Hepatitis C in Australia
Opportunities to end the epidemic.

Submission to:
The House of Representatives Standing Committee on Health

Inquiry into Hepatitis C in Australia
27 February 2015

Submitted by: Hepatitis Australia Inc.

Hepatitis Australia, incorporated in 1997, is the peak community organisation to progress national action on issues of importance to people affected by hepatitis C. Our mission is to provide leadership and advocacy on viral hepatitis and support partnerships for action to ensure the needs of Australians affected by, or at risk of viral hepatitis, are met. Our members consist of the eight state and territory hepatitis organisations.

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Introduction

Hepatitis C (HCV) is the most prevalent blood-borne virus in Australia. The House of Representatives Health Committee Inquiry into Hepatitis C in Australia (the Inquiry) presents a unique opportunity to realign and enhance Australia’s response to HCV.

As the national peak community organisation for viral hepatitis, Hepatitis Australia actively engages with its members to seek the views of community stakeholders, including people living with, or directly affected by HCV.

The goal of the Fourth National Hepatitis C Strategy (National Strategy) is to ‘reduce transmission of, and morbidity and mortality caused by hepatitis and to minimize the personal and social impact of this epidemic’. Australia is lagging behind in attaining this goal.

Australia’s response to HIV has demonstrated how an appropriately resourced, multifaceted approach that engages with the affected community can be effective in responding to an infectious disease. Hepatitis C is preventable and is now, for the vast majority of Australians, a curable condition. It is now time to emulate the same level of commitment to turn around the way Australia responds to HCV.

Australian governments must work with the community and act immediately to:

- Stop the rising death toll from HCV;
- Improve the quality of life for all people living with HCV; and
- Set this country on a path to eliminate HCV within a generation or so.

To achieve this, there will need to be increased support from all political parties and demonstrated political will from government, along with increased investment in a revitalised response to HCV in Australia. Consultation with our constituents indicate the following key elements are necessary for a revitalised response to hepatitis C:

- Increased community awareness of HCV;
- Access to the best available medicines that can cure HCV;
- Enhancing prevention strategies to optimum levels;
- Supporting community-based organisations to fully implement the National Strategy; and
- Accountable on-the-ground action that is of high quality and meets the needs of people affected by HCV.

This submission outlines each of these key elements that relate to the Terms of References of the Inquiry. Hepatitis Australia believes that if there is political will from Australian Governments, sensible and evidenced-based decisions and appropriately applied resourcing, Australia has the capacity to reduce the increasing burden of HCV and end the HCV epidemic in this country. Australia must act now, as the urgency has never been greater. 1,600 people living with chronic hepatitis C per year (30 per week) are estimated to be progressing to decompensated cirrhosis, liver cancer or they are dying.¹

¹“While deaths from HIV/AIDS have been reduced from 1.7 million in 2005 to 1.3 million in 2013, deaths from viral hepatitis have increased by 50% in the last 20 years, and show no sign of slowing. … Inexplicably, the lessons learnt from tackling the enormous burden of other infectious diseases simply haven’t been applied to viral hepatitis, resulting in a spiraling epidemic.” - Charles Gore, President, World Hepatitis Alliance.
Summary of recommendations

1. All Australian governments apply the lessons learnt from the HIV response and act immediately to elevate the response to HCV in Australia and stop the rising death toll.

2. The Australian Government invests in and works with peak non-government hepatitis organisations to develop, implement and evaluate a comprehensive, national HCV awareness campaign.

3. Australian governments legislate for the use of proven devices for the testing of HCV antibodies and that these devices may be used by appropriately trained personnel in both community and clinical settings.

4. The Australian Government approves the listing of the latest, most effective medicines for the treatment of HCV on the Pharmaceutical Benefits Scheme and that these medicines are made available equally to all people in Australia living with chronic HCV without discrimination.

5. The Australian Government works with the State and Territory Governments and non-government organisations to increase the capacity of the health system (primary and tertiary) to deliver treatment to all people living with HCV, regardless of where they live in Australia.

6. The Australian Government takes action to allow community-based prescribing and dispensing of medicines for the treatment of HCV as they have already done for people living with HIV.

7. The Australian Government restates its commitment for NSPs and delivers on the previous announcements from April 2014 to increase the funding available to enhance Australia’s response to blood-borne viruses.

