key responses). The data collection forms used are available from the Victorian Government Department of Health for hepatitis B and hepatitis C.[14,15]

We calculated the proportion of cases where any care provision information was collected. Of those with information complete, the proportion of cases where PCR testing was provided, and the proportion where treatment was offered by the diagnosing clinician, were assessed. Of those not offered treatment by the diagnosing clinician, the proportion of people with each reason was identified. This analysis was conducted for all

HBV cases, and for HCV cases that did not have a negative PCR test reported (who would not require treatment). For hepatitis B, offering treatment, assessing clinical need, and monitoring are grouped; these all represent acceptable management pathways (as most cases do not require treatment).

The proportion of cases where cascade of care information was available, and reported care provision among those with complete data, was assessed according to the case's region of residence (metropolitan/non-metropolitan); age group; sex; and year. Notifier information was analysed to identify the diagnostic setting (e.g. primary care, hospital, correctional facility), and data were analysed within these categories where case numbers were able to be reported (5 or more cases in a given category). Significance testing for comparison of these proportions was generated using the chi-squared test.

Additional demographic factors (country of birth, Indigenous status, and injecting drug use) are only collected for a subset of cases, and limited completeness prevented assessment of cascade of care information according to these factors.

Analysis and data management were conducted in Microsoft Excel and Stata Standard Edition version 18.0 (STATAcorp Texas US).

Results

Summary and demographics

During the period 1 January 2023 to 31 December 2024, there were 2,823 cases of unspecified HBV and 2,426 cases of unspecified HCV notified. There were more male cases for both HBV (53.9%) and HCV (66.0%). Median age was 41 (IQR: 32–54) years for HBV and 46 (IQR: 35–57) years for HCV (Table 1).

The majority of cases were diagnosed by clinicians in primary care settings (general practice and community health), for both HBV (59.7% of cases) and HCV (57.4%, Table 1). Hospitals were a more common setting for HCV (15.6%) than HBV (8.1%), as were correctional facilities (8.8% for HCV, 1.0% for HBV), while immigration was more common for HBV (23.1%) than HCV (4.2%).

The 1,686 HBV cases from primary care were notified by 1,049 individual clinicians, with the majority of those clinicians (774, 73.8%) notifying only one case. For HCV, 1,392 cases were notified by 1,120 clinicians, and 970 (86.6%) notified only one case. The highest number of cases notified by a single clinician was 20 for HBV and 25 for HCV.

Cascade of care completeness

Cascade of care information (either PCR testing status, treatment status or both) was available for two thirds of cases for both HBV (1,888 cases; 66.9%) and HCV (1,581 cases; 65.2%). For most cases, information was available for both PCR testing and treatment status (Tables 2 and 3).

There was some variation in completeness by sex, by age group, and by diagnostic setting; however, in all groups more than half of cases had some cascade of care information complete (Table 1). The largest variation was according to region of residence, with completeness considerably higher in non-metropolitan than in metropolitan areas for both HBV (87.2% compared to 64.4%) and HCV (90.5% compared to 56.7%).

Table 1: Summary and demographics for unspecified hepatitis B (HBV) and hepatitis C (HCV) cases in Victoria, Australia,[a] 2023–2024

		HBV (N = 2,823)				HCV (N = 2,426)			
Classification	Category	Number	% of HBV cases	Number with any cascade of care data	% of all HBV cases in category	Number	% of HCV cases	Number with any cascade of care data	% of all HCV cases in category
Year of notification	2023	1,355	48.0	928	68.5	1,237	51.0	883	71.4
	2024	1,468	52.0	960	65.4	1,189	49.0	698	58.7
Sex	Female	1,299	46.0	866	66.7	819	33.8	564	68.9
	Male	1,521	53.9	1,021	67.1	1,602	66.0	1,014	63.3
Age distribution (years)	Median age (IQR)[b]	41 (32–54)	—	—	—	46 (35–57)	—	—	—
Age group (years)	0–19	47	1.7	38	80.9	30	1.2	21	70.0
	20–29	413	14.6	305	73.8	270	11.1	189	70.0
	30–39	756	26.8	511	67.6	490	20.2	312	63.7
	40–49	623	22.1	411	66.0	560	23.1	345	61.6
	50–59	436	15.4	268	61.5	511	21.1	340	66.5
	60–69	373	13.2	243	65.1	410	16.9	279	68.0
	70+	175	6.2	112	64.0	155	6.4	95	61.3
Region of residence	Metropolitan	2,454	86.9	1,581	64.4	1,682	69.3	953	56.7
	Rural and regional	296	10.5	258	87.2	632	26.1	572	90.5
Diagnosis setting[c]	General practice/ community health	1,686	59.7	1,183	70.2	1,392	57.4	987	70.9
	Immigration screening	650	23.0	433	66.6	102	4.2	71	69.6
	Hospital or outpatient specialist clinic	224	7.9	142	63.4	376	15.5	258	68.6
	Correctional facility	29	1.0	21	72.4	213	8.8	140	65.7
	Blood donor screening	31	1.1	24	77.4	24	1.0	14	58.3
	Sexual health	37	1.3	27	73.0	32	1.3	28	87.5
	Other[d]	22	0.8	16	72.7	45	1.9	26	57.8
	Not available	144	5.1	—	—	242	10.0	—	—

