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## REAL LIVES AND REDUCING HEPATITIS RELATED STIGMA AND DISCRIMINATION



Submission on systemic barriers and stigma and discrimination experienced by people affected by hepatitis B or hepatitis C in accessing health services for hepatitis B, hepatitis C and/or HIV prevention, care or treatment.

## EXECUTIVE SUMMARY

Stigma and discrimination is a reality for many people living with hepatitis B or hepatitis C. It affects most aspects of people's lives and can impact on their health and wellbeing. Societal stigma about hepatitis B and hepatitis C is often based on assumptions about the mode of transmission, most commonly through unsterile injecting drug use. Stigma can also be associated with cultural understandings of disease and disclosure; this is of particular relevance for people living with hepatitis B.

Hepatitis Australia, and particularly its member organisations, engage with people living with hepatitis B and hepatitis C. This submission outlines the experiences of many of those people, often in their own words. The lived experience is a particularly valuable element in community-led education and training workshops, providing insight into the real impact of stigma and discrimination, and should be an important element of education and training for the healthcare workforce.

While there have been significant improvements supporting access to treatment for hepatitis B and hepatitis C, there is still a need for a range of system improvements to reduce the impact of stigma and discrimination on the lives of people living with or at risk of viral hepatitis.

# Hepatitis Australia

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# Hepatitis Australia

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## ABOUT HEPATITIS AUSTRALIA

Hepatitis Australia works to improve health and social outcomes for all Australians who are at risk of, or living with, hepatitis B or hepatitis C. Incorporated in 1997, Hepatitis Australia is the peak community organisation to progress national action on issues of importance to people affected by hepatitis B and hepatitis C.

Our members are the eight state and territory hepatitis organisations.

Our mission is to lead an effective national response to hepatitis B and hepatitis C in Australia. To achieve this we work in a manner that:

- respects Aboriginal and Torres Strait Islander cultures, traditions, views and ways of life
- values cultural diversity and promote equality
- upholds harm reduction principles
- promotes the empowerment of hepatitis B and hepatitis C communities
- utilises evidence to inform our policies and activities
- is ethical, accountable, committed and professional.

Hepatitis Australia has four key areas of focus which cover community information and education; supporting service delivery; effecting change through advocacy and informing effective national policy; and maintaining good organisational governance.

Our work requires consultation with a broad cross-section of people, including people affected by hepatitis B and hepatitis C. This is generally via our member organisations who work directly with the affected communities, however Hepatitis Australia also conducts consultation activities direct with the Australian population.

Further information about Hepatitis Australia is available at [www.hepatitisaustralia.com](http://www.hepatitisaustralia.com)

## INTRODUCTION

Many people living with hepatitis B (HBV) or hepatitis C (HCV), or who have previously lived with HCV, may have experienced stigma or discrimination at some point during their infection. It impacts on every aspect of their lives. For the person affected, determining whether a particular situation is stigmatising or they are being discriminated against can be unclear – but both are unacceptable.

### **HCV-related stigma and discrimination.**

A significant amount of literature, going back as far as 1997 has indicated hepatitis C-related stigma or discrimination is often experienced when accessing health-related services, but it is certainly not limited to this environment. People living with HBV or HCV also report being stigmatised or being discriminated against by family members, friends, sexual partners and employers.

*“it [HCV] impacts on every aspect of my life both physically, emotionally and socially” - Lyn from Victoria*

Stigma and discrimination related to HCV is often due to assumptions about the how the person may have become infected with the virus. This is often due to the close association between HCV and unsterile injecting drug use, the most common mode of HCV transmission, and public stereotyping. These assumptions can often have a negative impact for people whether they are a current injecting drug user, someone who has ceased injecting or someone who has never injected. These judgements can also have an impact on a person’s access to health services.

### **HBV-related stigma and discrimination.**

There has been much written about HCV-related stigma and discrimination, but there is little documented about HBV. Most people living with HBV are often from marginalised and already stigmatised communities, including migrant communities, Aboriginal and Torres Strait Islander people, men who have sex with men and people who inject drugs. Historically there has been very little investment in non-clinical research or community-based programs for HBV which can limit our understanding of the experiences of this community. Some of the comments made by people living with HBV reinforce that cultural understandings of health, social behaviours, communication and shame are factors to consider.

### **Systemic barriers to health care**

Recent changes affecting how treatment for HBV and HCV is accessed has presented both opportunities and new challenges for people living with HBV or HCV. This was highlighted by the shift to community-based prescribing and dispensing of HCV treatment (commenced in March 2016) where most people, depending on clinical factors, would no longer be required to access hospital-based clinics for management and treatment.

Hepatitis organisations have played an important part in responding to stigma and discrimination for many years. This includes supporting people who have experienced discrimination or feel stigmatised and the delivery of education and training to other organisations or services, including health services. Another approach, and the aim of the *Love Your Liver* project, has been to normalise discussion about hepatitis through a focus on liver health. This approach has been effective in the general community as well as engaging people from the affected communities by side-stepping stigma.