8. All Australian governments commit to the introduction of needle and syringe programs in Australian correctional facilities and apply a timeline for the achievement of this goal.

9. All governments work with relevant non-government organisations to support the involvement of people living with HCV to participate in the national response to HCV.

10. The Australian Government ensures appropriately resourced, multi-year funding agreements are in place with national peak non-government organisations to ensure a coordinated national community-led response to HCV.

11. All Australian governments ensure a stable and appropriate funding environment that enables non-government organisations to plan and implement comprehensive awareness campaigns and client-focused programs.

12. Australian governments work with clinicians, researchers and the non-government sector to identify gaps in essential data to inform program design and implementation.

13. All governments ensure services (government and non-government) involved in the response to HCV are appropriately resourced and accountable with clear performance indicators linked to the implementation of the Fourth National Hepatitis C Strategy.
Increasing awareness of hepatitis C.  
(Terms of Reference sections a, c, d.i, d.ii and d.iii)

Public awareness of HCV in Australia is considered to be low. An awareness campaign must be instigated to address a variety of populations and aspects of HCV.

Awareness about transmission, prevention, health outcomes and available treatment, which varies for each form of viral hepatitis, is a priority. The Australian Government needs to make significant investment in, and support the community sector to develop effective, large-scale campaigns to raise the public profile of viral hepatitis in Australia.

Awareness campaigns

Unlike the Australian Government response to HIV, there have been no federally-funded, government-led public awareness campaigns for HCV. The Australian Government funded two major public awareness campaigns for HIV: the Grim Reaper campaign and later an anti-discrimination campaign.

Historically, this approach from the Government was established due to the significant stigma and discrimination and limited capacity of the community sector to rely on other sources of funding, including fundraising to conduct such projects. This same approach must be applied to HCV in Australia.

Non-government organisations, such as Hepatitis Australia, are best placed to develop and deliver programs to increase community awareness of HCV.

Creating supportive environments

Many people living with, or at risk of HCV, often experience stigma and discrimination. A recent survey by Hepatitis Australia found that 68% of respondents had personally experienced stigma or discrimination due to their having HCV and 58% of all respondents were aware of or had witnessed stigma or discrimination related to HCV.

To ensure awareness campaigns are sensitive to and support a reduction in stigma and discrimination related to HCV, the non-government sector must play a lead role in their development and implementation.

Parliamentarians and governments must be prepared to speak up about HCV in a way that supports community engagement and frames HCV as an important health issue in Australia.
Linkage to measurable outcomes

It is important that an awareness campaign for HCV includes calls-to-action that are measurable. Measuring general awareness is challenging. However, it can be done.

Monitoring the number of tests being conducted to detect HCV can indicate increased awareness of the risk factors leading to transmission. Australia must emulate the HIV response and introduce the use of point-of-care/rapid testing in the community to improve access to testing and subsequent engagement in care. Locally run awareness campaigns can be linked to a testing call-to-action for those with increased risks of infection.

There also needs to be appropriately targeted messages highlighting the importance of liver health and advising people diagnosed with HCV many years ago, to re-engage with health services to discuss new treatment options. The number of liver health checks being conducted can be an indicator of how whether people are engaged with health services.

An effective and comprehensive awareness campaign will require a coordinated and collaborative effort by all stakeholders.

Recommendation

2. The Australian Government invests in and works with peak non-government hepatitis organisations to develop, implement and evaluate a comprehensive, national HCV awareness campaign.

3. Australian governments legislate for the use of proven devices for the testing of HCV antibodies and that these devices may be used by appropriately trained personnel in both community and clinical settings.

Access to the best available medicines to cure hepatitis C

(Terms of Reference sections a, c, b, d.i and d.ii)

The new generation medicines for HCV offer the best possible opportunity for people to cure their infection and be free of HCV. However, this is about more than curing a disease. It is also about enabling people to live a full and productive life and supporting a reduction in the number of people requiring long-term care and support.

Affordable and highly effective medicine for all

The latest medicines for HCV offer benefits to all people with hepatitis, regardless of stage of disease. It is therefore vital that all people living with chronic HCV have equal access to the latest and most effective medicines.

Any approach other than ‘equal access’ would be discriminatory and potentially lead to litigation if denial of curable treatment to any person later led to development of cirrhosis, liver cancer or to death.