a Totals will not add due to suppression of case numbers where data are missing.

b IQR: interquartile range.

c Diagnosis setting derived from notifier information.

d 'Other' includes research institutions, clinical trial services, forensic medicine services, and notifications provided from other jurisdictions' departments of health that relate to Victorian residents.

Table 2: Reported polymerase chain reaction (PCR) testing and treatment provision following notification for unspecified hepatitis B (HBV) cases in Victoria, Australia, 2023–2024

Classification	Category	Number of cases	Proportion of cases (%)[a]
Cases with PCR testing status reported	**Total**	**1,693**	**100**
PCR testing not provided	—	883	52.2
PCR testing provided	All tested	810	47.8
	Reported positive	711	42.0
	Reported negative	99	5.8
Cases with treatment status reported	**Total**	**1,773**	**100**
Offered treatment or under management by the diagnosing clinician	Subtotal	669	37.7
	Offered treatment by diagnosing clinician	328	18.5
	Assessed as clinically not eligible by diagnosing clinician	255	14.4
	Already on treatment[b]	20	1.1
	Already managed by another clinician	66	3.7
Referral or assessment in progress	Subtotal	951	53.6
	Referred to another clinician	792	44.7
	Pending further follow-up/testing	159	9.0
Not offered treatment due to patient factors	Subtotal	82	4.6
	Lost to follow-up	30	1.7
	Case leaving Victoria	25	1.4
	Patient undecided/declined	12	0.7
	Patient ineligible for Medicare	9	0.5
	Patient deceased or has advanced disease	6	0.3
Not offered treatment due to other reasons	Subtotal	71	4.0
	Invalid reason provided	40	2.3
	Further information not available	31	1.7

a Proportion of cases among those with PCR testing status reported, or those with treatment status reported, as appropriate.

b Of which eight were providers based in Australia and twelve were providers based overseas.

Table 3: Reported polymerase chain reaction (PCR) testing and treatment provision following notification for unspecified hepatitis C (HCV) cases in Victoria, Australia, 2023–2024

Classification	Category	Number of cases	Proportion of cases (%)[a]
Cases with PCR testing status reported	**Total**	**1,516**	**100**
PCR testing not provided	—	390	25.7
PCR testing provided	All tested	1,126	74.3
	Reported positive	514	33.9
	Reported negative	612	40.4
Eligible[b] cases with treatment status reported	**Total**	**838**	**100**
Offered treatment by the diagnosing clinician	—	279	33.3
Referral or assessment in progress	Subtotal	458	54.7
	Referred to another clinician or already under management	295	35.2
	Pending further follow-up/testing	121	14.4
	Reported prior treatment but no PCR testing reported	42	5.0
Not offered treatment due to patient factors	Subtotal	87	10.4
	Lost to follow-up	69	8.2
	Patient undecided/declined	5	0.6
	Patient deceased or has advanced disease	6	0.7
	Other[c]	7	0.8
Not offered treatment due to other reasons	Subtotal	14	1.7
	Invalid reason provided	9	1.1
	Further information not available	5	0.6

a Proportion of cases among those with PCR testing status reported, or those eligible and with treatment status reported, as appropriate.

b 'Eligible' excludes those reported to be PCR negative, i.e. not indicated for treatment.

c 'Other' includes cases planning to leave Victoria, and cases ineligible for Medicare; groups have been combined where number of cases < 5, to protect privacy.

Reported care provision

HBV

Of the HBV cases with the testing field complete (1,693 cases), approximately half reported that PCR testing had been conducted (810 cases; 47.8%), and the majority of those were reported as positive (711; 87.8%).