The voice of people living with HCV has played an increasing role in education and advocating for change. Most hepatitis organisations include a ‘positive speaker’ program in some form. This is where people living with HBV or HCV are supported to share their lived experience of having the virus through public speaking or sharing their stories in education or training workshops. Understanding how stigma and discrimination in healthcare impacts on access to care can be powerfully demonstrated by the inclusion of personal stories in clinical training modules.

## THE EXPERIENCE OF STIGMA AND DISCRIMINATION AMONG PEOPLE LIVING WITH HEPATITIS B OR HEPATITIS C

### STIGMA

Many people living with viral hepatitis are affected by stigma associated with HBV and HCV. Stigma is often defined as a mark of disgrace that sets a person apart. When a person is labelled by their illness, they are seen as part of a stereotyped group. Negative attitudes create prejudice which leads to negative actions and discrimination.

In general, society associates contracting an infectious disease with unclean, unsavoury or immoral behaviours. The vast majority of new infections occur through sharing unsterile injecting equipment. Public perceptions of drug use result in unwarranted stereotypical judgements that do not reflect the true picture. Many people who have lived with HCV for some time have never injected drugs or have ceased their injecting drug use. Other people living with HCV may have contracted the virus through infected blood products before 1990 or through other means, such as sharing unsterile tattooing or body piercing equipment. Regardless of how a person contracts a disease, the focus of healthcare services should be on achieving the best health outcomes for that individual without moral or prejudicial overlays.

*"I should be living life to its fullest instead of waiting for a treatment that will cure me, release me from the stigma, fear & uncertainty that is my world." – Neil from Qld.*

Incorrect assumptions about how a person may have become infected with HCV is not contained to those with limited health knowledge. During the last year, a person seeking treatment for HCV found that her doctor had stated on her file that the infection was acquired through injecting drug use and, once treated, noted he was proud that she (the patient) was "clean". It was suggested that this comment on her file then led to inappropriate pain management for another health matter.

The impact of stigma on people living with HCV is evident in their own words. Participants of the *Speak Out* project, conducted by Hepatitis Australia in 2015, talk of changing lifestyle behaviours as a form of self-care and to increase their chances of a cure. Others talk about living with stigma, fear and feeling ashamed. *Speak Out* asked people with HCV what a cure would mean for them. Following are quotes from some of those people.

*"I have eliminated all things that increase the problem – zero caffeine, don't smoke, drink alcohol or take any drugs whatsoever." – Shane from Qld.*

*"...I constantly got asked if I had ever taken drugs! I had smoked a couple of times but it made me sick, and no I never injected or shared personal items. So how did I get it? I'm assuming from a blood transfusion... before 1985. The time I found out I had hep C I felt ashamed, I didn't know and still don't know how I got it, I lost friends because I was afraid I would give it to them somehow, my children suffered because I had become so meticulous in cleaning, making sure my clothes were not washed with theirs, my dishes, just about anything." – Dee from Victoria*

*"The years of being both physically unwell, and also the years of battling the stigma associated with Hep C could be put behind me" – Kathryn from Victoria*

*"It was a bolt out of the blue, an awful reminder of a brief period of adolescent rebellion in the 1970's when I engaged in risky behaviour which included an experiment with intravenous drugs. After a brief*

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*flirtation I went on to finish uni, get married, get a job and generally get on with life. Half a lifetime later I am paying a very expensive price for what was a small detour in my life's path. As others have experienced, I felt enormous shame and anxiety. After the initial diagnosis I was too frightened to return to the doctor – for any medical treatment – for some years. I did not talk to my husband. The sense of isolation and despair has been overwhelming.” – Anne from NSW.*

A video interview with five HBV positive speakers in 2014 highlighted some of the stigmas associated with living with HBV. The participants were from different cultural backgrounds. One participant talked about having HBV as a “family secret” and the sense of guilt felt by mothers who transmitted HBV to their child during childbirth.

Participants also talked of a sense of “shame” or “self-imposed stigma”, which could be prompted by the way a person looked at them and a perception of being judged. This emphasised the need to feel a sense of trust with others, including health professionals.

In a health environment where there has been a significant focus on HBV immunisation, including the school-based catch up programs from 2000, a focus on understanding more about chronic HBV can be lost. It is important to remember that people from more isolated Indigenous communities or people who have migrated from countries where HBV is prevalent may not have had access to such programs, and have been living with HBV for some time without any support.

## DISCRIMINATION

Discrimination is generally defined as the practice of unfairly treating a person or group of people differently from other people or groups of people. Discrimination can be subtle or overt but in any form, whether perceived or actual, can have significant impacts for a person living with HBV or HCV.

Throughout Australia, in most circumstances it is against the law to discriminate against a person because s/he is living with HBV, HCV, or any other infection. The Federal Disability Discrimination Act 1992 makes it an offence to discriminate on the basis of a person's disability, which includes chronic viral hepatitis. This provides a foundation for establishing and lodging formal complaints about experiences of discrimination. However, pursuing a formal complaint may be complex and confronting for some. Complaints procedures for many services, including health services can be difficult to identify and the process may vary significantly from that of a public hospital environment to a local GP clinic. The need to disclose hepatitis status to others may also affect on a person's decision whether or not to report or pursue a formal complaint.

