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The Silent Disease

Inquiry into Hepatitis C in Australia

House of Representatives Standing Committee on Health

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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

Committee Secretariat

Secretary	Ms Stephanie Mikac
Inquiry Secretary	Mr Colby Hannan (until 13 February 2015)
	Mr Shane Armstrong (from 17 February 2015)
Senior Research Officer	Ms Lauren Wilson (until 8 May 2015)
Administrative Officers	Mrs Alex Fabbo (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.

1

Introduction

1.1 Hepatitis C is the most prevalent blood-borne virus in Australia.[1] Affecting an estimated 230 000 Australians,[2] hepatitis C is an infectious disease that attacks the liver and can lead to cirrhosis, end-stage liver disease and liver cancer.[3]

1.2 Infections are caused by the contagious blood-borne hepatitis C virus. Left untreated, hepatitis C can progress to the chronic stage, and[4] as symptoms of infection may be mild or not evident after exposure, hepatitis C may go undetected until significant liver damage has developed.[5]

1.3 Estimates suggest that 90 per cent of all new hepatitis C infections, and 80 per cent of existing hepatitis C infections are the consequence of reusing or sharing injection equipment.[6] Other causes of hepatitis C infection include: unsafe tattooing or body piercing practices, exposure to contaminated blood products, or breakdowns in infection control in healthcare. These methods of transmission are discussed in further detail in Chapter 2.

1.4 Recent scientific advances in prevention, testing and treatment provide an opportunity to reduce new infections and improve health outcomes for those living with hepatitis C. Since the virus was first identified in 1989,[7]

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1 Hepatitis Australia, *Submission 84*, p. 3.

2 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 15.

3 Cancer Council Australia, *Submission 79*, p. 4.

4 Figures vary by country. Australian data indicates that 75 per cent of people with hepatitis C will develop a chronic infection. Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 3.

5 World Health Organisation, 'Hepatitis C', Fact Sheet 164, Updated April 2014. <http://www.who.int>

6 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 3; see also, Australasian Society for Infectious Diseases, *Submission 11*, p. 8.

7 World Health Organisation, 'Hepatitis C – An Introduction', <http://www.who.int>

Australia's response to hepatitis C indicates that progress has been made, but that there is more to do.

1.5 The National Hepatitis C Strategy is the Australian Government's response to addressing the challenge posed by hepatitis C and is one of five national strategies aimed at reducing sexually transmitted infections and blood borne viruses.[8]

1.6 The *Fourth National Hepatitis C Strategy 2014-2017* was developed in consultation with State and Territory governments and hepatitis stakeholder organisations. The Strategy details how priority actions will be implemented, the roles and responsibilities of all stakeholders, timeframes and lines of accountability, and how goals, targets and objectives will be monitored.[9]

About the inquiry

Objectives and Scope

1.7 On 7 November 2014, the then Minister for Health, the Hon Peter Dutton MP, referred the Inquiry into Hepatitis C in Australia (the inquiry) to the Standing Committee on Health (the Committee).

1.8 In respect to the release of the Australian Government's *Fourth National Hepatitis C Strategy, t*he terms of reference required the Committee to inquire into and report on:

- prevalence rates of hepatitis C in Australia
- hepatitis C early testing and treatment options available through:
  - ⇒ primary care
  - ⇒ acute care
  - ⇒ Aboriginal Medical Services
  - ⇒ prisons
- the costs associated with treating the short term and long term impacts of hepatitis C in the community
- methods to improve prevention of new hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through:

8 The other four strategies are: The Second National Hepatitis B Strategy 2014-2017, The Third National Sexually Transmissible Infections Strategy 2014-2017, The Fourth National Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections Strategy 2014-2017, and The Seventh National HIV Strategy 2014-2017.

9 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 7.

- ⇒ the public health system
- ⇒ public health awareness and prevention campaigns to reduce morbidity and mortality caused by hepatitis C
- ⇒ non government organisations through health awareness and prevention programmes.

1.9 The inquiry terms of reference relating to the *testing and treatment options available through prisons* attracted considerable comment during initial hearings. Taking this into consideration, the Committee held a roundtable on the prevalence and prevention strategies and testing and treatment of hepatitis C in prisons. This hearing was attended by representatives of prison officer unions and hepatitis C advocacy organisations.

1.10 While additional evidence was received in respect to the issue *of testing and treatment options available through prisons*, the Committee has sought to comment on the matter in the wider context of evidence received and in response to the terms of reference.

Inquiry Conduct

1.11 The inquiry was announced on 2 December 2014 via media release, with submissions sought by 27 February 2015. In an effort to capture as much evidence as possible for the duration of the inquiry, the Committee accepted submissions after this date.

1.12 In total, the Committee received 110 submissions and 16 exhibits from a wide range of individuals and organisations. Submissions and exhibits received during the inquiry are listed at Appendixes A and B respectively.

1.13 The Committee held five public hearings (as shown below). Three of these (Canberra, Melbourne and Sydney) were in a roundtable format.

Date	Place
21 January 2015	Melbourne, Vic
22 January 2015	Sydney, NSW
10 March 2015	Perth, WA
20 March 2015 4 May 2015	Canberra, ACT

1.14 The witnesses who gave evidence at these hearings are listed at Appendix C. Submissions received and transcripts of public hearings are available on the Committee's webpage at: <www.aph.gov.au/health>.

Report Structure

1.15 The report is comprised of five chapters and outlines the Committee's findings, comments and recommendations in relation to its Inquiry into Hepatitis C in Australia. More specifically:

- Chapter 2 defines hepatitis C, and outlines how infections are commonly acquired, basic prevention techniques, and current testing and treatment options available in Australia. Data on the prevalence and incidence of hepatitis C in Australia are also presented. The chapter concludes with an overview of the national strategies in place for responding to hepatitis C.
- Chapter 3 seeks to provide an insight into living with hepatitis C, and outlines issues associated with the stigma and discrimination which may accompany a hepatitis C diagnosis. This chapter also discusses hepatitis C awareness in the general population.
- Chapter 4 addresses the key issues identified during the inquiry that relate to testing and treatment. Issues include:
  - ⇒ challenges and innovations in testing;
  - ⇒ new treatments;
  - ⇒ information about, and awareness of hepatitis C in the health care system; and
  - ⇒ the treatment delivery models.
- Chapter 5 highlights efforts to address hepatitis C for identified as being at high risk of infection: injecting drug users, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds and people in custodial settings.

Figure 1.1 The Committee taking evidence in Sydney

Source *Standing Committee on Health Secretrariat*

2

Overview – Hepatitis C in Australia

Introduction

2.1 This chapter provides background information about the hepatitis C virus, its causes, and current prevention strategies. There is also discussion about the prevalence and testing of, and treatment options available in Australia.

2.2 The chapter then discusses the costs associated with hepatitis C in Australia and the *Fourth National Hepatitis C Strategy* that has been progressively developed as a coordinated national response to hepatitis C.

What is Hepatitis C?

2.3 'Hepatitis' means inflammation of the liver which is commonly caused by a hepatitis virus. The types of viral hepatitis are identified by alphabet letters, such as hepatitis A, B and C. The hepatitis C virus (HCV) was identified in 1989; prior to this it was known as non-A, non-B hepatitis.[1]

2.4 HCV is spread by blood-to-blood contact. The majority of individuals infected with HCV have no symptoms; however, mild and non-specific symptoms that may occur include fatigue, muscle pain, and low grade fever.[2]

2.5 Once infection occurs, the first six months is the acute phase. During this time, the virus may be cleared without treatment.[3] However, most people[4]

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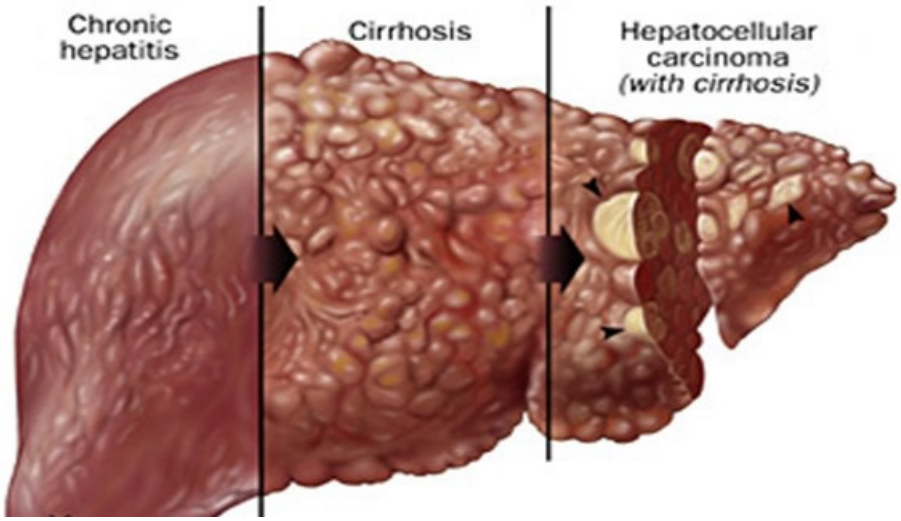
1 For more information on the discovery of HCV, see M Houghton, 'Discovery of the Hepatitis C Virus' *Liver International*, vol. 29, no. s1, January 2009, pp 82-88.

2 Jacinta Holmes, Alexander Thompson, and Sally Bell, 'Hepatitis C: An Update', *Australian Family Physician*, July 2013 Vol 42 (7), p. 453.

3 Jacinta Holmes, Alexander Thompson, and Sally Bell, 'Hepatitis C: An Update', *Australian Family Physician*, July 2013 Vol 42 (7), p. 453.

will move to the chronic phase, which can last for the rest of their life. Chronic hepatitis C can lead to cirrhosis,[5] end-stage liver disease, and liver cancer.[6]

Figure 2.1 The progression of hepatitis C related liver disease



Source *The Burnet Institute*

2.6 There are believed to be six major genotypes (1 to 6) of HCV, although there are also subtypes. The genotypes most prevalent in Australia are genotypes 1 (54 per cent) and 3 (37 per cent). Genotype 2 represents around five per cent of cases.[7]

2.7 When asked to explain why hepatitis C does not cause liver damage until many years after the virus enters a person's body, Professor Geoff McCaughan who, among other roles, is the Chair of the Transplant Society of Australia and New Zealand, compared hepatitis C to HIV using a World War I trench warfare analogy:

> HIV goes down into the trench while hepatitis C sits up at the trench and actually fights the immune system to try to establish

4 Figures vary by country, but Australian data indicates that 75 per cent of people with hepatitis C will develop a chronic infection. Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

5 Cirrhosis is a chronic degenerative disease that changes the structure of the liver. Normal liver cells are damaged and replaced by scar tissue. M Haggerty, R Frey, and L Cataldo, 'Cirrhosis', in L Fundukian, ed, *The Gale Encyclopaedia of Medicine*, 4th ed, Detroit: Gale, 2011.

6 Australian Government, *Fourth National Hepatitis C Strategy 2014-2007*, July 2014, p. 18; World Health Organization 'Hepatitis C', *Weekly Epidemiological Record*, vol. 86, no. 41 (7 October 2011) <http://www.who.int>.

7 Department of Health, 'Hepatitis C Genotypes', viewed 14 November 2014, <http://www.health.gov.au>.

> dominance over the immune system. So the immune system is always attacking the hepatitis C virus. But because of its very nature it mutates ... By varying its sequences, through quasi-species, it escapes the immune attack all the time.
>
> That leads to a situation where the virus becomes established in the host, or the human, and the immune system can no longer recognise it, if you like, over a period of time, and it continues to replicate. But the immune system continues to try to fight it, and that is what damages the liver. The war between the immune response and the virus is happening largely inside the liver, and the collateral damage is to the liver cells themselves, and the development of cirrhosis.[8]

2.8 Professor McCaughan added that any liver damage caused by hepatitis C is dependent on how the body reacts to the virus. Professor McCaughan noted that if the virus is no longer recognised by the immune system and "stays at reasonable levels' then liver damage may be minimal or not occur at all:

> It is well known that there are patients who live for 50 years with this virus with virtually no liver damage, or minimal liver damage.[9]

Causes

2.9 In Australia, cases of hepatitis C largely stem from unsafe injecting practices.[10] This accounts for approximately 90 per cent of newly-acquired infections and 80 per cent of existing cases.[11]

2.10 Other exposures to infected blood that may result in infection or increase the risk of infection include:

- tattooing or body piercing where non-sterile equipment is used;
- breakdowns in routine practices of infection control in healthcare settings;
- medical procedures involving contaminated blood or blood products although transmission by this means is now rare in Australia;[12] and

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8 Professor Geoff McCaughan, Chair of the Transplant Society of Australia and New Zealand, Australian Liver Association, *Committee Hansard*, Sydney 22 January 2015, p. 34.

9 Professor Geoff McCaughan, Australian Liver Association, *Committee Hansard*, Sydney 22 January 2015, p. 35.

10 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

11 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

12 In the 1970s and 1980s, infection as a result of blood transfusions and other medical procedures involving blood products was a more common cause of infection in developed

- mother-to-child transmission.[13]

2.11 Sexual transmission of hepatitis C is also possible, but not common.[14]

Prevention

2.12 Unlike those available for the hepatitis A and B viruses, there is no vaccine to prevent hepatitis C infection. A previous hepatitis C infection does not make a person immune to reinfection.[15] There are, however a range of behaviours that are recommended to stop the spread of hepatitis C. Among others, these behaviours include:

- not injecting drugs (or if a person continues this form of drug use, that sterile needles or syringes are used and other injecting equipment is not shared);
- ensuring equipment involved in body piercing, tattooing, electrolysis or acupuncture is single-use or sterilised;
- not sharing personal hygiene items such as toothbrushes or razors;
- not following infection control guidelines in the healthcare environment; and
- taking precautions such as wearing single-use gloves when in contact with blood in other health situations such as providing first aid.[16]

2.13 Behavioural change is also supported by specific services, with needle and syringe programs (NSPs) being a key service for preventing hepatitis C infections.[17]

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countries. The research that led to the identification of the virus in 1989, however, also demonstrated that blood screening tests could effectively eradicate the transmission of transfusion-associated HCV. Blood screening for HCV has been in place in Australia since February 1990. C M Houghton, 'Discovery of the Hepatitis C Virus', *Liver International*, vol. 29, no. s1, January 2009, p. 82; Department of Health and Ageing, *National Hepatitis C Testing Policy*, 2012, p. 12.

13 An estimated risk of 5 to 6 per cent, Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 4.

14 Heterosexual transmission is rare; however, more recently some cases have been attributed to unprotected sexual contact between men involving men co-infected with HIV and hepatitis C. Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 4.

15 Australian Government Fourth National Hepatitis C Strategy 2014-2017, July 2014, p. 4.

16 A more comprehensive list can be found at Victorian Department of Health 'Hepatitis C', Better Health Channel, viewed 14 November 2014, <http://www.betterhealth.vic.gov.au>.