Treatment information was available for 1,773 cases, of which 669 (37.7%) reported current treatment or management, either by the diagnosing clinician or by another provider. Another 951 cases (53.6%) reported referral or pending follow-up (Table 2); referral was the most common category (792 cases; 44.7% of those with treatment information available).

For 82 cases (4.5% of those with treatment information available), treatment was not able to be offered, most commonly due to cases being lost to follow-up (55 cases, 67.1% of those not offered treatment). In another 40 cases (26.1% of those not offered treatment), the reason stated for not offering treatment was invalid/inconsistent with clinical guidelines (e.g. because the case was asymptomatic, or had had HBV for many years).

HCV

Of those with the 'testing' field complete (1,516 cases), the majority reported HCV PCR testing had been conducted (1,126 cases; 74.3%). Of those where testing was reported, 612 were negative (54.4%), while in another 10 cases, the case was stated to be PCR negative in the treatment field. This left 894 cases where treatment may be required, of which 838 had treatment information available.

Of those 838 cases, 279 cases (33.3%) reported treatment was offered by the diagnosing clinician, while 458 (54.7%) reported referral or pending assessment (Table 3). Referral was the most common category (295; 35.2% of the total with information available), while another 121 cases (14.4%) reported pending follow-up. Forty-two cases (5.0%) reported previous treatment but did not report PCR testing, limiting full assessment.

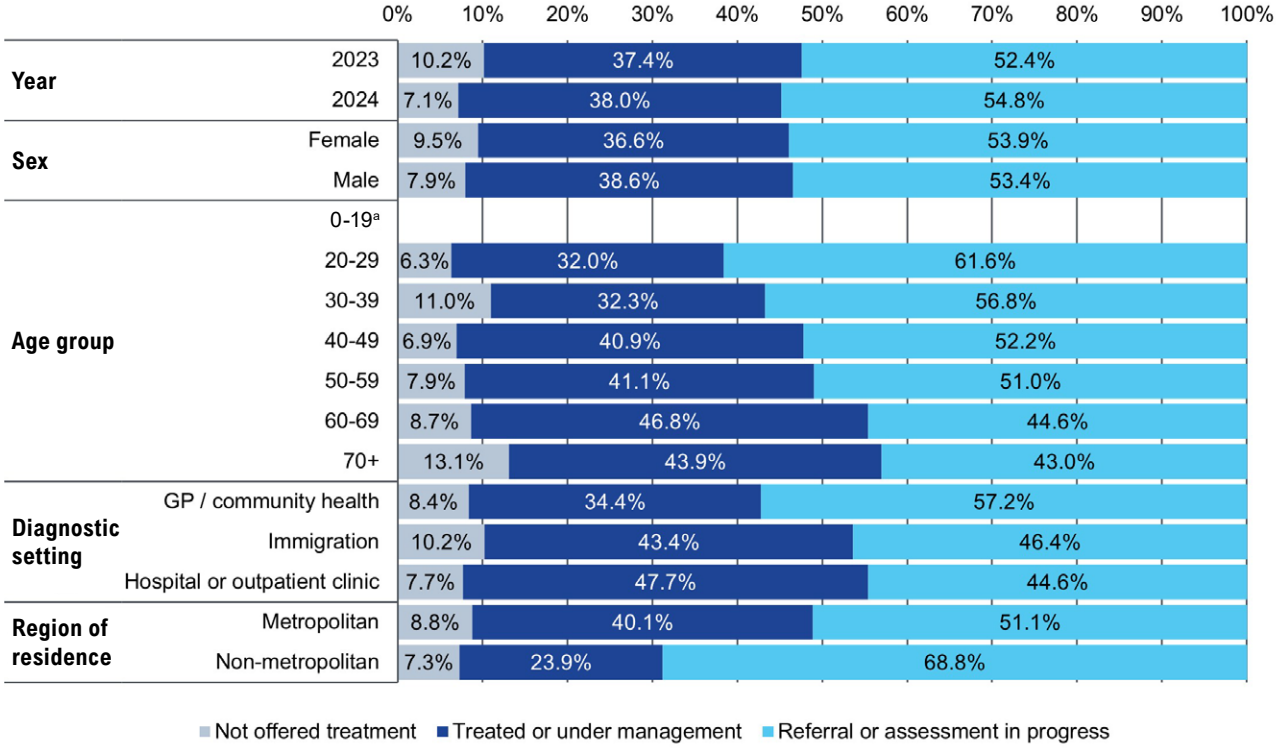
For 87 cases (10.4% of those with treatment information available), treatment was not offered, most commonly due to loss to follow-up (69 cases; 79.3% of those where treatment was not offered).