People living with HBV and HCV report having been refused access to services or being treated unfairly due to having been diagnosed with the virus. People have described being discriminated against by doctors, employers, health services, social welfare services and family members. This includes people living with HCV who have cleared the virus naturally or through treatment but continue to test positive to HCV antibodies.

Health services are the most likely environment where people disclose their infection with HBV or HCV, as this can have implications for the management of other health issues. This may also explain the higher proportion of reports of discrimination regarding health professionals. It should be expected that staff in health services would have a good knowledge of how viruses are transmitted and basic infection control procedures. However, the experiences of some people living with HCV would suggest this basic knowledge is either not present, or clouded by the stigma associated with HCV or assumed behaviours.

*“The test was antibody positive. The GP had shock on his face, he put on some gloves to check my high blood pressure. He wrote on my notes in red “Hep C positive”. I explained to him that I had had treatment and my PCR will be negative to confirm. He wouldn't listen. He did the PCR and it came negative but he wouldn't hear of it that I was cured. With my PCR negative result, he continued to*



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*write warnings in red, "hep C positive" wherever I was going for testing. It could be checking my glucose level, vitamin--there was warning that I was hep C positive. He would always use gloves to touch my skin. He refused to remove his warning in his notes" – Angela from Qld. (Speak Out 2016)*

*"When I presented at a doctor's surgery (not 1st time there), I asked for a tetanus injection because I had trod on a rusty nail. The doctor filled a syringe and placed it on the desk in front of me and walked across the room and stood there. I asked him 'do you expect me to inject this myself?' and he replied 'well I don't want what you have' (there was obviously an alert sticker denoting a hep C infection on my notes). I was disgusted with this doctor so I jabbed the needle into my arm and left the surgery." – John from SA (Speak Out 2016)*

The issue of stigma and discrimination can be heightened in smaller communities and affect the decision to treat.

In late September 2016, Hepatitis NSW received a call via the Hepatitis Infoline, from a seventy-year old woman who had accessed a country GP to ask for a hep C test. Upon presentation, the woman was told *"they don't see that kind of patient in their practice. That theirs is a family practice and for that reason they don't treat people with hepatitis C"*. As a result, the woman said she practically ran out of the surgery in *"burning shame"*, and that she didn't want to talk to anyone about it. The woman finally confided in her closest friend and said she won't get treatment now. She said she's *"already 70, only has another 10 years of quality life so does it really matter if she doesn't get treatment"*. After much convincing, the woman finally let her friend call the Hepatitis Infoline. Through long conversations with the Infoline worker, the merits of treatment were discussed along with confidentiality and choice. The woman was referred to a doctor in a clinic a safe distance from her home town and who is currently treating patients for hepatitis C.

An ongoing survey conducted by the Australian Injecting and Illicit Drug Users League (AIVL) has shown that even though there has been some reduction in reports of discrimination by doctors and hospitals since 2012, these health providers continue to be the most highly represented in 2015.

It is clear that discrimination relating to HBV or HCV extends beyond health services and can exist in the everyday personal lives of people living with the virus. A fifth of Australian respondents to the Global HCV Quest survey felt they had suffered discrimination at work or in education, and over half said they would feel uncomfortable talking about their hepatitis C with their boss or colleagues, or with staff at their school/university.

Personal experiences told to hepatitis organisations talk of how discrimination occurs within family and social networks and how disclosure of a person's status can be used against them.

*"Son-in-law refuses to let the grandchildren stay at our home. He believes all people with hep C are/were filthy drug users and they deserve what they get. He does not believe that hep C is only transmitted through infected blood entering another's blood stream - he thinks you can be infected through casual contact." – Jean from SA (Speak Out 2016)*

## SYSTEMIC BARRIERS IN THE HEALTH SYSTEM

When discussing stigma and discrimination and barriers to accessing health services, it is important to acknowledge that while legislation or service protocols may change for the better, this does not necessarily effect a change of mindset among the associated workforce.

In recent years there have been legislative changes specifically relevant to the way in which people living with HBV and HCV access medical treatment. Previously, access to treatment for HBV and HCV was only through specialist, hospital-based clinics and pharmacies. In 2015, the prescribing and dispensing of medicines for HBV was expanded to general practitioners and community pharmacies. In March 2016, the new generation medicines for treating hepatitis C were given a dual listing (s85 and s100) on the PBS which enabled prescribing by GPs and specialists. These medicines are simpler to take and have significantly less side-effects. These changes also enabled dispensing through community pharmacies.

The changes to prescribing and dispensing of medicines were welcomed and reduced many barriers to accessing treatment. All of these changes, as well as the public advocacy to achieve them, placed HCV in the spotlight for many months with significant news coverage by mainstream and social media.

Extending the ability to prescribe HCV medicines to more medical practitioners, such as GPs, included the requirement to consult with a specialist experienced in hepatology, such as a gastroenterologist, prior to prescribing. This involves the GP gathering clinical information about the patient prior to consulting the specialist about proposed treatment and then prescribing. This approach did not acknowledge that some doctors working in the area of alcohol and other drugs (AOD) had already had some experience working with HCV treatment. In an environment such as an AOD clinic where a doctor has demonstrated experience with HCV and the decision to treat may need to be acted on within a single consultation, and their ability to prescribe without further consultation should be considered.