17 National Centre in HIV Epidemiology and Clinical Research, *Return on Investment to: Evaluating the Cost-Effectiveness of Needle and Syringe Programs in Australia*, 2009; cited in Australian Government *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 15.

Tests for Hepatitis C

2.14 There are two key tests for hepatitis C. An anti-HCV antibody test determines whether a person has been exposed to HCV. The hepatitis C RNA test shows whether the person has an ongoing infection. Professor Margaret Hellard, a noted infectious diseases researcher and clinician, told the Committee the antibody test 'is a highly specific and sensitive test' that should be undertaken before the RNA test This is because the antibody test is 'considerably cheaper' than the RNA test and it would not be necessary to conduct an RNA test if the person is antibody negative. Although the antibody and RNA tests are the key tests, following an RNA test that detects an ongoing infection, a number of other tests may be needed.[18]

Management and Treatment

2.15 Regular monitoring and treatment is necessary to detect progressive liver disease and liver cancer, and to reduce the risk of cirrhosis, liver cancer and liver failure. The management of hepatitis C can also take into account other aspects of care and support, such as referrals to drug and alcohol, community health and mental health services. Care becomes more complicated if the patient is co-infected with hepatitis C and HIV; in these cases hepatitis C can be more severe and progress more rapidly to liver disease. [19] Further, even if an infected patient's treatment results in a 'sustained virological response' (meaning the person is considered to have cleared hepatitis C), they will continue to have a higher risk of liver cancer if cirrhosis has developed.[20]

2.16 Liver transplants are another aspect of the burden associated with chronic hepatitis C. However, liver transplants are only a temporary solution as the disease recurs in the transplanted liver. Ten years after a transplant, the incidence rate of cirrhosis among hepatitis C patients is 50 per cent.[21]

18 Professor Margaret Hellard, Director, Centre for Population Health, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, pp 17-18.

19 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p 20.

20 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p 3.

21 Professor Geoff McCaughan, Australian Liver Association, *Committee Hansard*, Sydney 22 January 2015, p. 15.

Specific Treatments

2.17 Treatment for HCV has predominately been based on pegylated interferon and ribavirin,[22] however, the current treatments used for hepatitis C in Australia now depend on the genotype of HCV the patient has.

2.18 For genotype 1 (54 per cent of cases in Australia), new direct acting antiviral medicines taken daily support a regimen of weekly pegylated interferon injections and daily ribavirin tablets.[23] These medicines, boceprevir and telaprevir, were registered by the Therapeutic Goods Administration (TGA) in 2012 and became available through the Pharmaceutical Benefits Scheme (PBS) in April 2013.[24]

2.19 For genotype 2, treatment continues to be based on interferon and ribavirin.[25] Genotype 3, requires a combination of weekly pegylated interferon injections and daily ribavirin tablets over a period of 26 weeks).[26]

2.20 Treatments involving pegylated interferon and ribavirin can cause significant side-effects. HepatitisWA advised that these can include:

- mild-to-severe mood disturbances;
- anaemia;
- slow blood-clotting;
- fatigue;
- flu-like symptoms;
- dry skin and skin rash;
- insomnia;
- decreased appetite;
- weight loss;
- hair loss; and

22 Interferons are proteins produced by the human body in response to a viral infection. Pegylated interferon is a modified form of interferon designed to extend the duration of the therapeutic effect. Ribavirin is a drug that alters the body's immune response to viruses. See Department of Health, 'Treatments: Pegylated Interferon and Ribavirin', viewed 18 November 2014, <http://www.health.gov.au>

23 Hepatitis Australia, 'Treatment of Hepatitis C', viewed 14 May 2015, <http://www.hepatitisaustralia.com>.

24 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 5.

25 HepatitisWA, 'Hepatitis C Treatment and Side Effects', viewed 14 May 2015 <http://www.hepatitiswa.com.au>.

26 Hepatitis Australia, 'Treatment of Hepatitis C', viewed 14 May 2015, <http://www.hepatitisaustralia.com>.

- in relation to ribavirin, birth defects.[27]

2.21 However, a new generation of medications for treating chronic hepatitis C have progressed or are progressing from discovery and development stages to being available for use. These medications offer simpler treatment regimens, fewer side effects and more favourable health outcomes than current treatments.

Incidence and Prevalence in Australia

2.22 Hepatitis C is one of the most common notifiable diseases in Australia.[28] It is estimated that in 2013 there were 310 000 people living in Australia who had been exposed to hepatitis C (that is, they were HCV antibody positive). An estimated 230 000 people had a chronic hepatitis C infection; of these 155 000 had early liver disease, 64 000 had moderate-to-severe liver disease and 11 400 had hepatitis C-related cirrhosis. In 2013 there were an estimated 630 liver-related deaths linked to hepatitis C.[29]

2.23 Globally, it is thought that 130 to 170 million people are chronically infected with hepatitis C. The World Health Organization (WHO) estimates that each year 350 000 to 500 000 people die from hepatitis C-related liver diseases.[30] Available data comparing the prevalence of hepatitis C in Australia and other countries are at Table 2.1.

27 HepatitisWA, *Submission 9*, p. 2.

28 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3. Hepatitis C was made a notifiable disease in most states and territories in 1990 (and has been notifiable in all states and territories since 1995), meaning that cases of newly diagnosed hepatitis C infection are required to be reported to the National Notifiable Diseases Surveillance System. Department of Health and Ageing, *National Hepatitis C Testing Policy*, 2012, p. 18.

29 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 7.

30 World Health Organization 'Hepatitis C', April 2014, viewed 12 November 2014 <http://www.who.int>.

Table 2.1 Number of people with chronic hepatitis C infections, by selected country or region

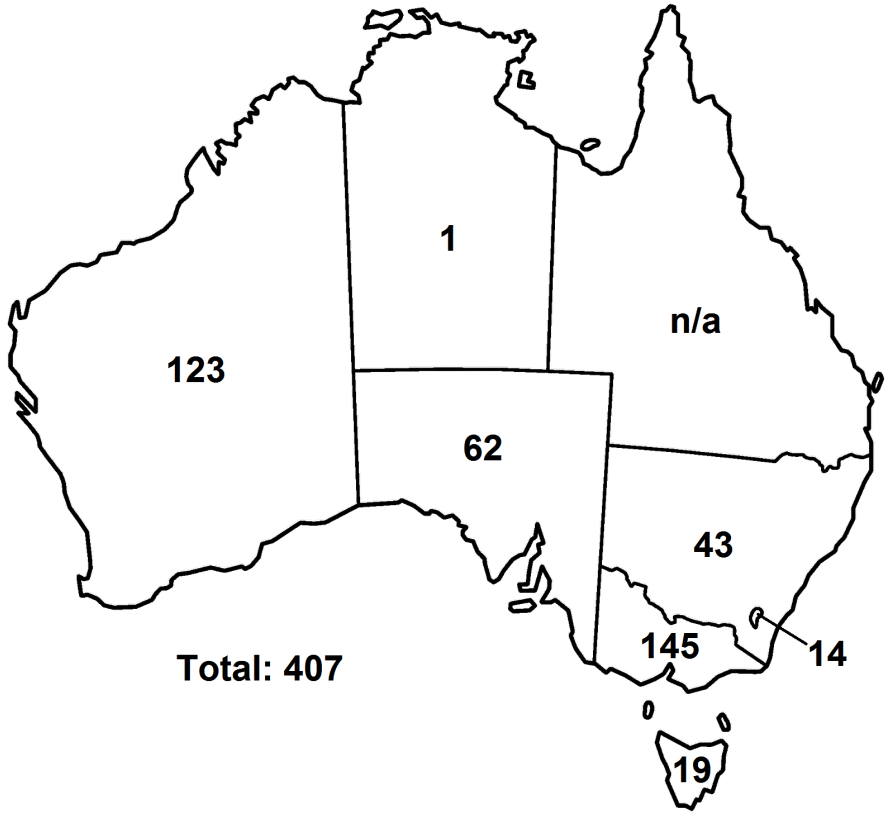
Country/region	Estimated number of people infected	Estimated prevalence
Sweden	n/a	0.04% (2008)[a]
United Kingdom	214 000	England: 0.4% (2005)[b] Scotland: 0.7% (2013)[b]
Canada	242 000 (2007)	0.8% (2007)[c]
France	n/a	0.84% (2004)[a]
United States	3.2 million (2002)	1.3% (2002)[d]
Australia	230 000 (2013)	1.4% (2013)[e]
Italy	n/a	2.6% (2007)[a]
Globally	130–170 million	2–3%[f]
China	n/a	> 3%[f]
Pakistan	n/a	> 3%[f]
Egypt	n/a	22%[f]

Sources [a] European Centre for Disease Prevention and Control, *Surveillance and Prevention of Hepatitis B and C in Europe*, 2010, p. 24; [b] Public Health England, *Hepatitis in the UK: 2014 Report*, July 2014, p. 17; [c] Public Health Agency of Canada, *Hepatitis C in Canada: 2005-2010 Surveillance Report*, 2012, p. 4; [d] Center for Disease Control and Prevention, 'Hepatitis C Information for the Public' <www.cdc.gov/Hepatitis/C/cFAQ.htm> viewed 13 November 2014; [e] The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 16; [f] WHO, *Weekly Epidemiological Record,* vol. 86, no. 41 (7 October 2011), viewed 13 November 2014, <http://www.who.int>.

2.24 Data for the annual number of hepatitis C diagnoses is available in two categories: all diagnosed infections and infections that have been newly-acquired (within the previous two years). In 2013, there were 10 715 diagnoses of hepatitis C infection in Australia. The number of newly-acquired infections was 407.[31] A breakdown of the newly-acquired infections in 2013 by location, age, sex, and exposure category is at Figure 2.1 and Table 2.2.

31 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 58. The data for newly-acquired hepatitis C infections does not include Queensland as data for that State is not available.

Figure 2.2 Number of newly acquired hepatitis C infections in 2013 by location



Source *The Kirby Institute, HIV, Viral Hepatitis and Sexually Transmissible Infections In Australia: Annual Surveillance Report 2014, p. 58.*

Table 2.2 Number of diagnoses of newly acquired hepatitis C infections in 2013, by age group, sex and exposure category

Age group	**Sex**				**Exposure category**	**Sex**		
	M	*F*	*Total*			*M*	*F*	*Total*
0–4	3	1	4		Injecting drug use	205	93	300
5–14	0	0	0		Sexual contact	12	4	16
15–19	19	12	31		Blood/tissue recipient	2	0	2
20–24	63	29	92		Skin penetration procedure	4	2	6
25–29	61	28	90		Healthcare exposure	4	2	6
30–39	73	37	110		Household contact	2	1	3
40–49	42	16	58		Other	24	9	33
50–59	11	4	15		Undetermined	25	16	41
60+	6	0	6					
Not reported	0	0	1					
Total	278	127	407		Total	278	127	407

Source The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 59.

** Includes diagnoses in people whose sex was not reported*

2.25 In recent years, it is considered that the incidence of hepatitis C in Australia has been stable or possibly decreasing.[32] While the overall rate of diagnosis fell from 52.7 per 100 000 in 2009 to 46.3 per 100 000 in 2013, the number of diagnoses of newly-acquired hepatitis C has been relatively stable – 399 instances were diagnosed in 2009 compared to 407 in 2013.[33] Declining incidences have been most prominent in the 25 to 29 and 20 to 24 year age groups; over the past ten years the diagnosis rates for these groups have decreased by 50 per cent and 43 per cent respectively.[34] However, new diagnoses of hepatitis C have been gradually increasing in the Aboriginal and Torres Strait Islander population (from 130 per 100 000 in 2008 to 166 per 100 000 in 2012).[35]

2.26 Despite the overall incidence rate remaining stable or possibly declining, the consequences of existing hepatitis C cases remain significant. Although there is a high diagnosis rate of hepatitis C in Australia (over 80 per cent), the estimated number of people being treated for chronic hepatitis C is very low, with only approximately one per cent accessing treatment.[36] An increase in the number of people living with hepatitis C presenting with liver damage is becoming more evident: for example, the estimated number of people with moderate to severe liver disease has increased by 115 per cent over the past ten years.[37] Chronic hepatitis C was also considered to be the underlying cause of liver disease in 22 per cent of the liver transplants that occurred in 2012.[38] Hepatitis C is the most common reason for liver transplants in Australia, as it is globally.[39]

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32 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 2.

33 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 59.

34 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 14.

35 It is also expected that the figures for the Aboriginal and Torres Strait Islander population are likely to be under-reported, partly because Aboriginal and Torres Strait Islander status is not always included when an infection is notified. See Australian Government, *Fourth National Aboriginal and Torres Strait Islander Blood-Borne Viruses and Sexually Transmissible Infections Strategy, 2014-2017,* July 2014, p. 4, 6.

36 Based on a 2012 study. Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

37 The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 7.

38 Hepatitis Australia, *A Guide to Current and Emerging Hepatitis C Treatments in Australia*, 2012; cited in Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

39 Economist Intelligence Unit, *The Silent Pandemic: Tackling Hepatitis C with Policy Innovation*, 2012, p. 2, <http://www.economistinsights.com>, viewed 14 November 2014 ; Professor Alex Thompson, Director, Department of Gastroenterology, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 6.

2.27 Witnesses told the Committee that without intervention, the burden will increase further. Ms Helen Tyrrell, the Chief Executive Officer of Hepatitis Australia informed the Committee that three-quarters of people with hepatitis C in Australia are in what is termed the 'liver danger zone'; that is, they are 'over 40 years of age and are judged to be at significant risk of developing serious liver disease'.[40] Professor Alex Thompson advised that, according to current estimates, the number of people living with hepatitis C-related cirrhosis in Australia is expected to increase to 38 000 by 2030. Further, the annual number of people expected to be diagnosed with liver cancer related to hepatitis C – 590 people in 2015 – is expected to increase by 400 per cent by 2030.[41]

2.28 Associate Professor Joseph Torresi from the Australasian Society for Infectious Diseases (ASID) used the available data and likely trends to sum up the hepatitis C situation in Australia as follows:

> We know there has been some reduction in die number of new cases of hepatitis C which have been reported. However, we also know that the proportion of people with advanced liver disease requiring more complex therapy has increased and that is no surprise as the population of hepatitis C infected people will age and will be more likely to develop complications. The other important point is that the incidence of hepatitis C among people who inject drugs has increased, not decreased.[42]

High Risk Groups in Australia

2.29 The main group of people in Australia who are at high-risk of acquiring a hepatitis C infection are those who inject drugs. For people in this group, the risk of acquiring the disease is highest in the first year of injecting. In addition, injecting drug users from the following groups (and other people who have injected drugs from them) have a particularly heightened risk of acquiring hepatitis C:

- people in custodial settings or with a history of incarceration;[43]
- people from Aboriginal or Torres Strait Islander backgrounds;

40 Ms Helen Tyrrell, Chief Executive Officer, Hepatitis Australia, *Committee Hansard,* Melbourne, 21 January 2015, p. 2.

41 Professor Alex Thompson, Director, Department of Gastroenterology, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 6.

42 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 7.

43 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 3.