Variations in reported care provision

There was limited variation in reported care provision according to demographic factors for HBV: in all groups, some follow-up was reported for > 85% of cases (Figure 1). The proportion of cases reported to be offered treatment or under management (compared to those referred or pending assessment) was higher in those in diagnosed in tertiary or immigration settings ($p < 0.001$) and those living in non-metropolitan areas ($p < 0.001$).

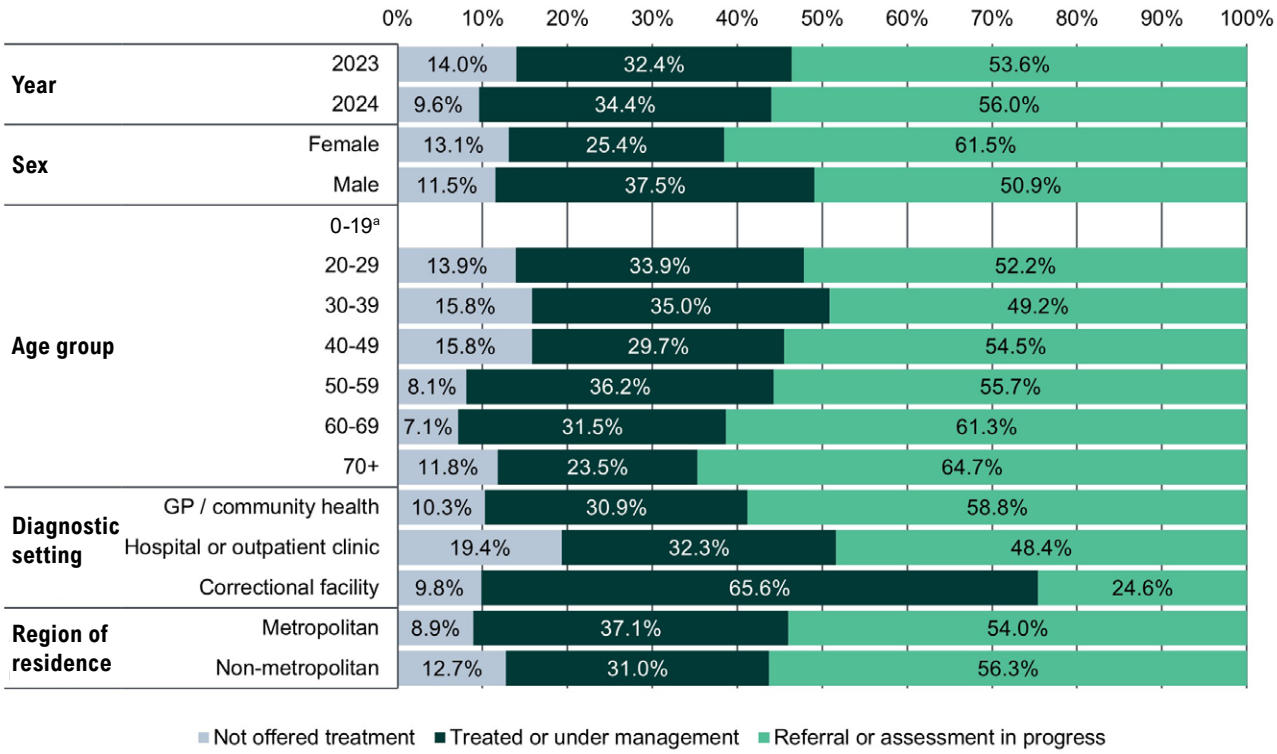
For HCV, reported care provision was > 80% in all groups (Figure 2). The proportion reported to be offered treatment or under management (compared to those referred or pending assessment) was lower in those diagnosed in a hospital setting and higher in those diagnosed in a correctional facility ($p < 0.001$), as well as being lower with increased age (Figure 2; $p = 0.023$).

Figure 1: Reported care provision following notification for unspecified HBV cases in Victoria, Australia,[a] 2023–2024



a Data suppressed for those aged < 20 years due to low numbers. Data only reported where the number of cases was ≥ 10 in each treatment category.

