

The legal needs and experiences of people living with hepatitis B in Australia

Findings from Australia's first national study of the legal needs of people with blood-borne viruses

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A research partnership to identify and eliminate legal barriers to testing and treatment for people living with hepatitis B and HIV in Australia



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- Ethnic Communities Council of Queensland (ECCQ)
- Hepatitis ACT
- Hepatitis B Voices Australia
- Hepatitis NSW
- Hepatitis Queensland
- Hepatitis SA
- HepatitisWA
- LiverWELL
- Living Positive Victoria (LPV)
- Meridian
- Northern Territory AIDS and Hepatitis Council (NTAHC)
- PEACE Multicultural Services
- Positive Life NSW
- Positive Life SA
- Positive Women Victoria (PWV)
- Queensland Positive People (QPP)
- South Australia Mobilisation + Empowerment for Sexual Health (SAMESH)
- Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCahrd)
- WAAC

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Health +Law

A research partnership to identify and eliminate legal barriers to testing and treatment



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The Legal Needs Study (LeNS)

Study aims



- The first study investigating everyday experiences of law among people living with hepatitis B and HIV in Australia.
- Focused on the **nature, prevalence and impact of legal problems** ('justiciable issues') faced by people living with hepatitis B.

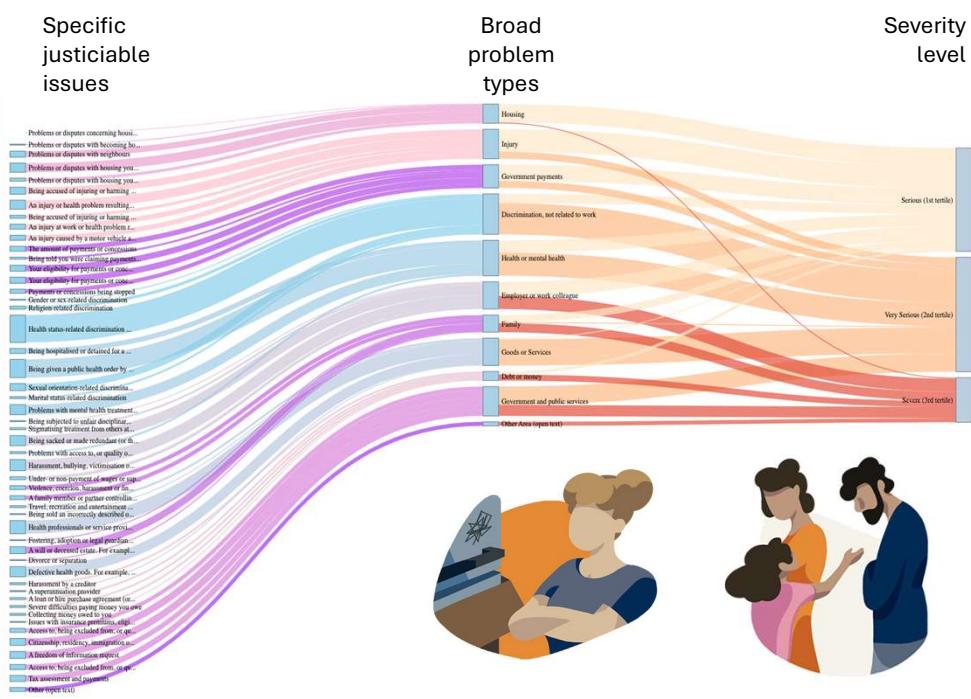
Justiciable issues (Genn, 1999). A problem or event experienced by a person that has *the potential* for legal resolution, regardless of whether the person recognises it as legal or takes any action involving the legal system. (Used sometimes interchangeably with 'legal issue' or 'legal problem')

- LeNS measured:
 - What **the most common** and **high-impact justiciable issues** are
 - What **areas of the law** they occur in
 - How they **affect people's health and wellbeing**, including whether they act as obstacles to testing, treatment, monitoring and ongoing engagement in care.
 - How people **address or resolve** these issues ('**Access to Justice**')
 - What are people's **understanding** of and **attitudes** towards law and justice ('legal capability' and 'legal consciousness')

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LeNS Survey

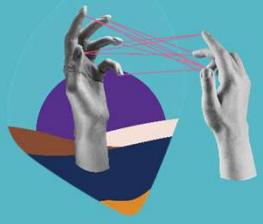
Survey structure



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LeNS Findings

Type and prevalence of legal issues



Legal Problem Prevalence

- 92.4% reported at least one justiciable issue during the two-year reference period
- This is almost double the rate reported in recent studies of the Australian general population (42%).