- people from culturally and linguistically diverse backgrounds; and
- sex workers.[44]

2.30 Hepatitis C rates among Indigenous Australians are three times higher than for the rates for the non-Indigenous population. Ms Sandra Bailey, Chief Executive Officer of the Aboriginal Health and Medical Research Council of NSW, stated that among the Aboriginal and Torres Strait Islander population prevalence rates are six times higher for 15 to 19 year olds, and five times higher for 20 to 29 year olds, compared to the non-Indigenous population.[45] Among Indigenous Australians who inject drugs, the rate of hepatitis C infection is estimated to be between three and 13 times higher than that of the non-Indigenous injecting drug user population.[46]

2.31 In prison populations, the prevalence of hepatitis C infection is estimated to be 35 to 47 per cent of male inmates and 50 to 70 per cent of female inmates (overall, up to half of the full-time prison population).[47] The heightened prevalence of hepatitis C in prison populations is attributed to the 'high rate of imprisonment for drug-related offences and unsafe injecting drug use in prisons'.[48]

2.32 Individuals can fall within multiple high-risk groups, compounding the risk. For example, 43 per cent of Indigenous Australians in custodial settings tested for blood-borne diseases were found to be infected with hepatitis C, compared with 33 per cent of non-Indigenous inmates.[49]

2.33 In addition to the established high-risk populations and activities, emerging behaviours are of concern to hepatitis C experts. Although drugs such as heroin and methamphetamines are commonly associated with hepatitis C, other groups of injectors, such as those using performance and image-enhancing drugs, are now recognised as being at

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44 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 13.

45 Ms Sandra Bailey, Chief Executive Officer, Aboriginal Health and Medical Research Council of NSW Inc., *Committee Hansard*, Sydney, 22 January 2015, p. 9.

46 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 17. Most notifications of diagnosis do not report Aboriginal and Torres Strait Islander status as demonstrated by the data presented by the Kirby Institute. See The Kirby Institute, *HIV, Viral Hepatitis and Sexually Transmissible Infections in Australia: Annual Surveillance Report 2014*, p. 65.

47 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, pp 17, 39; Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, Hepatitis C Subcommittee, *Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings*, July 2008, p. [1].

48 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 17.

49 T Butler and C Papanastasious, *National Prison Entrants' Blood Borne Virus and Risk Behaviour Survey 2004 & 2007,* 2008; cited in Australian Government Fourth National Hepatitis C Strategy 2014-2017, July 2014, p. 26.

a heightened risk of infection.[50] Another issue is the large number of Australian travellers visiting countries with high endemic rates, an issue that the ASID warned is 'under-appreciated'.[51] Associate Professor Joseph Torresi explained that studies show 'around 20 per cent of travellers engage in very high-risk activities for a range of sexually transmitted diseases and blood-borne viral infections'.[52] The low-price tattoos available in countries frequented by Australian travellers were also considered to be a potential risk.[53]

Costs Associated with Hepatitis C

2.34 One measure of the effects hepatitis C has on the Australian community as a whole is the economic cost associated with hepatitis C infections and treatment. One aspect of this is the consequences of hepatitis C for government budgets. The Boston Consulting Group estimated that the combined annual cost associated with hepatitis C to Commonwealth, State and Territory budgets was $252 million in 2012, and was projected to cost $1.5 billion over the following five years.[54]

2.35 The medical costs associated with hepatitis C are a significant expense. The expenditure on subsidised medicines for the treatment of hepatitis C under the Pharmaceutical Benefits Scheme exceeded $87 million in 2013-14. Hepatitis C-related medical services subsidised under the Medicare Benefits Schedule, such as specialist or general practitioner appointments and tests, totalled $7.6 million in 2013-14.[55] The cost of a liver transplant in Australia is reported to be around $140 000.[56]

2.36 Medical research into hepatitis C is also supported. The Department of Health advised that from 2004 to 2013, the National Health and Medical

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50 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 15.

51 Australasian Society for Infectious Diseases, *Submission 11*, p. 4

52 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 30.

53 Australasian Society for Infectious Diseases, *Submission 11*, p. 4; Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, pp 29-30.

54 Boston Consulting Group, *The Economic Impact of Hepatitis C in Australia*, August 2012, p. 7, viewed 14 November 2014, <http://www.hepatitisaustralia.com>.

55 Professor Chris Baggoley, Chief Medical Officer, Department of Health, *Committee Hansard*, Sydney, 22 January 2015, p. 2.

56 Professor Geoff McCaughan, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 15.

Research Council 'provided funding of $86 million for a wide range of research projects on hepatitis C'.[57]

2.37 Another source of expenditure is the support given to NSPs, which aim to minimise the spread of blood borne viruses in general/ not just hepatitis C. The Department of Health advised that in the decade from 2000 to 2009, Australian governments invested $243 million in NSPs with a historical average of around $9.5 million per annum.[58]

2.38 The Boston Consulting Group report also concluded that for every dollar spent by governments treating chronic hepatitis C, an additional four dollars are spent 'to deal with the consequences of a failure to prevent, treat and cure it'. The report estimated that over five years, $640 million would be spent on Commonwealth assistance for 'those who are disabled by their illness, who are too ill to work or who have lost their jobs for HCV-related reasons'.[59]

2.39 The economic impact of hepatitis C is, however, broader than the cost to government budgets and the burden on the health system. Another aspect is the work days lost to the economy. In general, employee absences trigger direct costs for the employer from personal leave and additional wages or overtime for any replacement employees. Absences can also result in lost productivity or income for a business. In the United States, a 2010 study provided evidence in support of a relationship between hepatitis C infection, reduced productivity and increased health-related work absences, finding that employees with hepatitis C had 1.8 times more absence days than employees who did not have hepatitis C.[60]

2.40 Witnesses argued that without changes to the current approach to hepatitis C in Australia, the costs related to hepatitis C will increase. Professor Alex Thompson, Director of Gastroenterology at St Vincent's Hospital in Melbourne, told the Committee that if the projected increase in the number of people with cirrhosis is realised, direct medical costs related to hepatitis C will increase from approximately $224 million per year to over $300 million per year by 2030.[61] However, increased treatment rates could potentially decrease costs and the burden on the health system. For

57 Professor Chris Baggoley, Department of Health, *Committee Hansard*, Sydney, 22 January 2015, p. 2.

58 Mr Graeme Barden, Assistant Secretary, Health Protection Policy Branch, Department of Health, *Committee Hansard,* Sydney, 22 January 2015, p. 4.

59 Boston Consulting Group, *The Economic Impact of Hepatitis C in Australia*, August 2012, p. 7, viewed 14 November 2014, <http://www.hepatitisaustralia.com>.

60 J Su et al, 'The Impact of Hepatitis C Virus Infection on Work Absence, Productivity, and Healthcare Benefit Costs' *Hepatology*, vol. 52, no. 2, 2010, pp 438-441.

61 Professor Alex Thompson, St. Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 7.

example, the Australasian Society for Infectious Diseases stated that 'targeting treatment towards patients with advanced liver disease results in the lowest overall cost with an annual cost of $143 million in 2030'.[62]

2.41 Treatment costs are examined further in Chapter 4.

National Strategies for Responding to Hepatitis C

2.42 There are currently five national strategies intended to support a coordinated, national response to blood-borne viruses and sexually transmissible infections. The most recent versions of the strategies were endorsed by the Council of Australian Governments (COAG) Health Council in June 2014.[63]

2.43 One of the strategies specifically addresses hepatitis C: the *Fourth National Hepatitis C Strategy*. Another strategy, the Fourth National Aboriginal and Torres Strait Islander Blood-Borne Viruses and Sexually Transmissible Infections Strategy 2014-2017, is also relevant to hepatitis C. In addition to the national strategies, some state and territory governments have developed their own hepatitis C strategies.

2.44 The stated goal of the Fourth National Hepatitis C Strategy is 'to reduce the transmission of, and morbidity and mortality caused by, hepatitis C, and to minimise the personal and social impact of the epidemic'.[64] The objectives identified to achieve this goal are:

- reducing the incidence of hepatitis C;
- reducing the risk behaviours associated with the transmission of hepatitis C;
- increasing access to appropriate management and care for people with chronic hepatitis C;
- reducing the burden of disease attributed to chronic hepatitis C; and
- eliminating the negative impact of stigma, discrimination, legal and human rights issues on people's health.[65]

2.45 Underpinning the goal and objectives are a number of priority areas.

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62 Australasian Society for Infectious Diseases, *Submission 11*, p. 3; Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 8.

63 Department of Health, 'National Strategies for Blood-Borne Viruses and Sexually Transmissible Infections', viewed 17 November 2014, <http://www.health.gov.au>.

64 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 6.

65 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 6.

Table 2.3 Priority areas under the *Fourth National Hepatitis C Strategy 2014–2017*

Category	Stated priority areas for action
Prevention	■ Increase availability, access to and use of sterile injecting equipment among people who inject drugs. ■ Continue to support increased access to evidence-based harm-reduction and drug treatment programs, including NSPs, peer education and opioid pharmacotherapy programs. ■ Build greater understanding of, and skills within, priority populations, healthcare professionals and the community sector as they relate to hepatitis C transmission. ■ Consider the impact of new drug therapies that will cure the large majority of hepatitis C cases.
Testing	■ Increase voluntary testing of hepatitis C in priority populations. ■ Improve referral and access to high quality support services at the time of diagnosis for people with or at risk of hepatitis C to initiate a pathway to care. ■ Assess the feasibility, accessibility and cost effectiveness of the range of existing and emerging testing methods. ■ Implement targeted initiatives to improve understanding and skills related to hepatitis C testing for priority populations, healthcare professionals and services, and the community sector.
Management, care, support	■ Improve awareness and knowledge in priority populations about treatment options. ■ Support and implement appropriate models of care for primary healthcare, drug and alcohol services, health services in custodial settings, Aboriginal community-controlled health services and community health services. ■ Implement strategies to increase the involvement of primary healthcare professionals in the management of people with hepatitis C. ■ Implement strategies to encourage increased involvement of primary healthcare governance at the local level to ensure better integration of services.
Workforce	■ Improve awareness and knowledge of hepatitis C in the health workforce. ■ Provide the primary healthcare workforce with support and mentorship to ensure successful testing, management and treatment in primary healthcare. ■ Support community organisations and the healthcare workforce to increase appropriate engagement with priority populations to improve health literacy and maximise health.
Enabling environment	■ Explore the development of a national hepatitis C public education campaign. ■ Create supportive and enabling environments, promote the health and rights of those living with or at risk of hepatitis C, and support access to hepatitis C prevention, treatment and care services. ■ Identify and work to address legal barriers to evidence-based prevention activities across jurisdictions. ■ Support the implementation and expansion of post-release testing, management and treatment programs for priority populations in custodial settings.
Surveillance, monitoring, research and evaluation	■ Strengthen the hepatitis C component of the National BBV & STI Surveillance and Monitoring Plan. ■ Improve our understanding of the burden of disease attributable to hepatitis C and the associated risk factors. ■ Develop appropriate evidence-based public health responses and evaluate the impact of these programs on the increasing morbidity and mortality due to hepatitis C. ■ Promote balance in research to take account of social, behavioural, epidemiological and clinical research to better inform all aspects of the response. ■ Evaluate health promotion, testing, treatment, care, support and education and awareness programs and activities to ensure they are effective.

Source Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, pp 15–27.

2.46 The latest iteration of the strategy is the first to include specific targets. By 2017, the Fourth National Hepatitis C Strategy aims for the incidence of new hepatitis C infections to have been reduced by 50 per cent and the number of people receiving antiviral treatment each year to have increased by 50 per cent.[66]

2.47 Progress against the objectives and targets will be measured where possible. For example, the objective of reducing the risk behaviours associated with the transmission of hepatitis C will be measured with reference to the following three indicators:

- the per capita number of needles and syringes distributed in the previous calendar year;
- the proportion of all injections by people who inject drugs in which a new needle and syringe was used in the previous calendar year; and
- the proportion of people who inject drugs reporting re-using another person's used needle and syringe in the previous month.[67]

2.48 It is recognised in the Strategy, however, that there are gaps in the ability to monitor the implementation of the Strategy and measure success against the objectives and targets. The Strategy stated that 'existing national hepatitis C surveillance systems need to be improved to provide accurate data to inform the planning and delivery of prevention and disease management options'.[68] A key gap identified to be addressed is 'the lack of a nationally agreed indicator for measuring progress in reducing the health impact of stigma, discrimination, and legal and human rights in the context of this Strategy'.[69]

2.49 The Strategy also described 'an urgent need' to develop an indicator for reliable reporting on disease related mortality and morbidity attributed to chronic hepatitis C infection nationally. 'Possible areas identified included 'indicators that report on hospitalisations or the number of deaths attributed to hepatitis C, and the proportion of liver cancer attributable to hepatitis C'.[70] Estimates around the undiagnosed proportion of hepatitis C was another area noted for review and update.[71]

2.50 In response to questions about the *Fourth National Hepatitis C Strategy*, the Department of Health told the Committee that an implementation plan is being developed that will set out the tasks to be achieved during the life of

66 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 6.
67 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 8.
68 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 27.
69 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 7.
70 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 27.
71 Australian Government, *Fourth National Hepatitis C Strategy 2014-2017*, July 2014, p. 7.

the Strategy.[72] Further, the implementation of all the national strategies for blood-borne viruses and sexually transmissible infections will be reviewed in 2017.[73]

2.51 A Department of Health official told the Committee that progress against the implementation plan will also be regularly reviewed, with progress measured against the data compiled by the Kirby Institute:

> [The Kirby Institute data] will tell us whether our testing and our treatment targets are being met. It will record for us on an annual basis how many people are still undiagnosed, how many people are accessing treatment and where they live anywhere in Australia, whether they are urban, regional or very remote, and it will tell us that jurisdiction. So we have a very complete picture of the hepatitis C incidence and prevalence across any year. That is the data that will tell us whether we are achieving our targets.
>
> The implementation plan is overseen by a number of committees. One is the standing committee of the Australian Health Protection Principal Committee. All chief health officers sit on that committee and they will be reviewing the implementation plan, probably annually, to see whether all partners – states and territories, community based [organisations], researchers and the Commonwealth – are actually implementing the priority action items that we all agree to.[74]

Concluding Comment

2.52 As it is globally, hepatitis C is a significant public health issue in Australia, with an estimate that 230 000 Australians live with chronic hepatitis C.

2.53 The currently high prevalence and expected future prevalence of hepatitis C is of concern. If the gap between the numbers of people estimated to be living with hepatitis C compared with the number of people undergoing treatment widens, there is likely to be an increased reliance on the health system.

2.54 The Committee endorses the *Fourth National Hepatitis C Strategy* and acknowledges renewed commitments by all Australian jurisdictions to address hepatitis C. In particular, the Committee considers the Strategy's

72 Professor Chris Baggoley, Department of Health, *Committee Hansard,* Sydney, 22 January 2015, p. 3.

73 Mr Graeme Bardon, Department of Health, *Committee Hansard,* Sydney, 22 January 2015, p. 6.

74 Ms Teresa Gorondi, Director, Blood Borne Viruses and Sexually Transmissible Infections Section, Department of Health, *Committee Hansard,* Sydney 22 January 2014, p. 6.

inclusion of targets for reducing the incidence of new hepatitis C infection through various measures and increasing the number of people receiving antiviral treatment important developments.

