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The Parliament of the Commonwealth of Australia

# The Silent Disease

## Inquiry into Hepatitis C in Australia

### House of Representatives Standing Committee on Health

June 2015  
Canberra

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## Chair's Foreword

Hepatitis C, an infectious disease is the most prevalent blood-borne virus in Australia, affecting an estimated 230 000 people. Hepatitis C is difficult to diagnose in its early stages, and over time, hepatitis C adversely affects the liver, and may lead to cirrhosis, liver disease, and liver cancer. Hepatitis C is the leading cause of liver transplants in Australia.

While Australia has one of the highest diagnosis rates for hepatitis C in the world (at approximately 80 per cent), it is estimated that 40 000 to 50 000 Australians are unaware that they are living with the disease. Exploring ways in which testing can be delivered in non-hospital settings, such as through community health clinics and medical services in rural and remote areas may increase the diagnosis rate for the disease as well as reach people who may not be able to seek medical treatment through more traditional avenues.

Approximately one per cent of people living with hepatitis C are undergoing treatment at any time. There are many reasons why the treatment rate for hepatitis C is low - one is that current therapies are long term commitments and have varying success rates depending on the genotype of hepatitis C carried by the person infected. Further, the location of treatment services in hospital settings can make treatment difficult to access for varying reasons including geographic proximity.

From a social perspective, there is a stigma associated with hepatitis C which can act as a disincentive to seeking treatment. As hepatitis C is a blood-borne disease, the majority of transmissions occur due to unsafe sharing of injecting equipment. There are, however other means of transmission, including mother-to-child transmission, unsafe tattooing or piercing, or through breakdowns in routine infection control practices in a medical setting. Transmission can also occur through receipt of unscreened blood product (received before 1990).

Raising awareness and understanding about hepatitis C can reduce the stigma associated with the disease. Hepatitis C is a virus carried by many everyday Australians, however, medical practitioners may still be unaware of how it can be transmitted. The Committee recommended that there be a specific campaign targeted at those at high risk of infection, focusing on: prevention strategies and

testing options, as well as a campaign focusing on people living with hepatitis C, who may not have sought advice about treatment options after their initial diagnosis. The Committee also recommended exploring ways in which the patient experience in general practice could be improved for people living with hepatitis C, through better information provision, improved treatment processes, and patient counselling.

Developed in consultation with State and Territory governments, and hepatitis stakeholder organisations, *the Fourth National Hepatitis C Strategy 2014-2017* is one of five national strategies aimed at reducing sexually transmitted and blood-borne viruses. The strategy identifies priority populations, how actions to address hepatitis C will be implemented, and the roles and responsibilities of all stakeholders.

The Committee found the need for a more robust reporting and review framework to support the *Fourth National Hepatitis C Strategy*, recommending that the Department of Health develop key performance indicators and annual reporting against those indicators to measure progress in addressing the challenge of hepatitis C.

Additionally, the Committee recommended that targets be set and reported against annually for the rates of testing for hepatitis C. Improved testing regimes, including the use of rapid point of care testing, offer opportunities for earlier diagnosis and treatment.

During its inquiry, the Committee examined testing and treatment options for several high risk groups identified in the *Fourth National Hepatitis C Strategy 2013-2017* including: people who inject drugs, people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds, and people in custodial settings.

The Committee recommended that there be an improved focus on reaching migrant communities with high rates of hepatitis C infection, and that all Australian jurisdictions work together to address the high hepatitis C infection rate amongst Aboriginal and Torres Strait Islanders.

The Committee was also interested in the issue of needle and syringe programs in prisons, and was grateful for the evidence it received. Evidence received will inform the ongoing broader debate in state and territory jurisdictions.

In response to evidence received, the Committee also made several recommendations concerning people in custodial settings. The Committee found inconsistencies between jurisdictions in the way prisoner health data is collected and reported, and recommended the development of a standardised approach to data collection and reporting. Improvements in this area have been identified as an important foundation for dealing with hepatitis C infections in custodial settings. The development of a national strategy for blood-borne viruses and



sexually transmitted infections in prisons to complement the five existing national strategies concerning these viruses and infections was also recommended by the Committee. Thirdly, the Committee recommended that the issue of hepatitis C in prisons, including exploring the provision of safe tattooing and barbering services, and the establishment of national standards in prison health delivery be discussed as part of the Council of Australian Governments Health Council process.

The Committee greatly appreciated hearing from people living with hepatitis C. They described the effect a hepatitis C diagnosis has on their life, as well as their experiences in seeking further information about their diagnosis and treatment.

I thank all the individuals, community and health organisations and government agencies who contributed to this Inquiry. In particular, I thank the many individuals who are living, or have lived with hepatitis C who participated in the inquiry. I also thank Committee Members for their contribution and participation.