Another area where prescribing needs to be expanded is to experienced nurse practitioners. As the prescribing of treatment for HCV becomes simpler and pan-genotypic medicines become more readily available, the role of nurses in HCV management and treatment will need to increase. Nurse practitioners, with the ability to prescribe some medicines, have shown to be valuable in hospital and community-based clinics. This nurse practitioner-led service is often linked to the management of chronic conditions. Further investigation into expanding prescribing rights will support an increase in access to medicines and the goal to eliminate HCV in Australia.

The changes to prescribing and dispensing also presented some challenges for people living with HCV. People had greater choice in which medical practitioner could be managing their treatment. The ability to obtain the new medicines from local pharmacies, while increasing accessibility, meant disclosure of their status to more people. Initial teething problems with dispensing through community pharmacies created some anxiety among the community.

From the introduction of the new medicines on the PBS, hepatitis organisations around Australia starting receiving calls from the community about pharmacies not having the new medicines available, or that some GPs were not prepared to prescribe the medicines. Investigation into the matter revealed that despite PBS reimbursement, the initial wholesale cost of medicines was a barrier to smaller pharmacies, some of which decided not to stock the new medicines for HCV.

The situation regarding access through pharmacies has now eased with more accessible information becoming available about which community pharmacies do stock the new medicines. However, the introduction of the new treatments for HCV has highlighted other challenges.

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When the PBS listing of new HCV medicines was announced, the Australian Government, made a point to say people in prisons would have access to the medicines. This has been facilitated through the dual s100 and s85 PBS listing. However, practical challenges arise as the prescribing of the new HCV medicines requires the doctor to obtain authority from the PBS and the patient's Medicare number is required. This results in practical difficulties for many inmates and causes significant delays as their Medicare number may not be known, particularly for long-term prisoners.

Hepatitis C treatment for forensic inpatients of mental health care institutions is another example of a systemic problem. The arrangements for treatment access for prisoners do not apply as the forensic patients are outside the prison system, additionally Medicare agreements preclude the federal government funding access to PBS medications for forensic hospital inpatients. Ultimately, the concerns come down to who has to pay for these high-cost medicines, state governments or the federal government. Greater clarity about access to new HCV medicines for people in state or territory-run facilities is required.

General practitioners have to respond to a broad range of medical needs. This means having ready access to information and effective referral networks. It is evident through the comments by community members that the HBV and HCV knowledge among GPs is generally low and needs to be improved. This low level of knowledge may contribute to the stigma and discrimination experienced by people living with HBV or HCV. Some people living with HBV or HCV have spoken of preparing themselves by seeking information from the internet before visiting a GP and often impart knowledge to the GP.

In May 2015, Hepatitis Australia lodged a submission to the Medical Services Advisory Committee (MSAC) – Protocol Advisory Sub-Committee, supporting an application to have transient elastography included under the MBS. Transient elastography, usually referred to as Fibroscan®, is often held up as the most tool for checking the extent of liver damage and for quickly informing treatment decisions. With some basic training, the equipment can be used onsite by nurses or doctors, providing immediate results instead of waiting on the results of blood tests. However, use of this equipment is not currently covered under the national Medical Benefits Scheme and access to the equipment is limited in some regions. In April 2016, and after the Health Minister's announcement to list new HCV medicines on the PBS, MASC advised that the application to publicly fund the use of transient elastography had been declined.

## ANNOTATED BIBLIOGRAPHY – PUBLISHED ARTICLES

### STIGMA AND DISCRIMINATION AROUND HIV AND HCV IN HEALTHCARE SETTINGS: RESEARCH REPORT

**Author:** ASHM and the National Centre in HIV Social Research

#### **Publication details**

This report, published in 2012, provides an analysis of the experiences of research participants living with either HIV or HCV and includes three recommendations.

**Link:** <http://www.ashm.org.au/resources/pages/1976963391.aspx>

#### **Key findings**

Key themes from the literature review and the stakeholder consultations show that stigma and discrimination can have a negative influence on both mental and physical health. The document includes strategic recommendations for the NSW Ministry of Health which continue to have relevance today. These included:

- implementation of a multi-pronged three-year social marketing and education campaign targeted at health professionals
- funding research into protective and resilience-building factors for people living with HIV and/or hepatitis C
- engagement with people with experience of HIV and/or Hepatitis C in the development of any action plan for reducing discrimination.

#### **Recommendations**

Education campaigns about HBV and HCV targeting health professionals should be conducted and that these are informed by people who have lived experience of each virus.

### UNDERSTANDING BARRIERS TO HEPATITIS C VIRUS CARE AND STIGMATIZATION FROM A SOCIAL PERSPECTIVE

**Authors:** Treloar C, Rance J and Backmund M.

#### **Publication details**

This article was published 2013 by the Oxford Journal, Clinical Infectious Diseases, Volume 57.