2.55 The Committee has, however, found it difficult to determine how progress is being made against the targets identified in the *Fourth National Hepatitis C Strategy*. The Strategy could be enhanced with the inclusion of a comprehensive reporting and review framework which includes an annual report, and reporting against key performance indicators.

2.56 The Committee notes that the Department of Health is developing an implementation plan to support the *Fourth National Hepatitis C Strategy*, and recommends that the implementation plan be part of the overall reporting framework as mentioned above.

Recommendation 1

2.57 **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

Introduction

3.1 Hepatitis C carries significant physical challenges resulting from progressive liver inflammation which may progress to scarring (fibrosis and cirrhosis), moderate or serious liver disease and, in some cases, liver cancer and liver failure.[1] Undergoing treatment for the virus can have debilitating side effects including fatigue, low energy and motivation, weight loss, hair loss, anaemia, nausea, diarrhoea, difficulty sleeping, headaches, bleeding gums, shortness of breath, muscle aches, joint aches, rashes, acrid mouth, mouth ulcers, thyroid problems, 'brain fog', anxiety, and severe depression.[2]

3.2 Furthermore, people living with hepatitis C are very likely to experience stigma and discrimination as a result of the virus. Stigma and discrimination can have adverse effects on mental and physical health, and can deter individuals affected from prevention, testing, treatment and accessing support services.[3]

3.3 This chapter will present the experiences of those living with hepatitis C, their reactions to diagnosis and their reasons for seeking, or rejecting, treatment. Although this chapter will touch on issues that are discussed throughout this report, the chapter will focus on personal accounts and the impact of the virus on the personal lives of Australians.

3.4 The chapter will also reflect on some of these personal experiences, and discuss the importance of promoting awareness and access to accurate information as part of Australia's public health response to hepatitis C.

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1 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 1.

2 Hepatitis SA, *Submission 33*, p. 6.

3 Centre for Social Research in Health, *Submission 28*, p. 3.

This Chapter also focuses on awareness raising activities to improve prevention, testing and treatment rates.

Diagnosis and Treatment Experiences

Testing and Diagnosis

3.5 Testing is a 'critical component of the hepatitis C care and treatment continuum', and importantly, the testing experience can 'determine further engagement with care and treatment'.[4] According to Hepatitis SA, the majority of people with hepatitis C are diagnosed by a general practitioner (GP).[5]

3.6 Despite the importance of a positive experience for long-term care, the Committee received personal accounts from inquiry participants which described confusion, shock and anxiety after receiving their diagnosis.[6] For example, Ms Justine Doidge, who was diagnosed in her mid-20s, commented:

> I was pretty surprised and confused when I was first told over the phone that I had tested positive to something called hepatitis C. At the time I did not really understand what hepatitis C was. When I got the phone call I thought I had just been given a death sentence. It was about a week before I could get an appointment with my doctor to discuss what was going on. It was a really long week.[7]

3.7 Mr Paul Kidd recounted how he was initially diagnosed with hepatitis C and stated:

> I wish my doctor had not told me that I was lying when I told him that I had not been injecting drugs. As I said, my infection was sexual, and his response to that was: 'Well, that's so rare that it's essentially fanciful, and people lie about injecting drugs. I'm a

4 Centre for Social Research in Health, *Submission 28*, p. 1.

5 Hepatitis SA, *Submission 33*, p. 5.
Hepatitis SA conducted a survey of its clients and found that 61 per cent were diagnosed in a GP clinic; 9 per cent in an Alcohol and Other Drugs setting; 9 per cent in a hospital; 7 per cent in an STI clinic; 7 per cent at the blood bank; 5 per cent in a prison; and 2 per cent in a specialist's surgery.

6 For example, Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 40; Mr Paul Kidd, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 37; Mr Grenville Rose, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 41; Ms Pam Wood, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 39; Hepatitis SA, *Submission 33*, p. 6.

7 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 40.

> doctor; I see this all the time.' And then he made some notes and we moved on. I wish that he had been more aware of sexual transmission, because I went on and, within six months of that, I infected two other people with hepatitis C sexually, and one of them was my partner. So it would have been good to have had a greater willingness to accept the veracity of what I was saying and not merely dismiss it as some kind of attempt to cover up taboo behaviour.[8]

3.8 Receiving a positive diagnosis of hepatitis C can have a highly emotional impact on individuals and their families. Ms Pam Wood explained her initial reaction to her diagnosis, stating:

> I felt shocked, confused, frightened, uninformed and unsupported. I was fearful of the future and what it would hold, and very quickly jolted back to unresolved problems of the past. I felt ashamed, guilty, dirty and stigmatised. I kept my disease very much to myself and fretted considerably over such things as disclosure, who to disclose to and how I could continue to work.[9]

3.9 These personal accounts are mirrored in the findings of a number of studies conducted in Australia. In 2014, the Australian Research Centre in Sex, Health and Society (ARCSHS) conducted an online survey of 170 Australians living with hepatitis C. The survey found that 57 per cent of survey participants who received their diagnosis from a GP 'did not receive any or only limited information about hepatitis C when first diagnosed'.[10] The ARCSHS noted that the lack of information provided after diagnosis is inconsistent with the *National Hepatitis C Testing Policy*.[11]

3.10 The ARCSHS survey also found that only 14 per cent and 58 per cent of participants had pre-test and post-test discussions respectively with their GP. Seventeen per cent of participants reported that they had no discussion with their GP at the time of diagnosis.[12]

3.11 Similarly, research conducted by the Centre for Social Research in Health at the University of New South Wales (CSRH) found that the diagnosis experience 'was poor' among those recently diagnosed, relative to the best practice recommendations of the *National Hepatitis C Testing Policy*.[13] In line with the ARCSHS survey, the study conducted by the CSRH found that:

8 Mr Paul Kidd, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 40.

9 Ms Pam Wood, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 39.

10 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.

11 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.

12 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.

13 Centre for Social Research in Health, *Submission 28*, pp 1-2.

- Participants indicated confusion regarding tests and the implications of results; and
- Post-test discussions were incomplete, with insufficient information, support and referrals provided.[14]

3.12 The CSRH concluded that there is a need to support diagnosing doctors and increasing their awareness of the *National Hepatitis C Testing Policy*, particularly among doctors in sexual health clinics and alcohol and drug services.[15]

3.13 In a recent survey of its clients, Hepatitis SA reported that in the twelve months following diagnosis, the follow up provided for survey respondents was:

- 34 per cent were provided with information;
- 45 per cent were provided with follow up consultations with a GP;
- 45 per cent were provided with a specialist referral; and
- 21 per cent were provided with a referral for support.[16]

3.14 However, Hepatitis SA stated that it was 'disturbed' by the finding from the survey that 37 per cent of respondents received no follow up at all in the 12 months following diagnosis.[17]

3.15 Hepatitis SA reported that its survey respondents stated that the following would have been desirable upon receiving their diagnosis:

- 'Well informed and empathic GP
- GP follow up/monitoring, including mental health monitoring
- Information - including written information about the virus, symptoms, living well lifestyle
- information, how to prevent transmission to family and friends, and in particular, treatment options and side effects and what happens if you don't have treatment
- Information about disclosure, stigma and discrimination
- Referrals for support, support groups and counselling
- Referral to specialist/viral hepatitis nurse within 12 months
- To be offered the latest treatments – from GP or tertiary treatment clinic
- Psychological assessment prior to treatment'.[18]

3.16 The Government of Western Australia also acknowledged that the *National Hepatitis C Testing Policy* should be 'more widely promoted to

14 Centre for Social Research in Health, *Submission 28*, p. 2.
15 Centre for Social Research in Health, *Submission 28*, p. 2.
16 Hepatitis SA, *Submission 33*, p. 5.
17 Hepatitis SA, *Submission 33*, p. 5.
18 Hepatitis SA, *Submission 33*, pp 5-6.

health professionals', but also noted that 'further strategies need to be developed to detect hepatitis C without necessarily requiring the disclosure of risk factors'.[19]

3.17 A patient demand-driven model was recommended by the Government of Western Australia, which would see informed patients initiating a discussion about testing for the virus with their GP. The strategy of public awareness campaigns to increase the testing rate is further discussed later in this chapter. Clinical aspects about testing methods and strategies are also discussed in Chapter 4.

Treatment

3.18 As briefly described in Chapter 2, current treatment options involve weekly injections for a period of six to twelve months and have a cure rate of between 50 and 75 per cent.[20] Furthermore, when data was collected in 2012, only one per cent of those infected with chronic hepatitis C were undergoing treatment.[21]

3.19 A number of participants in the inquiry expressed the view that treatment rates were dramatically impacted by the likely treatment experience. Professor Alex Thompson, Director of Gastroenterology at St Vincent's Hospital, commented on patients' ineligibility or refusal to commence treatment because of the notable side effects.[22] Professor Joseph Torresi commented that patients are not taking up existing treatment options because 'they know how bad the treatment is'.[23] This was reflected in the personal account of Mr David Pieper who described the side-effects of hepatitis C treatment: 'I can tell you that HIV is a walk in the park in comparison to hepatitis C'.[24] A similar account was provided by Mr Chris Lawrence, who, in a submission, stated that a medical practitioner had told him: 'The cure is sometimes worse than the disease'.[25]

3.20 Mr Grenville Rose also commented on the side-effects of hepatitis C treatments which left him unable to work:

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19 Government of Western Australia, *Submission 12*, p. 4.

20 Professor Alex Thompson, Director, Department of Gastroenterology, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 6.

21 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 3.

22 Professor Alex Thompson, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 7.

23 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 16.

24 Mr David Pieper, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 44.

25 Mr Chris Lawrence, *Submission 47*, p. 2.

> I have now done two rounds of… treatment. Neither worked. Both gave me flu-like symptoms for the duration of the treatment. The second treatment had so many spectacularly varied side effects that it left me unable to work for 18 months. Now the virus I cannot seem to shake is slowly causing more and more problems in my life. After seven years in my current job in mental health research and evaluation, I am leaving paid employment. I am too tired to turn up for work every day. It is a demand I can no longer meet.[26]

3.21 Further, Mr William Lenane described the side effects of existing treatments as 'worse than the disease itself', stating:

> I tried [a] triple combination therapy treatment… in late 2013, until 2014, but the side effects became unbearable. My body had become covered in sores. I had no warning or control over my bowels. I suffered nausea for three to four days after my… injection and the slightest bump to my body resulted in severe bruising.
>
> These side effects are worse than the disease itself.[27]

3.22 The challenges raised in these personal accounts are also reflected in the broader community of those living with hepatitis C. A study conducted by the ARCSHS in 2011 found that the most frequently reported barrier to treatment was fear of side effects.[28]

3.23 The ARCSHS noted that 'treatment decision making is not straightforward. Treatment involves a heavy time and, for some, a heavy financial commitment, involving weekly visits to specialist services for between six and twelve months'.[29]

3.24 The ARCSHS commented that as hepatitis C is 'mostly a silent infection, with few symptoms', that initial symptoms associated with hepatitis C are often not as significant as the potential side effects of available treatments. The ARCSHS also noted that this 'makes the decision to begin treatment particularly difficult', which is also compounded by the likely success of treatments.[30]

3.25 The ARCSHS 2011 study also found that of the 86 participants who had received treatment for the hepatitis C virus, 65 per cent had completed the treatment, of which 55 per cent had cleared the virus.[31] According to the

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26 Mr Grenville Rose, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 41.

27 Mr William Lenane, Private Capacity, *Committee Hansard*, Sydney 22 January 2015, p. 43.

28 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.

29 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 4.

30 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 5.

31 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.

ARCSHS study, the most frequently reported reason for ceasing a course of treatment was treatment failure (61 per cent) and unmanageable treatment side effects (43 per cent).[32]

3.26 Factors which have influenced a decision not to seek treatment include both personal and social reasons as well as clinical reasons. These include:

- Personal and social reasons:
  - ⇒ Impact treatment will have on family/friends and/or on work;
  - ⇒ Can't commit myself to a long treatment program;
  - ⇒ Wanting to have children in the near future;
  - ⇒ Costs associated with treatment;
  - ⇒ Liver clinic too difficult to get to;
- Clinical reasons:
  - ⇒ Because of feeling unwell;
  - ⇒ Treatment success rate is not good enough;
  - ⇒ Side-effects of treatment;
  - ⇒ Liver status is good (minimal scarring); and
  - ⇒ Because I don't know enough about treatment.[33]

3.27 Ms Justine Doidge, who, after treatment, cleared the hepatitis C virus and now volunteers for Hepatitis NSW's telesupport service,[34] commented that many callers have questions and concerns about commencing treatment, with many side effects, and relatively low cure rates. Ms Justine Doidge described the fear and concern of callers who are diagnosed or seeking treatment of the virus, and commented:

> People are really afraid, which is often the same response from people who find out that they are sitting next to someone who has hep C. So fear is a big one… The general things that they want to know are: 'What about these side effects? What's going to happen to me? What am I signing up for?... How can I plan for the next six months at a minimum, up to a year, of my life? How do I forecast that? How do I navigate it?' I was lucky, because it was just my partner and me, but I know a lot of these people have families and kids. It is like, 'I really want to access treatment, but I'm a bit worried about how I'm going to look after my kids.'[35]

3.28 Haemophilia Foundation Australia highlighted the fear and anxiety among those diagnosed with hepatitis C regarding treatment options and

32 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 3.
33 Australian Research Centre in Sex, Health & Society, *Submission 19*, p. 5.
34 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 41.
35 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 45.

their likely impact. The Foundation stated that those living with hepatitis C are often paralysed with 'fear and anxiety', noting:

> This community is stoic, and staying in the workforce and earning an income is a high priority. But many affected people have had to reduce or stop working from their mid-30s onwards, with a drastic impact on their income. Some have had to sell houses because they just cannot afford to continue owning their house.[36]

3.29 Similarly, Mr Gavin Finklestein, who was born with haemophilia and has hepatitis C, commented on the side-effects and impact of these existing treatments on his ability to work:

> I had my first hepatitis C treatment during the 2001-2002 period… the side effects were horrific. I had probably had 2,000 tablets and 200 injections over this 72-week period. I kept working in my government job during this time. It was not easy with both hepatitis C treatment and also haemophilia. Even with a medical letter advising of the impact of treatment, no-one was happy with my work. I could not perform as expected or as I had in the past. I had missed a lot of work during treatment, I could not concentrate, I made a lot of mistakes, I was erratic, I lost promotional opportunities and my coworkers stopped supporting me because they were fed up [with] picking up the slack… Eventually, I had to face giving up work because I could not cope with the impact of having both haemophilia and hepatitis C.[37]

3.30 Dr Mark Douglas stated that there is very little psychological and social support provided to individuals who are diagnosed with, or being treated for, hepatitis C.[38] Similarly, Professor Gregory Dore of the Kirby Institute noted that current treatment options can cause depression and other psychological side effects.[39]

3.31 Social support to those undergoing viral hepatitis treatment is provided by government-funded services of that state such as the MOSAIC Community Support and Counselling Services, delivered by Relationships Australia – South Australia.[40]

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36 Ms Sharon Caris, Executive Director, Haemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 5.