Figure 2: Reported treatment provision following notification for unspecified HCV cases in Victoria, Australia,[a] 2023–2024



a Data suppressed for those aged < 20 years due to low numbers. Data only reported where the number of cases was ≥ 10 in each treatment category.

Discussion

This analysis demonstrates the utility of enhanced surveillance data in measuring care provision in newly diagnosed HBV and HCV, and in identifying priority cases with gaps in care engagement for public health unit follow-up. Care provision information was reported for two-thirds of cases for both conditions, and the relatively high completeness and reported follow-up across most demographic groups is encouraging. However, there was evidence of disparities in treatment and care provision. Reported HCV treatment coverage was lower in those diagnosed in hospital settings, which may be due to the more complex nature of providing care to admitted or emergency patients.[11] This is in contrast to the correctional facility environment, where treatment coverage was higher than other settings. Although there were variations by region of residence and age group in the proportion referred compared to those offered treatment directly for HBV, overall the reported care coverage did not vary widely.

There was lower data completeness in metropolitan regions, highlighting the potential impact of higher case numbers requiring follow-up in these areas.[16] In some cases, the information provided highlighted barriers to care, including gaps in understanding of guidelines for treatment, demonstrating the potential need for increased support at the time of diagnosis. The high prevalence of referral reflects that the majority of hepatitis B and C treatment in Victoria is conducted by non-general practice specialists,[17,18] and emphasizes the strategic need to expand community access to treatment.[6,7]

Increasing use is being made of surveillance data to assess viral hepatitis care engagement and guide public health follow up in jurisdictions across Australia[12,19] and internationally,[20] and this can in turn be used by public health units to provide additional support to diagnosing clinicians where gaps in care are evident. This can also be facilitated with additional information regarding testing and treatment provision ascertained via laboratory data. Negative hepatitis C PCR testing data is an opportunity for identifying those not requiring follow-up without the need for contacting clinicians,[11] and this information would provide greater certainty regarding actual care provision by providing information about successful treatment outcomes. It would also allow for identification of re-infection and assessment of the cascade of care for those individuals. Process and regulatory changes to ensure reporting of all HBV and HCV PCR test results by laboratories is underway in Victoria to support more effective surveillance and public health responses. This would be supported by routine reflexive PCR testing of all HCV antibody positive cases. The reporting of full HBV viral load results could also assist diagnosing clinicians to identify treatment eligibility for individual cases.

Additional insight into care provision can also be ascertained via linkage to other datasets capturing testing and prescriptions, such as national health insurance (Medicare) data. This approach using retrospective linkage has found comparable levels of uptake in New South Wales among recently diagnosed cases to those observed here,[5] but the multi-year time lag usually involved is a barrier to ongoing surveillance. Ongoing real-time linkage would improve surveillance data, reducing the time burden on clinicians in providing data while allowing for tailored support as needed. Linkage to existing datasets, such as hospitalisations, can also increase completeness of variables such as Indigenous status, country of birth and injecting drug use status,[21] and would allow assessment of incidence and care uptake according to those factors.

As these data only relate to those who have been newly diagnosed, they are not representative of the total population with chronic HBV or HCV, and this likely explains the higher care uptake for these recently diagnosed cases compared to overall population-level data.[1,2] This emphasises the need to support re-engagement of those previously diagnosed and less likely to have been engaged in care, which could potentially utilise historical public health surveillance data.[22–24] Additionally, comparisons according to population group are limited by sample size and data availability constraints, and the addition of further sociodemographic characteristics would assist in assessing variations in uptake and priorities for intervention.

In the context of a commitment to the elimination of viral hepatitis as a public health concern, and the significant burden of unmanaged viral hepatitis in the Victorian community, this analysis describes specific gaps in relation to reaching this goal among newly diagnosed cases, demonstrating the potential utility of routine public health surveillance to measure access to care. It also highlights the potential for data to guide enhanced support to diagnosing clinicians, in particular those in primary care, as well as the potential to identify areas of priority for further improvement in systematic approaches. Without such public health approaches to support care provision, elimination of viral hepatitis in Australia will remain out of reach.

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Competing interests

No relevant competing interests to declare.

Ethical statement

An exemption from ethical review was granted by the Victorian Government Department of Health, as these activities were undertaken as part of active follow-up of new cases under the auspices of the *Public Health and Wellbeing Act 2008* (Victoria) and its associated regulations and in accordance with all relevant privacy and confidentiality requirements.

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