PLHBV experience multiple (and 'clustered') justiciable issues

- 68.5% faced issues **across 5 or more broad problem types**
- 12.5% reported at least one issue in every single legal problem type we measured

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LeNS Findings

Type and prevalence of legal issues



The legal problems faced by PLHBV are not confined to a narrow area of life or law

Legal Problem Type	LeNS Survey (PLHBV Australia)	PULS Survey (Victorian General Population)			
		Overall	No long-term illness or disability and low/no mental distress	Long-term illness or disability and low/no mental distress	Long-term illness or disability and severe mental distress
	Overall	% Reporting at least one justiciable issue			
Overall	92.4	42.0	35.8	40.4	73.1
Professional services and goods	83.3	20.9	17.9	19.9	28.1
Employment or workplace	71.8	6.9	4.4	3.8	18.1
Debt and money	69.4	4.2	2	3.3	20.3
Housing	66.7	10.5	7.9	9.7	25.7
Government and public services	65.3	3.6	2.1	4.4	14.6
Injury	62.0	3.9	2.1	4.6	19.3
Health or mental health	61.8	-	-	-	-
Government payments	60.2	4.5	2.3	4	19.9
Family	59.3	5.2	3.3	5.2	24.0
Discrimination, not related to work	51.9	-	-	-	-

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LeNS Findings

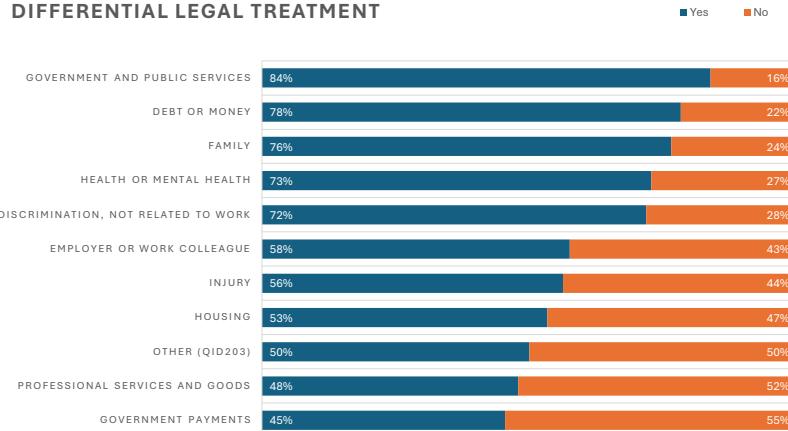
Impact of living with hepatitis B



Legal issues are made worse by living with hepatitis B

- 63.4% of survey participants living with HBV identified their HBV status activated differential legal treatment in relation to their most severe legal problem
- This proportion varied by broad problem type:

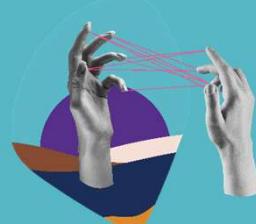
PROBLEM TYPES WHERE HBV STATUS ACTIVATED DIFFERENTIAL LEGAL TREATMENT



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LeNS Findings

Impact of living with hepatitis B



Most severe specific justiciable issues where HBV status activated differential legal treatment