37 Mr Gavin Finklestein, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 35.

38 Dr Mark Douglas, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 13.

39 Professor Gregory Dore, Head, Viral Hepatitis Clinical Research Program, Kirby Institute, *Committee Hansard*, Sydney, 22 January 2015, p. 18.

40 Relationships Australia – South Australia, *Submission 95*, p. 2.

Stigma and Discrimination Experiences

3.32 Throughout the inquiry, the Committee received many personal and anecdotal accounts of stigma and discrimination of those living with hepatitis C. For example, Ms Zoe Kelley, who was diagnosed in 2009, was of the view that the stigma associated with hepatitis C was sometimes worse than living with the virus itself:

> The terrible stigma that is associated with hep C can often, in my opinion, be more intolerable than having the disease itself. I know personally that every aspect of your life is affected by having hepatitis, not just your physical health.[41]

3.33 Indeed, a recent survey by Hepatitis Australia found that 68 per cent of respondents had personally experienced stigma or discrimination due to their positive status, and 58 per cent of all respondents were aware of, or had witnessed, stigma and discrimination related to hepatitis C.[42] In its submission, Hepatitis Australia quoted a counsellor working with people living with hepatitis C, who reportedly stated:

> I have heard many horror stories from clients. Individuals have been attacked and bashed because they were [perceived as] a dangerous threat and "lowlifes", and disowned by family members or prevented from mixing with their own young nephews and nieces. They were allowed to visit relatives only when the children were absent. Volunteers and workers have been fired, either for being [perceived as] a danger to other employees, or under a spurious pretext, or treated increasingly unfairly until they resigned.[43]

3.34 People living with hepatitis C reported experiencing social stigma, including at work, stigmatisation by healthcare providers, and a degree of self-stigmatisation. These experiences can have a significant impact on the decision to be tested for hepatitis C as well as seeking treatment of the virus.[44]

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41 Ms Zoe Kelley, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 36.

42 Hepatitis Australia, *Submission 84,* p. 4.

43 Quoted in Hepatitis Australia, *Submission 84*, p. 4.

44 C Treloar, J Rance and M Backmund, (2013), 'Understanding Barriers to Hepatitis C Virus care and Stigmatization from a Social Perspective', *Clinical Infectious Diseases Journal,* Oxford University Press, 57(2), 51 referred to in Women's Health Victoria, *Submission 52*, p. 4. See also Centre for Social Research in Health, *Submission 28*, p. 3; National Drug and Alcohol Research Centre, *Submission 55*, p. 6; Hepatitis Victoria, *Submission 59*, p. 17; Cairns Hepatitis Action Team, *Submission 61*, p. 2; Name Withheld, *Submission 67,* p. 4; National Association of People with HIV Australia, *Submission 69*, p. 3; Scarlet Alliance, *Submission 81,* p. 4; Hepatitis NSW, *Submission 91*, p. 47.

Social Stigma

3.35 A number of participants reported that much of the stigma associated with a hepatitis C diagnosis is established based on the media's portrayal of the virus and its general means of transmission.[45] Ms Doidge described the media's portrayal of a person living with hepatitis C: 'the picture in your head is media based, which is the skanky, bad language, dirty person. There is this misrepresentation of a gutter type junky. That is what hep C looks like to [the general community]'.[46] Mr William Lenane similarly noted that to 'put your hand up to acknowledge that you had hepatitis C would mean that straight away you would be ostracised'.[47]

3.36 Although hepatitis C is most commonly transmitted through intravenous drug use, almost half of the patients who currently are infected with hepatitis C are no longer using drugs or have caught the virus via other means of transmission.[48]

3.37 The Australian Liver Association commented on the stigma of former drug injectors and the challenges of reaching this population who may have contracted hepatitis C during this period of their lives:

> The people who have experimented [with intravenous drug use] and who are now CEOs and teachers and so forth have never been tested because that was something in the past and they are ashamed of admitting it.[49]

3.38 Mr Frank Carlus commented that much of the stigma associated with hepatitis C 'emerges from ignorance, the misunderstanding that it is primarily a disease of IV drug users, and the fallacy that it is highly contagious and there is no cure'.[50]

3.39 The Tainted Blood Product Action Group stated that those that had contracted hepatitis C prior to 1990 due to exposure through infected blood products experienced both a 'medical disaster' and 'first and foremost, a human tragedy'.[51] The Tainted Blood Product Action Group explained the experence of this group of people in living with hepatitis C:

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45 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 48; Mr Damien House, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 48; Mr David Pieper, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, pp 48-49.

46 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 48.

47 Mr William Lenane, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 46.

48 Ms Nicola Richards, Public Affairs and Policy Manager, Merck Sharp & Dohme, *Committee Hansard*, Melbourne, 21 January 2015, p. 17.

49 Professor Amany Zekry, Chair, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 29.

50 Mr Frank Carlus, *Submission 10*, p. 6.

51 Tainted Blood Product Action Group, *Submission 102*, p. 2.

> …they experienced debilitating symptoms, suffering under stigma, loss of employment, financial hardship, marriage break ups, discrimination, and a life of uncertainty.[52]

3.40 The Committee also received anecdotal evidence of people losing their jobs after disclosing their hepatitis C to employers.[53] In another case, Ms Pam Wood reported to the Committee that she was discriminated against because of her diagnosis when undergoing workplace training, and proceeded to take the matter to the then, Human Rights and Equal Opportunity Commission.[54] Other participants in the inquiry also reported their fear of discrimination in the workplace as a result of hepatitis C.[55]

Stigmatisation Within Healthcare Profession

3.41 A recurring theme in the evidence provided by individuals living with hepatitis C was stigmatisation by healthcare providers.[56] For example, Ms Zoe Kelley commented that a lack of information among healthcare providers can fuel the stigma and judgement of those living with hepatitis C:

> I have also experienced many occasions where I have seen GPs and they have not been aware of exactly what hepatitis is and how you transmit it. We need to ensure that doctors know what hepatitis is and how it is transmitted, because incorrect information not only creates unfair stigma and judgement but also prevents people who have hepatitis from being able to correctly

52 Tainted Blood Product Action Group, *Submission 102*, p. 2.

53 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 27; Hepatitis Australia, *Submission 84,* p. 4.

54 Ms Pam Wood, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 44.

55 Ms Jen Anderson, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 33; Name Witheld, *Submission 22*, p. 4; See also Hepatitis SA, *Submission 33*, p. 13.

56 Centre for Social Research in Health, *Submission 28*, p. 4; Glenda Clementson, *Submission 40*, p. 2; Anglicare Tasmania & Tasmanian Council on AIDS and Related Diseases & Tasmanian Aboriginal Centre, *Submission 41*, p. 18; Hepatitis SA, *Submission 33*, p. 13; Barbara Durward, *Submission 44*, pp 1-2; Chris Lawrence, *Submission 47,* p. 3; Women's Health Victoria, *Submission 52*, p. 6; National Drug and Alcohol Research Centre, *Submission 55*, p. 6; Australasian Society for HIV Medicine, *Submission 58*, p. 12; Deborah Warneke-Arnold, *Submission 76*, p. 1; Burnet Institute, *Submission 66*, p. 9; National Association of People with HIV Australia, *Submission 69*, p. 3; Hepatitis Australia, *Submission 84,* p. 5; Hepatitis NSW, *Submission 91*, p. 47; NSW Health, *Submission 94*, p. 6; Ms Zoe Kelly, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 36; Professor John de Wit, Director, Centre for Social Research in Health, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 13; Mr Grenville Rose, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 41; Mr Frank Farmer, Executive Director, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 8.

> manage sources of transmission to others or gain knowledge of new treatment options available, or any other information unless they visit a specialist.[57]

3.42 Similarly, Mr Grenville Rose commented that stigmatisation of hepatitis C within the healthcare system can cause considerable harm, stating:

> There is clear and abundant evidence that health professionals and the general public can hold negative attitudes towards people with hepatitis C. This means that fewer people access treatment and there is a reluctance to seek appropriate and effective support and advice.[58]

3.43 A study referred to the Committee by Women's Health Victoria, found that medical practitioners, nurses and complementary therapists reported that their willingness to treat people with hepatitis C was influenced by their attitudes towards injecting drug users rather than their knowledge about hepatitis C.[59]

3.44 Professor John de Wit of the CSRH discussed the importance of trust in health care professionals for hepatitis C patients seeking treatment:

> We are all well aware that trust in one's providers is important for anyone visiting a provider for any sort of health issue... But, for people living with hepatitis C, that issue of trust is particularly important and compounded by the legal position and the moral judgements regarding injecting drug use, which has been a major risk factor at some point in the life of people living with hepatitis C. Our research participants describe feeling distrusted by health services and themselves placing only rationed or limited trust in those services, and that results in a general reticence to attend or engage with services offered.[60]

3.45 The CSRH was also of the view that effective approaches to reduce stigma 'should be multifaceted and include strategies to tackle the structural and systemic aspects of the healthcare system that perpetuate stigma'.[61]

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57 Ms Zoe Kelly, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 36.

58 Mr Grenville Rose, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 41.

59 J Richmond, T Dunning, P Desmond, (2007), 'Health professionals' attitudes toward caring for people with hepatitis C', *Journal of Viral Hepatitis*, 14(9), 624-632; referred to in Women's Health Victoria, *Submission 52*, p. 5.

60 Professor John de Wit, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 13; See also Centre for Social Research in Health, *Submission 28*, p. 2; Women's Health Victoria, *Submission 52*, p. 5.

61 Centre for Social Research in Health, *Submission 28*, p. 4.

3.46 The Australasian Hepatology Association noted that patients are often emotionally traumatised when being diagnosed, an experience which is sometimes compounded by 'ill-informed' health practitioners:

> We in the clinics see people who are quite damaged from their experience with dealing with ill-informed and often very judgemental health professionals, even during the process of diagnosis. So there are workforce development issues and community awareness issues, and we need appropriate infrastructure to allow all of this to work together.[62]

Self-stigmatisation

3.47 At the two roundtable hearings in Melbourne and Sydney, participants who are living, or who have lived, with hepatitis C described a 'self-stigmatisation'[63] or a 'self-loathing'[64].

3.48 Mr Ross Williams commented that 'being stigmatised is a problem for many. Self-stigmatisation is a problem for most of us. It preys on many people's minds, which may be why they avoid both testing and treatment'.[65]

3.49 Similarly, Ms Mary Frances Sherwood described a sense of 'self-loathing' in having hepatitis C, commenting:

> Self-loathing, that is it, and feeling like you deserve it. Being Catholic, I thought God was really copping me, but I do not believe that any more. It was a lesson in my life I had to learn and I have done it and I am carrying on.[66]

3.50 Hepatitis Victoria noted that feeling 'contaminated' drives self-stigmatisation: 'universally, they talk about feeling contaminated and that affect[s] all their interactions at their workplaces, with their families and with their healthcare professionals'.[67]

3.51 Mr Kidd similarly commented that being stigmatised by others can affect the sense of self-worth:

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62 Dr Jacqui Richmond, Australasian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 27.

63 Mr Ross Williams, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 38.

64 Mr David Pieper, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 49; Ms Mary Sherwood, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 49.

65 Mr Ross Williams, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 38.

66 Ms Mary Sherwood, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 49.

67 Ms Melanie Eagle, Chief Executive Officer, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 25.

> Stigma is an incredibly, horribly insidious beast. It corrodes your sense of yourself, and the hardest thing about it is that it changes what you think about yourself. It is not just what other people think about you. When people engage in stigmatising behaviour—and that can be very, very small things, just slight differences in the way that you are treated—it changes your own sense of who you think you are, so it corrodes that sense of self.
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> …I personally have had the experience of being in a hospital in literally the worst pain of my life and being denied pain relief because, 'He has hepatitis C; therefore, he's probably a drug user; therefore, we can't give him opiates.' That is a really common thing that happens in hospitals all over the country, and it is terribly harmful. As I say, it changes what you think about yourself. You think 'I'm dirty' and 'I'm a lesser person'.[68]

Implications of Stigma and Discrimination

3.52 Stigma and discrimination can have a considerable impact on the initial decision to be tested for hepatitis C, and later decisions to seek treatment.[69] The National Drug and Alcohol Research Centre noted:

> Research shows that experiences and anticipation of stigma and discrimination are barriers to engagement with prevention, testing, treatment and other health services, and can have a significant negative impact on psychological and physiological health beyond that attributable to foregoing the treatment needed.[70]

3.53 For example, Mr Frank Carlus explained that stigma and misinformation can deter individuals from being tested for the virus:

> Individuals who may suspect they have been exposed to [hepatitis C] may also fear pursuing a diagnosis given the stigma that is associated with the disease, misinformation about 'absence of treatment', the actual or perceived extreme side effects of available treatments, and concerns about the need for invasive nature of

68 Mr Paul Kidd, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 43.

69 C Treloar, J Rance and M Backmund, (2013), 'Understanding Barriers to Hepatitis C Virus care and Stigmatization from a Social Perspective', *Clinical Infectious Diseases Journal,* Oxford University Press, 57(2), 51 referred to in Women's Health Victoria, *Submission 52*, p. 4. See also National Drug and Alcohol Research Centre, *Submission 55*, p. 6; Hepatitis Victoria, *Submission 59*, p. 17; Cairns Hepatitis Action Team, *Submission 61*, p. 2; Name Withheld, *Submission 67,* p. 4; National Association of People with HIV Australia, *Submission 69*, p. 3; Scarlet Alliance, *Submission 81,* p. 4; Hepatitis NSW, *Submission 91*, p. 47.

70 National Drug and Alcohol Research Centre, *Submission 55*, p. 6.

> procedures such as liver biopsy, which is no longer necessary in the detection or treatment of HCV.[71]

3.54 Professor John de Wit similarly noted that the specific stigma around injecting drug use can dissuade people who are at risk of hepatitis C from being tested.[72] Mr David Pieper commented that stigmatisation of the high-risk activities, such as injecting drug use, can impact not only testing and treatment, but also ongoing prevention efforts.[73] This was echoed by Mr Frank Carlus.[74]

3.55 Dr Jacqui Richmond, a Member of the Australasian Hepatology Association stated that although there are treatment services located in discrete centres, patients will not seek out the treatment and support services offered within these centres on the basis of the stigma associated with hepatitis C. Dr Richmond stated:

> There are people who will just not go. [A clinic in regional Victoria] is down the end of a road; there is nobody else there. I do not think we can underestimate the impact that stigma has. … We can offer all the treatments in the world but, if we do not reduce or address stigma of this condition, people may not take it up. It is so pervasive and so debilitating for so many people.[75]

3.56 The CSRH also noted that stigma and discrimination can have considerable effects on the mental health of those living with the virus.[76] In evidence to the Committee, a hepatitis C sufferer noted the isolation that the stigma of her hepatitis C has created: 'It's been a long haul … let alone the sad emotional journey of 'living this secret life' because of fear of discrimination with only my husband and one friend to share the journey'.[77]

Addressing Stigma and Discrimination

3.57 Addressing stigma and discrimination is vital to the overall efforts to combat hepatitis C in Australia. As discussed above, the stigma associated with the virus, and the high-risk behaviours which can lead to

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71 Mr Frank Carlus, *Submission 10*, p. 4.