“We are witnessing a revolution in the treatment of hepatitis C virus with powerful molecules capable of curing the infection. There is no question that these treatments that can save millions of lives must be made universally available at an affordable price.”

- Pr. Françoise Barré-Sinoussi, 2008 Nobel Laureate in Medicine
Our constituents tell us that they felt let down by the Pharmaceutical Benefits Advisory Committee (PBAC) not making a positive recommendation at its July 2014 meeting to list the most effective drug at that time on the Pharmaceutical Benefits Scheme (PBS) as it denied them access to the latest and more tolerable cure for HCV. This must not happen again in 2015 as bureaucratic delays will come at too high a human cost, including unnecessary deaths.

Reducing morbidity and mortality

Deaths from primary liver cancer in Australia are rising faster than for any other type of cancer, having tripled between 1982 and 2007. Untreated HCV (and untreated hepatitis B) infections are the major drivers of this rise in mortality. Hepatitis C mortality surpassed mortality related to HIV in the year 2000 and has continued to rise since. The annual number of HCV liver disease-related deaths was estimated to be 630 in 2013.

Recent modeling has indicated that:

- Without significant improvement in treatment rates, Australia faces escalating rates of liver disease from HCV, including a 230% increase in liver-related deaths; 245% increase in liver cancer; and a 180% increase in liver cirrhosis by 2030.

- Nearly three-quarters of people living with HCV in Australia are aged over 40 years, placing them in the liver danger zone where their risk of serious liver disease is significantly increased.

Treatment for HCV is associated with a reduction in all-cause mortality. Scaling up the number of people accessing treatment early in the disease will further reduce the overall death rate in Australia due to both hepatitis C and other causes.

A health system that supports accessible treatment for hepatitis C

We have listened to the experiences of people accessing health services and it is clear that there are inconsistencies in the quality of care available. While there are many examples of optimal care, there are also some disturbing examples of poor systems, processes and attitudes.

It is evident that more education of health care providers is needed to increase understanding of HCV diagnosis, management and treatment as well as developing a greater understanding of the lived experiences of people with HCV.

It is vital to ensure the health system as a whole works effectively and efficiently to meet the needs of people living with HCV and that standards of care are assessed and practitioners and Health Departments are held accountable for improving quality of care where needed. Within a changing treatment environment it is timely to consider and implement new, more appropriate models to ensure effective, efficient access to treatment and supportive pathways to care are in place.
People living with HCV should have access to treatment regardless of where they live and without the requirement to wait for access to hospital-based specialist clinics; many of which have long waiting lists. Additionally, all services must be person-centred and people living with hepatitis C actively empowered to make decisions about their own treatment and care.

To enable an increase in the number of people accessing treatment for HCV, Australia must move HCV treatment and care from hospital-based clinics into community-based primary care. The latest medicines for treating hepatitis make a shift to primary care a safe and cost-effective option for the delivery of hepatitis C treatment. Without this, Australia will not meet the treatment targets outlined in the National Strategy.

Australia has moved to make medicines for HIV more accessible through community prescribing and dispensing. The same must be done for new medicines to treat HCV, and quickly.

Recommendations:

4. The Australian Government approves the listing of the latest, most effective medicines for the treatment of HCV on the Pharmaceutical Benefits Scheme and that these medicines are made available equally to all people in Australia living with chronic HCV without discrimination.

5. The Australian Government works with the State and Territory Governments and non-government organisations to increase the capacity of the health system (primary and tertiary) to deliver treatment to all people living with HCV, regardless of where they live in Australia.

6. The Australian Government takes action to allow community-based prescribing and dispensing of medicines for the treatment of HCV as they have already done for people living with HIV.

“The GP who made the initial diagnosis was non-judgmental and was interested in exploring treatment options. He recommended follow-up PCR testing and referral to the liver clinic. The nurses at the liver clinic were fantastic; […] The registrar at the liver clinic who started my treatment was very positive and provided excellent pre-treatment information. My partner was also provided with detailed information about treatment, possible side effects and some tips on how he could best support me. On my last visit the specialist reminded me that despite the fact I had done everything in my power to be successful… it is still possible that I could be one of the unlucky people who don’t achieve a sustained response. This was a useful reality check that helped sustain me when I came to realize that I didn’t achieve an SVR.”
– Person living with HCV.