**Link:** [http://cid.oxfordjournals.org/content/57/suppl\\_2/S51.long](http://cid.oxfordjournals.org/content/57/suppl_2/S51.long)

#### **Key findings**

It provides a comprehensive overview of the role of stigma and discrimination and informs strategies for responding to hepatitis C-related stigma and discrimination in the health sector workforce. In its conclusions the *“review urges raising and prioritizing the profile and understanding of stigma and its central role in patient decision making about “if and how” to engage in HCV care.”*

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It also highlights relevant literature relating to the relationships between patients, health professionals and the health system as well as acknowledging the disconnect between the lived experience and assumptions made by health professionals and policy makers.

## **Recommendations**

The key message from this document, which remains relevant today, is captured in the following extract from its concluding statements.

*“Developing genuine partnerships with people living with HCV and consulting them on the design and operation of health services may be a first step toward establishing, modifying, or reforming health services to better address stigma as a barrier to HCV and treatment...”*

## **STIGMA, DISCRIMINATION AND HEPATITIS B: A REVIEW OF CURRENT RESEARCH.**

**Author:** Jeanne Ellard and Jack Wallace – Latrobe University

### **Publication details**

This review, published in 2015, involved a literature search conducted of the major sociological, psychological and medical databases as well as internet searches for other reports and policy documents.

**Link:** [https://www.latrobe.edu.au/\\_data/assets/pdf\\_file/0008/558638/Stigma-Discrimination-and-Hepatitis-B-A-review-of-current-research.pdf](https://www.latrobe.edu.au/_data/assets/pdf_file/0008/558638/Stigma-Discrimination-and-Hepatitis-B-A-review-of-current-research.pdf)

### **Key findings**

The review identified that there is limited information available and gaps exist in research related to hepatitis B stigma and discrimination.

### **Recommendations**

Further research into stigma and discrimination related to hepatitis B is needed to inform education initiatives.

## **“WE LIVE WITH IT ALMOST EVERY DAY OF OUR LIVES - AN AIVL REPORT INTO EXPERIENCES OF STIGMA & DISCRIMINATION,**

**Author:** Australian Injecting and Illicit Drug Users League - Written by Angella Duvnjak & Jason Hargraves

### **Publication details**

This report, published in 2015, provides an analysis of the experiences of 256 survey respondents who are either people who inject drugs, people on pharmacotherapy, and those with hepatitis C and/or HIV.

[HTTP://WWW.AIVL.ORG.AU/WP-CONTENT/UPLOADS/20151008\\_REPORT-WEB.PDF](http://www.aivl.org.au/wp-content/uploads/20151008_REPORT-WEB.PDF)

### **Key findings**

Key themes from the literature review and the stakeholder consultations show that stigma and discrimination can have a negative influence on both mental and physical health.

### **Recommendations**

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The report does not make specific recommendations but provides insight into the experiences of the affected communities and discussion about a variety of strategies that are undertaken and could be enhanced. This includes strategies targeted at the health workforce but also broader public awareness about hepatitis C and injecting drug use.

## HEP REVIEW - EDITION 88, MY STORY: SEAN

**Author:** Hepatitis NSW

### **Publication details**

Hep Review is a regular publication of Hepatitis NSW. In this edition, Sean tells his story of having been cured of HCV only to be confronted with alleged discrimination by a surgeon and pursued legal action.

**Hyperlink:** <https://issuu.com/hepatitisnsw/stacks/78f1f94e360348bcb4f59af788d5bc0c>

### **Key findings**

This article highlights a number of issues. Firstly, not all specialist health professionals have the same understanding of what 'curing' hepatitis means. Secondly, that practices relating to referrals or recorded information can be harmful and discriminatory for people living with HCV. Finally, it demonstrates that pursuing a formal complaint, while often protracted, can have a positive outcome for the affected individual.

### **Recommendations**

Education of the health sector workforce must address all levels of health professions, especially those involved in invasive or exposure prone procedures – whether this be giving an injection, drawing blood or conducting surgery.

## ANNOTATED BIBLIOGRAPHY – UNPUBLISHED RESEARCH OR ARTICLES

### SPEAK OUT PROJECT – 2015,

**Author:** Hepatitis Australia

#### **Publication details**

*Speak Out* in 2015 was an online survey that enabled people living with HCV to share why access to the new generation treatment for HCV was important to them. With the permission of all contributors, all personal stories were published on the Hepatitis Australia website enabling others to read them. The information gathered was used to inform Hepatitis Australia's submission to the Pharmaceutical Benefits Advisory Committee (PBAC) regarding the listing of new medicines for HCV on the Pharmaceutical Benefits Scheme (PBS).

[HTTP://WWW.HEPATITISAUSTRALIA.COM/SPEAKOUTSTORIES/](http://www.hepatitisaustralia.com/speakoutstories/)

#### **Key findings**

The personal stories provide insight into the following:

- the role of stigma and how it can impact on the wellbeing of people living with HCV
- how hepatitis C impacts on the personal and social networks of people living with HCV
- what being able to cure HCV would mean to those living with the virus.

#### **Recommendations**

While the primary purpose of this project was to inform a submission to PBAC recommending the listing of new medicines on the PBS, it also describes how being cured of HCV may change the lives of people living with HCV. Not having to deal with stigma or discrimination featured as a benefit of no longer having HCV.

It is clear from the personal comments that the fear of stigma and discrimination is real and a factor in wishing to be cured of HCV. It also highlights that a broad reaching approach to challenging stigma and discrimination is needed.