72 Professor John de Wit, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 13.

73 Mr David Pieper, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, pp 44-45.

74 Mr Frank Carlus, *Submission 10*, p. 4.

75 Dr Jacqui Richmond, Australasian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 27.

76 Centre for Social Research and Health, *Submission 28*, p. 3.

77 Name Withheld, *Submission 17*, p. 3.

transmission, not only prevent a large number of people from being tested for hepatitis C, but also prevent people from seeking treatment.

3.58 Hepatitis Victoria stated that addressing stigma and discrimination should be at the forefront of strategies to combat the virus:

> The underlying prevailing issue that cross-cuts all of this is stigma. Until we really address stigma, we are not going to be able to progress through. We can talk about getting treatments out there, but we are not really going to get the people who need it, whether they are in prison, users of NSP services or ex-users sitting at home, asking the doctor or the doctor offering the service until we address stigma.[78]

3.59 Ms Jen Anderson, who was first diagnosed with hepatitis C in the early 1990s,[79] commented that raising community awareness will combat the stigma associated with hepatitis C:

> If we are to really tackle this business of stigma, we really need to raise awareness throughout the whole community, not just the general community but in the health profession as well, about what hepatitis C is and how to access testing and treatment for it.[80]

Raising Awareness

3.60 A number of individuals and organisations reported that there is limited awareness within the wider community about hepatitis C, how it is transmitted, how it can be prevented, and how it can be treated.[81]

3.61 Hepatitis NSW commented that insufficient investment in public health campaigns had led to a significant misunderstanding of hepatitis C, stating:

> …it is fair to say that there has been insufficient public investment at a federal level in hep C education and public health campaigns. Approximately one in 100 people in Australia, and up to one in 83 in New South Wales, are currently living with chronic hep C. Yet,

78 Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 24.

79 Ms Jen Anderson, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 33.

80 Ms Jen Anderson, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 42.

81 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 27; Mr Stuart Loveday, Chief Executive Officer, Hepatitis NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 25; Dr Mark Douglas, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 25; Hepatitis Australia, *Submission 84,* p. 4; Hepatitis NSW, *Submission 91*, p. 46.

> on the basis of community surveys, most people underestimate hep C prevalence and many mistakenly believe there is a vaccine.[82]

3.62 To address the lack of awareness and misunderstandings about hepatitis C, many inquiry participants called for an awareness campaign. The recommendations for awareness campaigns called for specific strategies to firstly address the broader stigma and discrimination in the general community, [83] then subsequent campaigns to:

- encourage testing for the virus;[84]
- provide information on how to prevent transmission;[85] and
- provide information on the range of available treatments.[86]

3.63 Several participants also recommended awareness and education strategies to improve the knowledge and awareness of hepatitis C among healthcare providers.[87]

Addressing Community Attitudes

3.64 The need for increasing awareness of hepatitis C in the broader community was raised by a large number of individuals and

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82 Mr Stuart Loveday, Hepatitis NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 25.

83 Mr Frank Carlus, *Submission 10*, p. 6; Professor John de Wit, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 26; Hepatitis SA, *Submission 33*, p. 12; Kirstie Monson, *Submission 37*, p. 3; Glenda Clementson, *Submission 40,* p. 2; Northern Territory AIDS and Hepatitis Council, *Submission 42*, p. 4; Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 7; Karen Brereton, *Submission 46*, p. 1; Name Withheld, *Submission 48*, p. 1; National Drug and Alcohol Research Centre, *Submission 55*, p. 1; Hepatitis Victoria, *Submission 59*, p. 17; Cancer Council Australia, *Submission 79*, p. 3; Scarlet Alliance, *Submission 81,* p. 4; Haemophilia Foundation Australia, *Submission 83*, p. 5; cohealth, *Submission 87*, p. 4; Hepatitis NSW, *Submission 91*, p. 47.

84 Mr Mik Raskine, *Submission 1*, p. 1; Professor Amany Zekry, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 25; Kirstie Monson, *Submission 37*, p. 3; Glenda Clementson, *Submission 40,* p. 2; Karen Brereton, *Submission 46*, p. 1; Name Withheld, *Submission 48*, p. 1; Haemophilia Foundation Australia, *Submission 83*, p. 5; Hepatitis NSW, *Submission 91*, p. 47.

85 Australasian Society for Infectious Diseases, *Submission 11*, p. 8; Professor Amany Zekry, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 25; Hepatitis SA, *Submission 33*, p. 12; Glenda Clementson, *Submission 40,* p. 2; Haemophilia Foundation Australia, *Submission 83*, p. 5; cohealth, *Submission 87*, p. 10; Victorian Department of Health and Human Services, *Submission 96*, p. 4; Hepatitis NSW, *Submission 91*, p. 47; Liver Foundation of Western Australia, *Submission 104*, p. 1.

86 Professor Amany Zekry, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 25; Chris Lawrence, *Submission 47,* p. 4; Name Withheld, *Submission 48*, p. 1; Haemophilia Foundation Australia, *Submission 83*, p. 5; Victorian Department of Health and Human Services, *Submission 96*, p. 4; Hepatitis NSW, *Submission 91*, p. 47.

87 Ms Justine Doidge, Private Capacity, Committee Hansard, Sydney, 22 January 2015, p. 47; Hepatitis SA, Submission 33, p. 14; Haemophilia Foundation Australia, *Submission 83*, p. 39.

organisations.[88] More specifically, the provision of information to the community through a well-researched campaign would assist to address the stigma and discrimination experienced by those living with the virus.[89]

3.65 Hepatitis Australia noted that the low levels of awareness about transmission risks and the new treatments for hepatitis C, combined with the fear of disclosure, is 'really limiting the effectiveness of current prevention and treatment efforts'. In the view of Hepatitis Australia, the creation of a better informed general community will provide 'a more supportive environment for people with hepatitis C'.[90]

3.66 A number of previous public health campaigns were discussed as models for a hepatitis C campaign. This included the Quit smoking campaign,[91] HIV awareness campaigns of the 1990s,[92] or the Slip! Slop! Slap! (sun protection) campaign that began in the 1980s.[93]

3.67 For example, Professor Joseph Torresi stated that the turning point in normalising attitudes to HIV was the success of information campaigns:

> In the case of HIV, I think the turning point was when we normalised HIV, if I can use that expression. This is a disease not of sexually promiscuous drug users; it is a disease of ordinary people. Hepatitis C is the same thing: it is a disease of ordinary people. But there are effective diagnostic strategies, treatment strategies that those people can actually pursue. The awareness of that needs to be increased within the general community, perhaps more so than it does within the healthcare professionals.[94]

3.68 However, Haemophilia Foundation Australia emphasised the importance of a positive awareness campaign, presenting the 'ordinary person' living with hepatitis C:

> I would say that the experience of people with bleeding disorders, around the Grim Reaper campaign, really demonstrates how careful you need to be with the message. The scale of the Grim Reaper campaign is very important, and the support and political will behind it is very important, but the message is about a person with hep C being an ordinary person—their experience; tell the

88 Frank Carlus, *Submission 10*, p. 6.

89 Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

90 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 24.

91 Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 25;

92 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 27;

93 Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 25.

94 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 27.

> story in a positive way… Looking at those sorts of approaches rather than something that demonises the person who has the health condition is very important, otherwise you are back to where you were, where people with bleeding disorders do not disclose to anyone.[95]

3.69 Haemophilia Foundation Australia further stated that an awareness campaign should present those living with hepatitis C as 'an ordinary person worthy of respect and empathy and portray their experience so that the audience can identify with them rather than judge them'.[96] The Foundation was also of the view that such a campaign would encourage those living with hepatitis C to be 'more confident about disclosing and seeking support in the workplace and in the health-care system, and more generally'.[97]

3.70 Professor Joseph Torresi was of the view that educating the community that hepatitis C is 'a disease of ordinary people', would help to address the discrimination experienced by those living with hepatitis C. Professor Torresi stated:

> How this disease is spread—and this will come with education of the general community—is not by kissing or by drinking from the same cup. By educating people on the modes of transmission would also help to reduce that discrimination. Perhaps we should be using the HIV model, which was implemented many years ago, and trying to put that into place for hepatitis C, to emphasise that this is a disease of just ordinary people.[98]

3.71 Ms Justine Doidge provided an account of the reactions of members of the general public after concluding an education and awareness program which seeks to present those living with hepatitis C in the ways recommended by Professor Joseph Torresi and Haemophilia Foundation Australia. Ms Doidge commented:

> It is simple: they see a person, whereas before people would be a little bit surprised. They would go, 'Oh, it's so nice to meet you.' People are so incredibly generous usually. They say to you, 'Thank you so much for being so brave,' which is really appreciated. But if

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95 Ms Suzanne O'Callaghan, Policy Research and Education Manager, Haemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

96 Ms Sharon Caris, Haemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 26.

97 Ms Sharon CarisHaemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 26.

98 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 27.

> they are brave enough they will be honest about the fact that they were expecting something else. They say, 'I've never met somebody with hep C before,' which is kind of always interesting, because, well, you probably have but you just did not know it. This is because the picture in your head is media based.[99]

3.72 A number of participants were of the view that an awareness campaign of this nature should be sufficiently resourced in order for it to be effective in contributing to an overall prevention strategy.[100]

Improving Testing Rates and Prevention Strategies

3.73 Though Australia has a relatively high diagnosis rate for hepatitis C compared to many other nations, one in six Australians infected with hepatitis C remains undiagnosed.[101] The *Fourth National Strategy* recognised that an estimated 40 000 to 50 000 Australians remain unaware of their hepatitis C positive status.[102] To address this issue, the Government of Western Australia stated:

> An undiagnosed reservoir of infection increases the likelihood of onward transmission. Strategies to increase community awareness of hepatitis C may encourage this group to seek testing, but need to be implemented in such a way that does not increase stigma and discrimination.[103]

3.74 As discussed earlier in this chapter, the stigma associated with high-risk behaviours, particularly intravenous drug use, has dissuaded many from discussing these behaviours with their GPs and being screened for the virus. A number of organisations and individuals noted that increasing general awareness in the community about how hepatitis C is transmitted will encourage greater testing rates.[104]

3.75 For example, the Australasian Society for Infectious Diseases (ASID) commented on the capacity of awareness raising campaigns to prevent

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99 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 48.

100 Professor Margaret Hellard, Director, Centre for Population Health, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 29; Mr John Ryan, Chief Executive Officer, Penington Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

101 Ms Helen Tyrrell, Chief Executive Officer, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 2.

102 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 18.

103 Government of Western Australia, *Submission 12*, p. 4.

104 Adjunct Associate Professor Levinia Crooks, Chief Executive Officer, Australasian Society for HIV Medicine, *Committee Hansard*, Sydney, 22 January 2015, p. 28; Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 26; Mr John Ryan, Penington Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 29; Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

further transmissions. The ASID stated that a successful prevention strategy must include a 'significant effort' to improve the knowledge of hepatitis C transmission in the general population and those at a higher risk of infection. The ASID stated, this will be achieved through 'effective health promotion, education and awareness activities, which include up to date information about hepatitis C, transmission risk and prevention strategies'. [105]

3.76 The Australasian Society for HIV Medicine provided similar evidence, and stated:

> Those people will know that they have injected drugs in the past, even if they are not prepared to admit that or share that. So I think there is a very great need to raise that broad public awareness so that people can access services if they think 'I really should check up if there is a risk'… I think community awareness is a particular one so that people can realise their own previous exposure and check, especially if they might have a niggling concern.[106]

3.77 Haemophilia Foundation Australia stated that an awareness campaign targeting testing and transmission would need to be specifically targeted to the needs of different risk groups.[107]

3.78 The Penington Institute also commented that specific strategies should be developed to target those people who are new to injecting drug use. The Institute emphasised the importance of targeting this group noting the increasing trend of the injection of methamphetamine. The Penington Institute commented: 'that is a new population of injectors… [who] are really ignorant about their risk of hepatitis and how to manage their health'.[108]

3.79 Hepatitis Australia stated that steroid users are another emerging vulnerable population, and commented that specific information campaigns should be developed and provided at locations, such as gyms, where these users might want to collect such information. Hepatitis Australia emphasised that it is a 'critical part of a successful campaign' that information is easily 'absorbed'[109]

3.80 The Australasian Hepatology Association further stated that steroid users 'do not see themselves as injecting drug users, so they would not speak to

105 Australasian Society for Infectious Diseases, *Submission 11*, p. 8.

106 Adjunct Associate Professor Levinia Crooks, Australasian Society for HIV Medicine, *Committee Hansard*, Sydney, 22 January 2015, p. 28.

107 Ms Suzanne O'Callaghan, Haemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 31.

108 Mr John Ryan, Penington Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

109 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

their GP about being tested'.[110] Similar comments were made about the risks taken by tourists who get tattoos or manicures/pedicures while on holiday overseas.[111]

3.81 Importantly, increasing the testing for hepatitis C and the corresponding increase of knowledge of a positive diagnosis status can have a positive impact on the transmission rates of the virus. Professor Margaret Hellard, Director of Hepatitis Service, Infectious Diseases Unit at the Alfred Hospital, commented on evidence that intravenous drug users change their injecting behaviours if they are aware that they have hepatitis C.[112] Consequently, Professor Hellard commented that increasing testing rates will contribute to an overall prevention strategy as high-risk populations change their behaviours, thereby lowering transmission rates and the spread of the virus.[113]

Awareness of Available Treatments

3.82 Just one per cent of people with chronic hepatitis C received treatment in 2013.[114] Previous sections of this chapter discussed the factors which impact the decision of people with hepatitis C to seek treatment. However, the evidence collected throughout the inquiry also points to a lack of awareness about the available hepatitis C treatments both within the wider and hepatitis C communities,[115] and also among some healthcare providers.[116]

3.83 Professor de Wit from the CSHR expressed support for an awareness campaign targeting those with the virus which addressed available treatments, commenting that:

> I wholeheartedly support the previous calls for awareness campaigns, in particular around changing treatments so that people become aware of what their options are and what is entailed to address any barriers that people might feel and to also

110 Ms Megan Phelps, President, Australasian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

111 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, pp 29-30; Ms Megan Phelps, Australasian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 29.

112 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 26.

113 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 26.

114 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 2.

115 Kathryn Snow, *Submission 4*, p. 2; Burnet Institute, *Submission 66*, p. 9.

116 Kathryn Snow, *Submission 4*, p. 2; Burnet Institute, *Submission 66*, p. 9; Haemophilia Foundation Australia, *Submission 83*, p. 4; Hepatitis Australia, *Submission 84*, p. 6.