“My specialist tells me US [the United States of America] has made improved treatments available because even though it is expensive in the short term it will be far less costly in the long term. Australia should follow suit.”
– Person living with HCV

“I am tired all the time, I have 3 kids, please make [the new medicine] available, my kids deserve to have a mother with normal energy levels and one that is around for many more years to come.
– Person living with HCV

“[People] need access to advancing treatments even if they are still using drugs…more people will be accessing treatment with better outcomes reducing the overall rate of transmission amongst injecting drug users and ultimately lowering risk for the whole community, also mandatory adequate education to all health staff… time to step forward and upward and being a leading country once again in the prevention and treatment of hep C.”
– A healthcare worker.
Optimal prevention of hepatitis C
(Terms of Reference sections a, b, c, d.i and d.ii)

The primary strategy to prevent infections of HCV in Australia continues to be the provision of sterile injecting equipment through needle and syringe programs (NSPs). As well as enhancing NSP services, Australia must scale up education about risk behaviours, introduce the use of point-of-care/rapid testing devices and remove barriers to the introduction of NSPs in correctional settings.

Needle and syringe programs (NSPs)

Australia has one of the world’s best and most cost effective programs for preventing the transmission of blood borne viruses. The NSP has long been proven to be a cost effective strategy offering a high return on investment.

A report commissioned by the Australian Government showed the investment in the direct cost of NSPs to have a high cost-benefit ratio for a preventative health intervention, saving an additional $4 for every $1 spent. If patient/client costs and productivity gains and loss are taken into account, this extends to $27.00 returned for every $1 invested\(^\text{vii}\). The Australian Government’s investment in NSPs from 2000 to 2009 is estimated to have resulted in the prevention of more than 96,600 HCV infections and over 32,000 HIV infections.

The evidence is that the investment in NSPs is not yet at an optimal level for HCV prevention and that greater investment in NSPs will result in greater returns.

Prevention in correctional settings

The reality is that HCV transmissions have occurred in prisons in every jurisdiction in Australia and these prisoners usually return to the general community. Prisoners are exposed to increased risks of acquiring HCV due to a number of risk behaviours and the lack of needle and syringe programs, which they can access in the community.

The trialing of prison-based needle exchange programs was included in the 3rd National Hepatitis C Strategy. However, Australian Governments are now ‘burying their heads in the sand’ as all attempts to have this carried across to the 4th Strategy have been quashed.

Political support for NSPs in prisons is generally low. This is despite all the available evidence from other countries operating prison NSPs showing they can be successfully implemented, reduce risk behaviours for HCV transmission and make prisons safer for both inmates and staff.

Attempts by the ACT Government to introduce Australia’s first prison-based NSP into the Alexander Maconochie Centre have been ongoing but continue to face opposition, in particular from unions. Union officials do not dictate public health policy in any other area of health service delivery and it is highly inappropriate that they do so in our prison system.

“Prison populations are still exposed to the risks posed by shared injecting equipment. The political will for this group is close to nil and will require a miracle or a cataclysmic event to change. If society continues to overlook this significant group of its people and deny them access to needle exchanges then it will make eradication of the virus impossible.” – Jack

“Because many people know that hepatitis C is prevalent in IV [intravenous] drug users then they just assume it’s a drug users disease. They forget that in every active addict there is a human being who has a good chance at recovery given the right circumstances.” – Sonia
Youth education

Prevention knowledge in the ‘at-risk’ populations builds on their general knowledge gained at school or in the media. With an increasing culture of body decoration that involves skin penetration, targeting risk behavior education toward youth remains important. A primary focus on skin penetrating behaviours also supports discussion around the risks of injecting drug use.

Hepatitis Australia has strategically used mainstream media to target youth at times when risk taking may be elevated (e.g. Schoolies). This approach needs to be enhanced through the use of social media and supported by governments and Australian schools.

Hepatitis Australia, in consultation with its members lodged submissions to the review of the National Curriculum – Health and Physical Education. Initial drafts of the curriculum included a focus on blood awareness but this was missing from later drafts. A number of state and territory hepatitis organisations have developed kits for teachers and youth workers and this work must be acknowledged and supported by the relevant government departments.

Recommendation

7. The Australian Government restates its commitment for NSPs and delivers on the previous announcements from April 2014 to increase the funding available to enhance Australia’s response to blood-borne viruses.