Steve Irons MP  
Chair





## Committee Membership

**Chair** Mr Steve Irons MP

**Deputy Chair** Mr Tim Watts MP

**Members** Ms Lisa Chesters MP

Mr Andrew Laming MP

Ms Jill Hall MP

Dr Andrew Southcott MP

Ms Sarah Henderson MP

Mrs Ann Sudmalis MP

Mr Stephen Jones MP

Mr Ken Wyatt AM, MP

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(until 5 June 2015)

Ms Carissa Skinner





## Terms of Reference

In light of the recent release of the Australian Government's Fourth National Hepatitis C Strategy, the Standing Committee on Health inquire into and report on:

- a) prevalence rates of Hepatitis C in Australia
- b) Hepatitis C early testing and treatment options available through:
  - i) primary care
  - ii) acute care
  - iii) Aboriginal Medical Services
  - iv) prisons
- c) the costs associated with treating the short term and long term impacts of Hepatitis C in the community
- d) methods to improve prevention of new Hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through:
  - i) the public health system
  - ii) public health awareness and prevention campaigns to reduce morbidity and mortality caused by Hepatitis C
  - iii) non-government organisations through health awareness and prevention programmes.





## Abbreviations

ACT	Australian Capital Territory
ACCHS	Aboriginal Controlled Community Health Services
AHA	Australasian Hepatology Association
AH&MRC	Aboriginal Health and Medical Research Council
AIVL	Australian Injecting and Illicit Drug Users League
AMS	Aboriginal Medical Services
ARCSHS	Australian Research Centre in Sex, Health and Society
ARTG	Australian Register of Therapeutic Goods
ASID	Australasian Society for Infectious Diseases
CEO	Chief Executive Officer
COAG	Council of Australian Governments
CPSU	Community and Public Sector Union
CSRH	Centre for Social Research in Health
GP	General Practitioner
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
HSDs	Highlight Specialised Drugs
NSPs	Needle and Syringe Programs

NSW	New South Wales
OST	Opioid Substitution Treatment
PBS	Pharmaceutical Benefits Scheme
PBAC	Pharmaceutical Benefits Advisory Committee
QNU	Queensland Nurses' Union
RACGP	Royal Australian College of General Practitioners
RNA	Ribonucleic Acid
RPOCT	Rapid Point-Of-Care Testing
SA	South Australia
TGA	Therapeutic Goods Administration
Vic	Victoria
WA	Western Australia
WAPOU	Western Australia Prison Officers' Union
WHO	World Health Organization





# Recommendations

## 2 Overview – Hepatitis C in Australia

### Recommendation 1

The Committee recommends that the Department of Health enhance reporting on the *National Hepatitis C Strategy* by including a comprehensive reporting and review framework (which includes an annual report and reporting against key performance indicators) within the Strategy.

## 3 Living with Hepatitis C

### Recommendation 2

The Committee recommends that the Australian Government, in collaboration with the states and territories, work to develop well-informed hepatitis C awareness campaigns targeted at:

- *The general community* to provide information on how hepatitis C is transmitted, how it can be prevented, and how it can be treated;
- *Populations at high-risk of hepatitis C infection*, informing them of transmission risks, prevention strategies, and the availability of voluntary testing;
- *People living with hepatitis C* who have not sought advice about treatment options since their initial diagnosis; and
- *The wider community* to highlight the impact of stigma on the social and emotional wellbeing of people living with hepatitis C and their families.

## 4 Testing and Treatment

### Recommendation 3

The Committee recommends that the Department of Health, in consultation with relevant stakeholders, devise a specific target or targets

for hepatitis C testing and report on progress towards reaching the target or targets annually.

#### Recommendation 4

The Committee recommends that the Department of Health consider the ways in which rapid point of care testing (RPOCT) can assist in implementing the goals of the *Fourth National Hepatitis C Strategy* and the *National Hepatitis C Testing Policy*.

#### Recommendation 5

That the Department of Health work with the Royal Australian College of General Practitioners and liver clinics to examine appropriate information provision, treatment processes, and patient counselling for people diagnosed with hepatitis C.

## 5 Reaching Populations at High Risk of Infection

#### Recommendation 6

The Committee recommends that the Department of Health work with States and Territories to produce culturally and linguistically specific information for migrant groups with higher rates of hepatitis C infection to inform them about hepatitis C including: transmission methods, testing and treatment options.

#### Recommendation 7

The Committee recommends that the Department of Health work with States and Territories to develop strategies to address the high prevalence rates of hepatitis C in the Aboriginal and Torres Strait Islander population.

#### Recommendation 8

The Committee recommends that the Department of Health work with State and Territory health and corrections agencies to:

- develop a standard approach to data collection and reporting of prisoner health in custodial settings; and
- give consideration to the provision of support for safe tattooing, barbering and any other legal practices which may present a risk of hepatitis C transmission in custodial settings.

#### Recommendation 9

The Committee recommends that a national strategy for blood-borne viruses and sexually transmissible infections in prisons be developed. The strategy should accompany and support the five existing jurisdictional strategies and be developed, implemented, reviewed and assessed in the same way.

### **Recommendation 10**

The Committee recommends that the Australian Government raise the issue of hepatitis C in prisons, and the establishment of national standards in prison health delivery as part of the Council of Australian Governments (COAG) Health Council process.