> point them to community and other resources to make their decisions.[117]

3.84 The CSRH also stated that the focus on side-effects in current discourse indicates a need for a 'well-designed, evidenced-informed public awareness campaign providing targeted information regarding the changing treatment options'.[118] The Centre noted that those living with hepatitis C need improved access to community-based resources and support to find a healthcare provider that is appropriate for their needs.[119] The Victorian Alcohol and Drug Association also recommended the provision of better information about changing treatment options and their side-effects.[120]

3.85 A more challenging task will be to provide people who are living with a positive diagnosis, but who are no longer in consultation with healthcare practitioners, such as GPs, about their hepatitis C. Despite being diagnosed in 1970, Mr William Lenane reported that he had not heard of 'any of the available treatments' until about 2005 when he read a magazine at a methadone dispensary.[121]

3.86 The challenge to reach out to individuals who were diagnosed in the 1990s when few treatments were available to treat the virus, was noted by Merck Sharp & Dohme:

> It is also important to look at those patients who are at home, who had a diagnosis five or 10 years ago, there was nothing for them then, they have never readdressed it with their GP. .. [T]here is also a very large pool of patients we need to be looking at, at how to get them to come out of the woodwork, like an HIV patient in the 1980s, how we get them to be comfortable to talk to their GP, to a nurse or to any kind of clinic to say, 'I've had a diagnosis. What does it mean to me now?'[122]

3.87 Kathryn Snow, an epidemiologist primarily focussed on the hepatitis C infection was of the view that those with hepatitis C should make an informed decision about treatment options, stating

> It is simply unacceptable for someone in Australia to develop advanced liver disease due to an infection that was identified

117 Professor John de Wit, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 26.

118 Centre for Social Research in Health, *Submission 28*, p. 3.

119 Centre for Social Research in Health, *Submission 28*, p. 3.

120 Victorian Alcohol and Drug Association, *Submission 31*, p. 5.

121 Mr William Lenane, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 43.

122 Ms Nicola Richards, Merck Sharp & Dohme, *Committee Hansard*, Melbourne, 21 January 2015, p. 17.

> years or even decades previously, and which the health system failed to manage appropriately. There are of course people who are engaged with care and who have decided not to have treatment for their hepatitis, but this decision should be an informed one.[123]

Improving Awareness and Knowledge Among Healthcare Providers

3.88 The negative experiences of stigma and discrimination within the healthcare system have already been discussed in this chapter. However, participants also recounted instances of inaccurate clinical information being provided, necessary tests not being done or the necessary referrals not having been made.[124]

3.89 For example, Professor Joseph Torresi stated that he has encountered patients who have previously been provided with inaccurate information about their initial diagnosis from their GP and commented:

> There have been many times that I have had patients say, 'I'm going to die tomorrow.' They really think they are going to die in the short term, not in the long term. They also get the same wrong message from the GPs who do not understand the disease. They say, 'My GP told me that this is a death sentence'.[125]

3.90 Ms Kathryn Snow, an infectious disease epidemiologist, referred to research that reached a similar conclusion:

> Research in a high-prevalence area in Western Sydney has shown that GPs often lack basic knowledge about both hepatitis B and C, which compromises their ability to provide appropriate care to their patients. Many GPs surveyed were unaware that hepatitis B and C cause cancer, or that hepatitis C is curable. Given that chronic viral hepatitis affects 1 Australian in every 50, there is a clear need to improve the support available to primary care providers.[126]

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123 Kathryn Snow, *Submission 4*, p. 2.

124 Ms Pamela Wood, *Committee Hansard*, Melbourne, 21 January 2015, p. 41; Glenda Clementson, *Submission 40,* p. 2; Anglicare Tasmania, the Tasmanian Council on AIDS, Hepatitis and Related Diseases, Tasmanian Aboriginal Centre, *Submission 41*, p. 19; Barbara Durward, *Submission 44*, pp 1-2; National Drug and Alcohol Research Centre, *Submission 55*, p. 6; Australasian Society for HIV Medicine, *Submission 58*, p. 1; Hepatitis Australia, *Submission 84,* p. 6.

125 Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 28.

126 Kathryn Snow, *Submission 4*, p. 2. The research cited was M Guirgis et al, 'General Practitioners' Knowledge and Management of Viral Hepatitis in the Migrant Population', *Internal Medicine Journal*, vol. 42, no. 5, May 2012, pp 497–504.

3.91 Similarly, the Australian Liver Association commented that a lack of awareness of the availability of treatments both among GPs and those living with hepatitis C, contributes to 'a [greater] fear factor or phobia' of the virus.[127] Hepatitis Victoria stated that the lack of awareness among the population and particularly among healthcare practitioners is 'a major barrier' to undergoing treatments.[128]

3.92 For patients to receive optimal health care it is important for health care professionals to have access to the best information, and that the various links within the health system function well. The impact of well-informed practitioners was demonstrated by Ms Pamela Wood who described the impact of information and support from her GP: 'She knows what the resources are, she knows how to help me, and that has been a wonderful and very enlightening experience.'[129]

3.93 Importantly, improvements in the approach of health practitioners have occurred, and this was acknowledged by individuals who are living with hepatitis C. For example, Mr Gavin Finkelstein stated: that the current health system is 'not as cold … and as heartless as it used to be'.[130] Ms Pamela Wood also agreed that improvements have been made, although she suggested that 'there are some doctors who have not upgraded their skills in the past 15 years … [t]hey have not moved on'.[131]

3.94 Dr Mark Douglas, an infectious diseases physician, has been involved in various education programs, particularly with GPs. Although awareness is increasing, he nevertheless has been 'staggered by the lack of awareness' about hepatitis C treatments among some doctors:

> I give talks to [GPs], and I am always amazed that within the audience several people will come up to me afterwards—and this is over the last five years or so—who will say, 'I didn't realise you could cure hepatitis C', and it has been curable, at least in some patients, for 15 or 20 years, really.[132]

3.95 Numerous individuals and organisations recommended that health practitioners, particularly GPs, engage in educational activities to improve

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127 Professor Amany Zekry, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 25. See also Hepatitis SA, *Submission 33*, p. 2.

128 Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 3; See also Kathryn Snow, *Submission 4*, p. 2.

129 Ms Pamela Wood, *Committee Hansard*, Melbourne, 21 January 2015, p. 46

130 Mr Gavin Finkelstein, *Committee Hansard*, Melbourne, 21 January 2015, p. 45.

131 Ms Pamela Wood, *Committee Hansard*, Melbourne, 21 January 2015, p. 46.

132 Dr Mark Douglas, *Committee Hansard*, Sydney, 22 January 2015, p. 25.

their knowledge and understanding of hepatitis C as well as those who are most at risk of transmission.[133] For example, Hepatitis Australia stated:

> It is evident that more education of health care providers is needed to increase understanding of [hepatitis C] diagnosis, management and treatment as well as developing a greater understanding of the lived experiences of people with [hepatitis C].[134]

3.96 The National Drug and Alcohol Research Centre similarly recommended the implementation of a three year communication campaign which targets 'healthcare workers to increase knowledge around HIV and HCV in the hopes of decreasing discriminatory behaviour and stigmatising beliefs (so as to promote the use of standard precautions and inclusive practice)'.[135] The Australasian Society for HIV Medicine, Burnet Institute, the National Association of People with HIV Australia, Anglicare Tasmania, Tasmanian Council on AIDS and Related Diseases, and the Tasmanian Aboriginal Centre made similar suggestions.[136]

3.97 The Royal Australian College of General Practitioners (RACGP) has developed two strategies to improve the knowledge and understanding of hepatitis C among its members. First, the RACGP operates an online database of 'preventative guidelines' which are accessible to all RACGP members. According to the RACGP, these guidelines are:

> …designed to be accessed pretty simply and quickly, even in the context of our day-to-day work, but they are also available to us should we choose to look at them in more detail at any time… It does then rely on the general practitioner to engage with the resource.[137]

3.98 The second strategy developed by the RACGP is the use professional development courses, such as its annual GP conference, however, the

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133 Anglicare Tasmania & Tasmanian Council on AIDS and Related Diseases & Tasmanian Aboriginal Centre, *Submission 41*, p. 28; National Drug and Alcohol Research Centre, *Submission 55*, p. 6; Australasian Society for HIV Medicine, *Submission 58*, p. 12; Burnet Institute, *Submission 66*, p. 9; National Association of People with HIV Australia, *Submission 69*, pp 3-4; Hepatitis Australia, *Submission 84*, p. 7; NSW Health, *Submission 94*, p. 6.

134 Hepatitis Australia, *Submission 84*, p. 6.

135 National Drug and Alcohol Research Centre, *Submission 55*, p. 6.

136 Australasian Society for HIV Medicine, *Submission 58*, p. 12; Burnet Institute, *Submission 66*, p. 9; National Association of People with HIV Australia, *Submission 69*, pp 3-4; Anglicare Tasmania & Tasmanian Council on AIDS and Related Diseases & Tasmanian Aboriginal Centre, *Submission 41*, p. 28.

137 Dr Larissa Roeske, Chair, Sexual Health Medicine Network, Royal Australian College of General Practitioners, *Committee Hansard*, Canberra, 20 March 2015, p. 15.

RACGP noted that the benefit of these courses was only experienced by those who attended.[138]

3.99 The RACGP acknowledged that its educational activities require a self-initiation, but also recognised that:

> …there is definitely a case for a greater and more proactive exploration in the initiation or involvement. But that also needs to be considered in the context that currently many GPs cannot, for instance, access or would not feel that they may be skilled enough to manage or care for those who are needing particular management or treatment for hepatitis C. So there is a barrier there which has been there for good reasons historically.[139]

3.100 In response to reports of low levels of awareness or discriminatory attitudes to people living with hepatitis C among the healthcare profession, NSW Health developed a training module for its workforce focussing on stigma, discrimination and injecting drug use. NSW Health noted that:

> Efforts to engage with the Royal Australian College of General Practitioners (RACGP), the Nursing and Midwifery Board of Australia, and allied health professional associations, should also be made to ensure that such modules are embedded as core continuing professional development practice.[140]

A Possible Model: Hepatitis C Public Health Promotion Pilot Program

3.101 In 2010, the Pharmacy Guild of Australia received an Australian Government grant to develop the Hepatitis C Public Health Promotion Pilot Program as part of the Fourth Community Pharmacy Agreement.

3.102 The Pilot Program was collaboratively developed with Hepatitis Australia, the Australasian Society for HIV Medicine, the Australian Drug Information Network, Australian Injecting and Illicit Drug Users League, and Haemophilia Foundation Australia. The Pilot Program involved community pharmacies and consumers in areas identified with a high prevalence of hepatitis C. Within these settings, the Pilot Program delivered workforce development and information, awareness raising

138 Dr Larissa Roeske, Royal Australian College of General Practitioners, *Committee Hansard*, Canberra, 20 March 2015, p. 15.

139 Dr Larissa Roeske, Royal Australian College of General Practitioners, *Committee Hansard*, Canberra, 20 March 2015, p. 16.

140 NSW Health, *Submission 94*, p. 5.

activities aimed at prevention and early detection, and treatment of hepatitis C through community pharmacies.[141]

3.103 More specifically, a suite of materials was developed including pamphlets, posters, risk identifying tools as well as training and information manuals for pharmacies. The campaign was titled *Get Tested. Get Treated*, and all materials had referrals to the national hepatitis helpline.[142]

3.104 The Pharmacy Guild of Australia stated that post-event data indicated improvements in understanding and assisted in raising awareness of hepatitis C:

> The majority of participants reported a significant increase in their understanding and awareness of hepatitis C. The Program was successful in increasing the capacity of community pharmacies to provide information and advice for people with or at risk of contracting Hepatitis C. Furthermore, the Program was also successful in developing and improving linkages with relevant local health providers and key stakeholders in the targeted areas. This pilot clearly shows public health promotion via community pharmacy is effective in disseminating information to specific populations as well as the general community.[143]

3.105 In light of these results, the Pharmacy Guild of Australia was of the view that a national communication strategy modelled on the pilot program, where a public awareness component was complimented by e-learning components, would achieve significant public health goals.[144]

Concluding Comment

3.106 The Committee is appreciative to those who shared their personal experience of living with hepatitis C. Hearing directly from people who are living, or who have lived, with hepatitis C provided the Committee with an insight into the challenges, demands and impacts of hepatitis C.

Diagnosis and Treatment

3.107 The Committee is concerned by reports of unsupportive testing and diagnosis experiences – and sometimes inaccurate information – which have, in the past, been provided to patients by healthcare practitioners.

141 Pharmacy Guild of Australia, *Submission 106*, p. 11.

142 Ms Khin May, National Manager, Policy and Regulation, National Secretariat, Pharmacy Guild of Australia, *Committee Hansard*, Canberra, 20 March 2015, p. 48.

143 Pharmacy Guild of Australia, *Submission 106*, p. 11.

144 Pharmacy Guild of Australia, *Submission 106*, pp 11-12.

This concern is heightened by studies which have highlighted the role that supporive testing and diagnosis experiences have on postponed decisions to seek treatment.

3.108 Further, the Committee is concerned that after receiving a positive diagnosis for hepatitis C, some patients are not receiving correct or sufficient information about how to manage and treat the infection.

3.109 The Committee welcomes initiatives such as that recently introduced in South Australia where, after a GP notifies a case of hepatitis C, where a letter is provided to the GP to inform them about the availability of viral hepatitis nurses to assist with treatment.[145] It was reported that nurses have received a 'noticeable increase in calls from GPs'.[146] The Committee is of the view that provision of such information and resources in a similar manner in other jurisdictions would better allow GPs to access and maintain professional knowledge and best clinical practice.

Stigma, Discrimination and Raising Awareness

3.110 People living with hepatitis C, or who are at risk of acquiring hepatitis C, are a diverse demographic, most notably in respect of the role of drug use in their lives, both past and present.

3.111 The Committee believes that the stigma associated with hepatitis C and the resulting discrimination experienced by those living with the virus, is best addressed through raising awareness within both the hepatitis C community and more widely in the broader community.

3.112 The Committee also believes that specific strategies should be developed to target those living with hepatitis C, or who are at risk of acquiring hepatitis C, to better educate these demographics about transmission risks, prevention strategies as well as, encouraging testing and the consideration of undertaking treatment.

3.113 Further, the Committee is concerned about anecdotal evidence received in relation to the discrimination of people with hepatitis C within the healthcare system. The Committee believes that medical practitioner awareness about transmission risks of the disease needs to be improved to assist in eradicating existing stigmatisation of infected individuals.