### HCV QUEST: COUNTRY SPECIFIC REPORT - AUSTRALIA

**Author:** World Hepatitis Alliance

#### **Publication details**

Produced by the World Hepatitis Alliance and released on 13 April 2016. Almost 4,000 people from 73 countries were surveyed on how living with hepatitis C impacts all aspects of their lifestyle, how much they knew before they were diagnosed and their experience of diagnosis, care and treatment. This country-specific report summarises responses of 93 people from Australia, with insights into the experiences they shared and pertinent comparisons with regional findings.

#### **Link to document.**

<http://static1.squarespace.com/static/50ff0804e4b007d5a9abe0a5/t/570d8a4127d4bd5b280b25e9/1460505159757/HCV+Quest+Australia+%28EN%29.pdf>

## **Key findings**

The key findings relevant to stigma and discrimination include:

- only about 39% of those surveyed said they knew what hepatitis C was before their diagnosis (an indicator of low community awareness)
- about a fifth of respondents felt they had suffered discrimination at work or in education and over half said they would feel uncomfortable talking about their hepatitis C with their boss or colleagues or with staff at their school/university.
- few respondents felt their physicians (22%) and nurses (23%) completely understand the full impact of hepatitis C has on their life.

## **Recommendations**

This report demonstrates the importance of relationships between a person living with HCV and their health care providers, including those currently engaged in care. The report also highlights the real fear among people living with HCV of being stigmatised or discriminated against in their day-to-day lives, including by their employers and work colleagues. This suggests that responding to stigma and discrimination needs to extend beyond that experienced in health care settings.



## PERSONAL ACCOUNTS OR RESULTS OF YOUR ENQUIRIES

In preparing for this submission, state and territory hepatitis organisations (the members of Hepatitis Australia) were asked to provide information about cases of stigma or discrimination experienced by people living with HBV or HCV who access their service.

As is often said, stigma and discrimination is likely under reported. While the number of reports appears to have declined in recent years, the episodes are no less significant. One hepatitis organisation in a less populous Australian state recorded 40 reports of stigma or discrimination between 2010 to August 2016. Of these, ten related to doctors, five to health services and eight were about employers. The remainder were about social welfare issues of family members. Of those in the last year, two related to the behaviour of general practitioners, two about employers and one about a neighbour.

In 2015, Hepatitis Australia increased its engagement directly with people living with HCV to seek their views and inform advocacy. The initial online project called *Speak Out* asked people what a cure for their HCV infection would mean for them. Within these personal stories it is evident that escaping stigma and discrimination was important. As has been demonstrated more recently, curing a person's HCV does not prevent incorrect or unjust assumptions about that person.

In addition, to inform this document, Hepatitis Australia established an online survey called *Speak Out about stigma and discrimination* to seek input from people who had experienced or witnessed HBV or HCV-related stigma or discrimination. The findings of this are included below.

Quotes from the personal stories provided through *Speak Out* have been used throughout this document.

## SPEAK OUT – STIGMA AND DISCRIMINATION

**Author or Source of Information:** People who live with HBV or HCV, or have since been cured of HCV

**Collecting Agency:** Hepatitis Australia

**Date:** September 2016

**Hyperlink if available** <http://www.hepatitisaustralia.com/stigma/>

## KEY FINDINGS

It is important to note that there were several stigma and discrimination-focused surveys being conducted at the same time as *Speak Out*. The timeframe for promoting this survey was also short and relied on social media and promotion by others, hence the response rate was very low (8) at the time of writing this submission. However, the responses from those who participated (all having lived with HCV or HBV) are no less valuable and are consistent with past research in this area and support the need to reduce stigma and discrimination in health care settings. The following identifies where respondents had experienced stigma or discrimination:

- 75% from a GP
- 25% from a dentist
- 38% from nursing staff at a hospital and 25% from nursing staff at a local clinic
- 50% from a family member
- 38% from a sexual partner.

# Hepatitis Australia

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When respondents were asked about strategies to reduce stigma and discrimination, they identified a need to educate GPs in regard to interpreting tests for HCV and about stigma and discrimination so as to not alienate people.

## RECOMMENDATIONS

Despite the low number of responses the outcomes are consistent with previous research conducted and reinforce the need to provide education for health services.

## INITIATIVES TO ADDRESS STIGMA AND DISCRIMINATION

Hepatitis organisations have played an important part in responding to stigma and discrimination for many years. This includes supporting people who have experienced discrimination or feel stigmatised and the delivery of education and training to other organisations or services.

Most hepatitis organisations in Australia provide some form of education or training to other services or advocate for changes to service policies that may be stigmatising or discriminate against people living with HBV or HCV. As most hepatitis organisations have been funded for HCV projects, the focus of education and/or training workshops has focused on HCV more so than HBV. Due to the short timeframe for the development of this document, access to in depth evaluations of these projects has been difficult. Each hepatitis organisation has developed their education and training packages independently of Hepatitis Australia or other member organisations and as such, accessing full details or structure and evaluations is at the discretion of each organisations. However, key themes exist across state and territories.