8. All Australian governments commit to the introduction of needle and syringe programs in Australian correctional facilities and apply a timeline for the achievement of this goal.

Supporting effective community engagement.

(Terms of Reference sections a, b, c and d)

As has been demonstrated in Australia’s response to HIV, the involvement of the affected communities is vital. People living with HCV come from diverse backgrounds and the virus disproportionately impacts people from marginalised populations. Many people living with HCV experience stigma and discrimination.

The views of people affected by HCV must be valued and they must be supported in sharing their experiences and contributing to the Australian response to HCV.

Informing service design and implementation

People living with HCV come from very diverse backgrounds and have diverse needs. Whether it is establishing new models of care for the treatment of HCV or creating enabling environments for people to access diagnostic services, understanding the needs of people affected by HCV is important in informing the design and delivery of services intended for them as well as general health services.

As has been demonstrated through the public hearings and the development of submissions like this one, many people affected by hepatitis are prepared to share their experiences and provide input. It is important that this be fostered and people are supported to participate.
Government and non-government services alike must ensure mechanisms exist for people living with HCV to express their views and contribute to Australia’s response to HCV.

The critical role of non-government organisations

The ability of non-government organisations, such as hepatitis organisations and those supporting people who inject drugs to engage with the affected communities, and inform service design and delivery is crucial in all aspects of the response to hepatitis C. This includes public education about prevention and messages about health maintenance for people who are living with HCV.

The existing NGOs have established networks and tools that can be enhanced if organisational capacity is increased. This includes the use of social media, a network of direct and online services, centralised access through a national information line, the use of personal stories and supporting ‘positive speakers’ programs.

To enhance the capacity of non-government organisations, governments must provide a stable funding environment. This would enable a more strategic approach to project planning and program development. It would also enable organisations to be more efficient and focus on services delivery and achieving outcomes.

Currently, several hepatitis organisations, including Hepatitis Australia, are in a very precarious government funding arrangement with ‘drip feeding’ via six month contract extensions and no indication of when submissions to obtain longer contracts may be distributed. These arrangements significantly limit the ability of hepatitis organisations to work effectively and efficiently towards the goals of the National Strategies.

Recommendations

9. All governments work with relevant non-government organisations to support the involvement of people living with HCV to participate in the national response to HCV.

10. The Australian Government ensures appropriately resourced, multi-year funding agreements are in place with national peak non-government organisations to ensure a coordinated national community-led response to HCV.

11. All Australian governments ensure a stable and appropriate funding environment that enables non-government organisations to plan and implement comprehensive awareness campaigns and client-focused programs.

Action on the ground – not talk at the top

(Terms of Reference sections a, b, c and d)

Section 7.6.1 of the National Hepatitis C Strategy 2014-2017 states: “Existing national surveillance systems need to be improved to provide accurate data to inform the planning and delivery of prevention and disease management options.”

While this statement is accurate, the lack of more detailed data should not impede progress to implement urgent activities such as: increasing community awareness; enhancing prevention strategies and access to the latest available medicines, which are clinically proven to cure HCV for the vast majority of people.
The targets of the National Strategy must be acknowledged by all levels of government and the community sector alike. To help progress Australia’s response to HCV and increase accountability, the targets of the National Strategy must be immediately translated into key performance indicators (KPIs) for all relevant funded programs, government and non-government.

The inclusion of KPIs must also support high standards of service delivery that is person-centred and involves people affected by hepatitis C in service development, and where relevant, service delivery.

**Recommendations**

12. Australian governments work with clinicians, researchers and the non-government sector to identify gaps in essential data to inform program design and implementation.

13. All governments ensure services (government and non-government) involved in the response to HCV are appropriately resourced and accountable with clear performance indicators linked to the implementation of the Fourth National Hepatitis C Strategy.

**Attachments**

A. *Hepatitis Equity Report – Champions and Challenges: Australia’s responses to viral hepatitis and HIV.* Hepatitis Australia, October 2014

B. *Changing the Landscape of Hepatitis C: Affordable access to the most effective medicines is the start.* Hepatitis Australia’s submission to PBAC, February 2015

C. *Liver Danger Zone Report: Regular liver check-ups must be made available to avert a liver disease crisis.* July 2014

D. *Consensus Statement: Addressing hepatitis C in Australian Custodial Settings.* June 2011

**References**