Problem Type	Specific Justiciable Issue	HBV-Related
Discrimination, unrelated to work	Health status-related discrimination including living with a blood-borne virus like viral hepatitis B, hepatitis C or HIV-related discrimination	80.00%
Health or mental health	Being given a public health order by the health department or government, or detained in relation to an infectious or communicable disease or condition.	87.50%
Debt or money	Being unable to pay money you owe	100.00%
Goods or Services	Defective health goods. For example, problems or disputes with medicine, mobility aids, medical devices.	70.00%
Injury	An injury or health problem resulting from negligent or wrong medical or dental treatment	77.78%
Employer or work colleague	Being sacked or made redundant or threatened with the sack / redundancy	77.78%
Goods or Services	Health professionals or service providers. For example, problems or disputes relating to doctors, pharmacists, nurses, health care support workers.	60.00%
Family	A will or deceased estate. For example, a problem or dispute about your entitlements, probate or being an executor or trustee of a deceased estate.	85.71%
Government and public services	A freedom of information request (Note: Generally related to migration-related processes)	85.71%
Government and public services	Citizenship, residency, immigration or refugee status for you, a family member or partner	85.71%
Health or mental health	Problems with mental health treatment , medication or care. For example, treatment that was inadequate, wrong or against your will.	60.00%
Goods or Services	Defective household or personal items. For example, defective (e.g. faulty or broken) electrical goods, white goods, clothing, household items	45.45%
Goods or Services	Professionals. For example, problems or disputes with services provided by accountants, lawyers, migration agents, architects.	83.33%
Employer or work colleague	Harassment, bullying, victimisation or mistreatment at work	55.56%
Employer or work colleague	Problems concerning other rights at work. For example, problems or disputes about pay, hours, leave, your contract, superannuation or union membership.	55.56%

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LeNS Findings

Health- related effects of legal issues



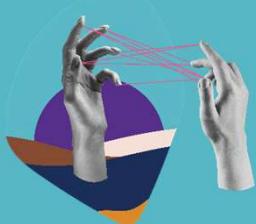
Health-related effects of justiciable issues

- **Health services access and quality issues** including:
 - legal problems or disputes with health professionals (23.8%)
 - exclusion from health services (15.5%)
- **Treatment quality and safety issues**, including:
 - mental health treatment, medication or care (28.7%)
 - negligent injury from health care (22.2%)
- **Health status-based targeting**, including:
 - workplace (6.3%) or
 - more generally (24.8%)
- **Coercive powers**, including problems regarding the use of public health powers (27.1%).

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LeNS Findings

Resolution of issues (‘access to justice’)



‘Access to justice’ refers to the ability of people to get a just resolution of their legal problems and enforce their rights. Sometimes this involves legal services, but not always as just resolution does not always require lawyers, courts or formal legal processes.

A key focus of legal needs research for multiple reasons, including that it shows where more services or supports are needed, and why people can’t or don’t access those. It is enshrined in art 14 of the International Covenant of Civil and Political Rights (ICCPR).

PLHBV report having:

- **low confidence** in their ability to achieve a fair legal outcome for their most severe justiciable issue (16.3% of participants)
- **low levels of legal capability**, including knowing where to get legal help and information
- **not seeking any assistance** for their most severe legal issue, because they felt seeking help would:
 - be too stressful (40.3%)
 - make no difference (43.4%)
 - take too long (37.7%)
 - cost too much (33.9%), or
 - they had bigger problems (20.7%)
- **HBV-related stigma was a barrier to seeking legal assistance** (30.1%)
- **High reliance on non-legal professionals for legal assistance**, including:
 - Professional, health and community services (26.8%), including HBV orgs (5.7%) and healthcare workers (6.2%)
 - friends and family (11.3%).

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Conclusions

- People living with hepatitis B in Australia experience extremely high levels of justiciable issues across multiple broad problem types, including significantly more justiciable issues than members of the general populations not living with HBV
- There is an urgent need to examine and potentially reform laws, policies and legal service delivery across key areas
- The Australian legal environment uniquely disadvantages PLHIV by transforming their health status into a significant source of increased exposure to legal problems, with significant consequences for health, wellbeing, rights and community participation
- Participants experienced differential legal treatment because of their hepatitis B status, including heightened exposure to health-related justiciable issues

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