The voice of people living with HCV has played an increasing role in education and advocating for change. The role of people living with hepatitis C also features highly in the delivery of training workshops. Most programs include a 'positive speaker' session. People sharing their lived experience of having the virus is particularly powerful and is generally highly valued by workshop participants.

Training sessions delivered by hepatitis organisations are delivered to a variety of audiences including government and non-government services as well as for-profit company employees. Mostly these workshops are offered for free. Training sessions featuring personal experiences are usually highly valued by workshop attendees. Examples of education and training by hepatitis organisations are provided under the Examples of Initiatives below.

In 2011, Hepatitis Australia embarked on the *Love Your Liver* project, linked to *World Hepatitis Day*. This multi-year activity aimed to increase community dialogue about liver health and gradually bring in greater discussion about viral hepatitis. Deploying this linked to *World Hepatitis Day* enabled community events to use *Love Your Liver* merchandise to engage with the public and frame hepatitis in broader discussion about liver health. Utilising this approach allows a focus on health rather than stigmatising any associated behaviours.

With a very limited community-based response focused on HBV it has been difficult to engage with the affected communities and raise awareness of HBV. In 2015, Hepatitis Australia commenced the Hepatitis B Grants Program which has enabled community-based organisations to develop projects focused on increasing awareness of testing and treatment for HBV. The funded projects require hepatitis organisations to engage with key population groups and the organisations working with them, including culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander communities.

While reducing stigma and discrimination is not a required outcome of Hepatitis Australia's Hepatitis B Grants Program, the increased dialogue within the target populations will facilitate greater understanding of the impacts of HBV within those communities, including stigma and discrimination.

Internet-based initiatives are used to engage with people living with HBV or HCV as well as enabling others to develop greater understanding of the issues faced by people living with HBV or HCV. In 2014, Hepatitis NSW launched the '*C the person, not the disease*' project. In 2015, Hepatitis Australia commenced *Speak Out*. Both initiatives enable the gathering of information about the experiences of people living with HCV and *Speak Out* was expanded to people living with HBV in 2016.

## EXAMPLES OF INITIATIVES

### HEPATITIS SA

Hepatitis South Australia coordinates several initiatives that work together to deliver workforce education sessions. These include participation from hepatitis educators, *HepTalk* positive speakers and peer educators. The positive speakers and peer educators are encouraged to speak about experiences of stigma and discrimination in the sessions.

The training focused on reducing fear and myths about hepatitis C (and viral hepatitis/blood borne viruses more broadly), particularly transmission risks, thereby aiming to reduce stigma and discrimination against people living with hepatitis B or C.

#### Health Services with whom this is Delivered/Run

Hepatitis SA provides workforce education to a variety of services and organisations including SA Police, Department of Correctional Services, youth services and other government and community services. The broad range of health-related services are included, some of which are listed below:

- dental health services
- rehabilitation centres
- SA Prison Health Services
- DASSA Clean Needle Program
- Anglicare
- district health services
- community mental health.

#### Dates/times

Workforce education sessions are conducted as needed. During 2015-2016, Hepatitis SA delivered a total of 34 education sessions.

**Hyperlink:** <http://hepatitissa.asn.au/services/education-training>

#### Evaluation of the Resource/Training Program

Participant evaluations are conducted to establish the effectiveness of each education workshop. In general this indicates an improved knowledge of HCV and stated changes in practice.

#### Could this Resource be Further Developed or Rolled Out?

Elements of the education and training workshops conducted by Hepatitis SA and other hepatitis organisations can be useful to establish a nationally consistent training package for a variety of audiences, including health professionals.

#### Additional Examples of Education and Training Programs

- Hepatitis NSW
  - Have a Bloody Go! (in service training)
  - Get Bloody Serious (professional development)
  - C-een & Heard (positive speaker project).
- Hepatitis Victoria
  - HEPReady.

Essentials

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## **INFECTIOUS PERSONALITIES.**

Launched on 1 December 2012, the *Infectious Personalities* film explores the emotional and physical impacts of stigma experienced by four Queenslanders and the barriers this can create to accessing healthcare.

### **Author:**

Infectious Personalities was filmed in Brisbane as a partnership between Hepatitis Queensland, Healthy Communities, Queensland Positive People, and the Queensland Positive Speakers Bureau, with funding assistance from Queensland Health

### **Health Services with whom this is Delivered/Run**

This initiative is an online resource open to the public.

### **Dates/times**

This initiative commenced in 2012

**Hyperlink:** <http://cmecommunityactiononhepc.tumblr.com/>

### **Evaluation of the Resource/Training Program**

An online survey was used to evaluate the survey. Early evaluation found that 96% of respondents believed the film was effective at decreasing discrimination and stigma towards people with hepatitis B, hepatitis C, and HIV/AIDS by health professionals

### **Could this resource be further developed or rolled out?**

This initiative demonstrates the use of the lived experience and the engagement of health professionals in responding to the use of online mediums such as YouTube make these resources accessible for use in a wide range of settings, including in the delivery of education and training.

## **C THE PERSON, NOT THE DISEASE.**

This initiative provides an online environment for people to share their thoughts and experiences of stigma and discrimination related to HCV. The focus is on an opening statement that *“Almost 1 in 3 people living with chronic hepatitis C report being discriminated against by a health professional on the basis of having hep C.”*

**Author:** Hepatitis NSW

### **Health Services with whom this is Delivered/Run**

This initiative is open to the public but illicit posts from both people living with HCV and health professionals.

### **Dates/times**

This initiative commenced in 2014.

**Hyperlink:** <http://cmecommunityactiononhepc.tumblr.com/>

### **Evaluation of the Resource/Training Program**

To date there is no formal evaluation of this project

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## **Could this resource be further developed or rolled out?**

The use of online mediums such as social media are valuable to support stigma and discrimination campaigns targeted at a broader audience. Health services who utilise social media could be encouraged to use these platforms to discuss hepatitis-related stigma and discrimination.

## **LOVE YOUR LIVER**

*Love Your Liver* was a multi-year initiative which commenced on World Hepatitis Day 2011. The aim of the campaign was to normalise hepatitis and portray it as a health condition without moralising.

**Author:** Hepatitis Australia

## **Health Services with whom this is Delivered/Run**

*Love Your Liver* was implemented nationally through Hepatitis Australia and its member organisations and included a dedicated website.

## **Dates/times (don't need to be specific)**

This initiative commenced in 2011 and concluded in 2015. Elements of the project remain in use.

**Hyperlink:** <http://loveyourliver.com.au/>

## **Evaluation of the Resource/Training Program**

A project evaluation is available from Hepatitis Australia.

## **Could this resource be further developed or rolled out?**

The use of online mediums such as social media are valuable to support anti stigma and discrimination campaigns targeted at a broader audience. Health services who utilise social media could be encouraged to use these platforms to discuss hepatitis-related stigma and discrimination.

## CONCLUSIONS

Based on the information provided in this submission, please provide a summary of the key actions your organisation thinks should be taken in an attempt to reduce stigma, discrimination and systemic barriers in the health system.

## STIGMA

### IMPACTING ON THE LIVED EXPERIENCE

Through the comments of people living with HBV and HCV and through previous research, it is clearly seen that stigma has a negative impact on the lives of people living with HBV or HCV, and that this is experienced in a variety of settings. Experiencing stigma can impact on decisions to disclose information about themselves, engage in care and seek timely treatment.

While experiences of stigma are not restricted to health services, people who are stigmatised because of an illness should be able to feel safe in healthcare environments. Environments where there is an expectation that the service provider will focus on the individual's health without judgement.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

The more recent comments from people living with HBV and especially HCV, suggest stigma about HBV and HCV is not limited to the healthcare sector but this is an environment where stigma and discrimination should be addressed as a priority. This includes GP clinics, community health centres and dental clinics.

### YOUR RECOMMENDED REMEDIATION

Addressing stigma means challenging long held community perceptions of transmissible infections such as HBV and HCV and of behaviours such as injecting drug use. There is a demonstrated need to address stigma and discrimination at a general community level and it is important to ensure people living with HBV or HCV have access to high quality health care services.

It is recommended that:

- education programs for medical practitioners include a focus on blood-borne viruses and stigma and discrimination
- greater support is provided to conduct community awareness campaigns aimed at reducing stigma and discrimination
- community-based hepatitis education programs delivered to a variety of participants, including healthcare professionals, are supported to include nationally consistent core learning outcomes.

## DISCRIMINATION

### REMEMBER, IT IS AGAINST THE LAW

The ability to access services and participate in everyday life without discrimination is not unreasonable to expect when laws are in place to address it. The stories of people living with HBV and HCV demonstrate that discrimination is not restricted to healthcare settings and can impact on employment, family and social networks.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

Discrimination, whether actual or perceived, has been experienced by people living with HBV and HCV in a variety of healthcare settings, including GP clinics, community health clinics, hospital emergency departments and dental health services.

### YOUR RECOMMENDED REMEDIATION

Addressing discrimination requires a number of factors to be in place. To support this it is recommended that:

- Understanding how stigma and discrimination in healthcare situations impacts on access to care is powerfully demonstrated by inclusion of personal stories in clinical training modules.
- Complaints mechanisms within health services are easily accessible and acknowledge that many people lodging complaints may be already experiencing stigma associated with their health condition.



## SYSTEMIC HEALTH SYSTEM BARRIERS

### IT'S ABOUT OPTIMAL HEALTHCARE.

In addition to stigma and discrimination there are a number of barriers that impact on the ability of people living with HBV and HCV to access optimal healthcare across a variety of healthcare settings. As treatments continue to improve, to cure or reduce the impact of viral hepatitis, it is important that the health system is responsive to, and supportive, of this.

### HEALTH SERVICE IN WHICH THIS IS EXPERIENCED

GP clinics, community health centres, community pharmacies, AOD clinics.

### YOUR RECOMMENDED REMEDIATION

Access to effective management and treatment is a key element to achieving the elimination of HBV and HCV in Australia and the consideration of the following of importance:

- more information that provides clarity about access to PBS listed medicines is developed and readily available to health care providers, regardless of the setting
- consideration is given to expanding independent prescribing rights to practitioners with a knowledge of HBV and/or HCV
- understanding how stigma and discrimination in healthcare impacts on access to care can be powerfully demonstrated by the inclusion of personal stories in clinical training modules.

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