145 Hepatitis SA, *Submission 33*, p. 2.

146 Hepatitis SA, *Submission 33*, p. 2.

Recommendation 2

3.114 **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

Introduction

4.1 In Australia, approximately 80 per cent of people with hepatitis C infection have been diagnosed. However, it is estimated that 40 000 to 50 000 Australians infected with hepatitis C, remain unaware that they are chronically infected.[1]

4.2 As hepatitis C is a disease that progresses slowly, 'early diagnosis of chronic infection and linkage to appropriate management is necessary to reduce hepatitis C transmission, morbidity and mortality'.[2]

4.3 With only a one per cent[3] treatment rate for hepatitis C, it is estimated that the burden on the health system into the future is likely to increase significantly. One study suggested that:

- the number of people with compensated cirrhosis will increase from 13 850 in 2013 to 38 130 people in 2030;
- the number of cases of hepatocellular carcinoma (a type of liver cancer) will increase from 590 in 2013 to 2040 in 2030; and
- liver-related deaths will increase from 530 in 2013 to 1740 in 2030.[4]

4.4 Australia currently spends between $224 million and $300 million per annum to treat one per cent of the hepatitis C infected population. The estimated cost of pursuing current hepatitis C treatment regimens

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1 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 18.

2 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 18.

3 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 3.

4 Australasian Society for Infectious Diseases, *Submission 11*, p. 6. The study cited was W Sievert et al, 'Enhanced Antiviral Treatment Efficacy and Uptake in Preventing the Rising Burden of Hepatitis C-Related Liver Disease and Costs in Australia', *Journal of Gastroenterology and Hepatology*, 2014, vol. 29, August Supplement, pp 1–9.

(pegylated interferon and ribavirin) for the next 15 years is approximately $5 billion.[5]

4.5 The low treatment rate for hepatitis C is reliant on several factors, including associated stigma and discrimination which may discourage people from seeking treatment. Being unable to cope with the routine and side effects of treatment regimens may have also served to discourage continued treatment.[6]

Testing

4.6 Approximately 40 000 to 50 000 Australians with hepatitis C remain undiagnosed and therefore unaware of their diagnosis status.[7] Encouraging testing of the virus is of great importance as an early diagnosis can prevent long term liver damage.[8]

4.7 The *Fourth National Hepatitis C Strategy (2014-2017)*, details four specific 'priority actions' in relation to testing for Hepatitis C which are to be achieved:

- Increase voluntary testing of hepatitis C in priority populations.
- Improve referral and access to high quality support services at the time of diagnosis for people with or at risk of hepatitis C to initiate a pathway to care.
- Assess the feasibility, accessibility and cost effectiveness of the range of existing and emerging testing methods.
- Implement targeted initiatives to improve understanding and skills related to hepatitis C testing for priority populations, healthcare professionals and services, and the community sector.[9]

4.8 In addition to the need for an awareness campaign to encourage voluntary hepatitis C testing, a number of organisations recommended policy changes to increase testing rates in high-risk or vulnerable populations. For example, Professor Margaret Hellard stated that Australia needs clear

5 Queensland Nurses Union, *Submission 32*, p. 3.

6 Ms Justine Doidge, Private Capacity, *Committee Hansard*, Sydney, 22 January 2015, p. 45.

7 Ms Helen Tyrrell, Chief Executive Officer, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 2.

8 Hepatitis Victoria, *Submission 59*, p. 6.

9 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 18.

guidelines for testing high-risk populations,[10] and that messages about testing high-risk patients should be targeted at GPs.[11]

4.9 Associate Professor Joseph Torresi suggested that consideration should be given to whether the *National Hepatitis C Testing Policy* should be 'reinvigorated' to align with the *Fourth National Hepatitis C Strategy,* and whether it should be known as a 'strategy' rather than as a 'policy'.[12] While he agreed that there needs to be definite guidelines, Professor Alex Thompson noted that Australia's diagnosis rate is nonetheless 'pretty high'—at approximately 80 per cent.[13]

4.10 The *Fourth National Hepatitis C Strategy*, calls for the *National Hepatitis C Testing Policy* to be promoted among primary healthcare professionals and that the guidance provided on testing includes information on 'the frequency of hepatitis C testing for individuals who continue to have exposure risk'.[14] In addition to policy development and promotion, a large number of participants in the inquiry recommended the wide-spread introduction of 'rapid testing' for the virus,[15] with some additional comments about where best to place such testing services.[16]

Rapid Testing

4.11 Rapid testing, or rapid point-of-care testing (RPOCT), is a testing tool that detects hepatitis C antibodies via a finger prick capillary blood sample at the time of presentation. Taking approximately 30 minutes, the test determines if hepatitis C antibodies are present in an individual and if further confirmatory testing is required.[17]

4.12 More specifically, RPOCT uses in-vitro diagnostic medical devices and is defined as any test performed 'that provides results at the time of testing, which enables a clinical decision to be made and an action taken that leads

10 Professor Margaret Hellard, Director, Centre for Population Health, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 17.

11 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 23.

12 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p. 20.

13 The diagnosis rate in Australia may be the highest in the world. Professor Alex Thompson, *Committee Hansard*, Melbourne, 21 January 2015, p. 17.

14 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 19.

15 Kirstie Monson, *Submission 37*, p. 1; Hepatitis ACT, *Submission 56*, p. 2; cohealth, *Submission 87*, pp 1-2.

16 Kirstie Monson, *Submission 37*, p. 1; Hepatitis Victoria, *Submission 59*, pp 7-8; cohealth, *Submission 87,* pp 5-6.

17 Hepatitis Victoria, *Submission 59*, pp 7-8.

to an improved health outcome'.[18] Further, such testing looks for hepatitis C antibodies in the blood, rather than looking for the virus itself, and as such, 'they are a screening test for current or past exposure – not a diagnostic test'.[19] As a result, the Pharmacy Guild of Australia commented:

> This requires an appreciation that some results cannot be considered definitive and a patient that receives a negative (non-reactive) result who is identified as within a high risk category should be encouraged to discuss the result with their GP. If a patient receives a positive (preliminary positive or reactive result) they should be counselled and referred to a GP or other appropriate service for PCR testing and confirmation of current HCV infection. Further, it is important to clearly explain to the consumer the difference between an indicative screening test which requires further testing or advice, and a diagnostic test which confirms whether the disease is present.[20]

4.13 The test can be performed by non-clinical staff and, outside Australia, has been integrated into a range of services including drug and alcohol services or needle and syringe programs, as a strategy to increase screening of high-risk populations.[21]

4.14 The community health organisation, cohealth, commented that rapid testing is used internationally, has a high accuracy rate and is a cost-effective model:

> RPOCT are currently used in a variety of settings in other countries including the United States with an accuracy of approx. 98% and have been found to be cost effective. This, in turn, has the effect of earlier detection, limiting disease progression and prevention of transmission to the at risk population.[22]

4.15 Further, it was the view of a number of hepatitis-support organisations that rapid testing, especially if targeted for high-risk populations, has the potential to increase the quantum of testing and reduce the extent of undiagnosed infections. These organisations referenced the experiences of rapid testing in the HIV sector where studies have concluded that such

18 Pharmacy Guild of Australia, *Submission 106*, p. 5.
19 Pharmacy Guild of Australia, *Submission 106*, p. 6.
20 Pharmacy Guild of Australia, *Submission 106*, p. 6.
21 cohealth, *Submission 87,* pp 5-6.
22 cohealth, *Submission 87,* p. 5.

services can encourage a person to undergo testing when they might not have otherwise taken up the opportunity.[23]

4.16 For example, Hepatitis Victoria commented that as these tests are easy to perform and can be implemented by 'skilled peer workers', the perceived barriers to testing (including stigma and discrimination), can be overcome.[24]

4.17 Similarly, the National Association of People with HIV Australia stated that rapid testing technologies would allow testing for the virus to be placed in community-based settings, where they are more likely to be accessed.[25] Community settings included community pharmacy;[26] sexual health clinics;[27] needle and syringe programs;[28] alcohol and drug centres;[29] peer-driven services;[30] and street doctors[31].

4.18 In respect to placing these tests in a community pharmacy, the Pharmacy Guild of Australia commented:

> Community pharmacy provides the added benefit of being able to clearly explain to high risk consumers such as those accessing NSP [needle and syringe programs] and ODT [Opioid Dependence Treatment] that a positive screening test may not equate to current infection, as people are more likely to test positive for antibodies due to past exposure and cleared or cured infection.[32]

4.19 The potential for placing such services in community settings, in contrast to traditional healthcare settings, where stronger relationships often exist between staff and the community, was recognised by the Government of Western Australia:

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23 Hepatitis ACT, *Submission 56*, p. 2; Hepatitis Victoria, *Submission 59*, pp 7-8; Ms Sally Rowell, Community Services Manager, HepatitisWA, *Committee Hansard*, Perth, 10 May 2015, pp 4-5.

24 Hepatitis Victoria, *Submission 59*, pp 7-8.

25 National Association of People with HIV Australia, *Submission 69*, p. 1, 3.

26 Pharmacy Guild of Australia, *Submission 106*, p. 6

27 Hepatitis Victoria, *Submission 59*, pp 7-8

28 Hepatitis Victoria, *Submission 59*, pp 7-8; cohealth, *Submission 87,* pp 5-6; Hepatitis NSW, *Submission 91*, p. 2; Ms Sally Rowell, Community Services Manager, HepatitisWA, *Committee Hansard*, Perth, 10 May 2015, pp 4-5; Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 21.

29 cohealth, *Submission 87,* pp 5-6.

30 Ms Sally Rowell, Community Services Manager, HepatitisWA, *Committee Hansard*, Perth, 10 May 2015, pp 4-5; Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 21.

31 Ms Sally Rowell, HepatitisWA, *Committee Hansard*, Perth, 10 May 2015, pp 4-5.

32 Pharmacy Guild of Australia, *Submission 106*, p. 6.

> We understand that [HepatitisWA] have got a different kind of relationship with people that government will always struggle to have directly, so we think the funding of others is important'.[33]

4.20 Rapid testing for hepatitis C is not currently listed on the Australian Register of Therapeutic Goods (ARTG). An ARTG listing is required before a hepatitis C test can be used in Australia.[34] The Pharmacy Guild of Australia explained the regulatory listing process for these tests:

> These or similar tests may be approved for entry on the ARTG in future if the sponsors of the tests make application to the [Therapeutic Goods Administration] and the tests meet the Australian regulatory requirements. In order to do so, the testing device must meet the acceptable levels of sensitivity and specificity as outlined by the Advisory Committee on Medical Devices… which recommends that the sensitivity of point of care testing devices for the detection of [hepatitis C] should be at least 99.5% and the specificity at least 99%.[35]

4.21 The *Fourth National Hepatitis C Strategy* recognises:

> Development of improved testing technology, including point-of--care tests, [to] assist in simplifying the testing process for individuals, including addressing improved access and acceptability for priority populations. These may prove particularly useful in settings commonly used by people who inject drugs. Testing strategies and models will need to be developed and reviewed to allow new testing technologies to be included as they become available.[36]

4.22 NSW Health also acknowledged the opportunities of rapid testing technologies to reduce undiagnosed hepatitis C infection in hard-to-reach populations.[37]

Treatment and Delivery

4.23 In 2013, less than 3000 Australians were treated for hepatitis C,[38] with the majority of treatments occurring in a tertiary hospital setting. The Burnet

33 Professor Tarun Weeramanthri, Executive Director, Public Health and Clinical Services, Department of Health, Western Australia, *Committee Hansard*, Perth, 10 March 2015, p. 10.

34 Australian Government, *National Hepatitis C Testing Policy*, 2012, p. 8, viewed April 2015, <http://testingportal.ashm.org.au>.

35 Pharmacy Guild of Australia, *Submission 106*, p. 6.

36 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 19.

37 NSW Health, *Submission 94*, p. 5.

Institute was of the view that the reasons for poor treatment uptake are 'multifactorial', and include 'long and often toxic treatment regimens, difficulties in accessing care provided from tertiary hospitals by specialists, and (historically) policies of excluding current [people who inject drugs] from treatment'.[39]

4.24 The Australasian Society for Infectious Diseases indicated that as the number of people with compensated liver cirrhosis was estimated to increase from 13 850 in 2013 to 38 130 in 2030, that projected costs of patient management would also increase from $224 million in 2013 to $305 million in in 2030.[40] Other modelling found that increasing the uptake of treatments currently available in Australia by five per cent each year from 2014 'would result in savings of $9 million per year over the next three decades.'[41]

4.25 In recognition of the cost-savings that can be made by increasing the rate of treatment, the *Fourth National Hepatitis C Strategy* set a target of increasing the number of patients undergoing treatment by 50 per cent.

New Medications

4.26 On 30 June 2014, a new medication known as sofosbuvir was registered by the Therapeutic Goods Administration (TGA).[42]

4.27 The large majority of individuals and organisations who participated in the Inquiry outlined the various benefits associated with new hepatitis C medications and what they may mean for treating hepatitis C in the future.[43] Professor Margaret Hellard, Director, Centre for Population Health, Burnet Institute, stated:

> When used in combination with high-quality rolled out harm reduction approaches … including opiate substitution therapy and needle and syringe programs, the evidence is mounting that we can eliminate this disease by 2030, if we start today. It requires us

38 Burnet Institute, *Submission 66,* p. 7.

39 Burnet Institute, *Submission 66,* p. 7.

40 ASID, *Submission 11*, pp 2–3.

41 Kathryn Snow, *Submission 4*, p. 1.

42 Therapeutic Goods Administration (TGA), *Australian Public Assessment Report for Sofosbuvir*, August 2014, p. 8, viewed 17 November 2014, <www.tga.gov.au>.

43 Government of Western Australia, *Submission 12*, p. 2; Australasian Hepatology Association, *Submission 23*, p. 2; Queensland Nurses' Union, *Submission 32*, p. 2; Glenda Clementson, *Submission 40*, p. 2.

> to start treating people … There is no need for hepatitis C related deaths any more. We simply have to understand that.[44]

4.28 In addition to noting that 'cure rates' associated with the new medications are 'greater than 95 per cent in most subgroups of patients', Professor Alex Thompson stated:

> The treatments are of short duration, with most regimens involving only 12 weeks of treatment. All patients can be considered treatment candidates, including those with liver failure, with decompensated liver disease, as well as those who are intolerant of interferon due to toxicity.[45]

4.29 The Burnet Institute stated that the new treatments will:

> …avoid the need for expensive genotyping prior to therapy, and probably reduce the frequency of NAT testing during therapy. The licensing of fixed-dose combination therapy of sofosbuvir and ledipasvir for 12 weeks, with high SVR, activity against most genotypes and few side-effects makes treatment simplification realistic.[46]

4.30 Associate Professor Joseph Torresi added that the ability of the new medications to treat people with advanced liver disease and cirrhosis 'means you can actually salvage people off liver transplantation lists—that is, they do not end up with a liver transplant which, in itself, is quite a significant cost'.[47] Ms Sharon Caris from the Haemophilia Foundation of Australia stated that new medications could potentially reduce use of the health system as well as the costs to the taxpayer associated with the disease.[48]

4.31 The favourable dropout rate for the new treatments compared to the existing treatments was also highlighted. Professor Thompson advised that for interferon based treatment the dropout rate is about 15 per cent, whereas in studies where interferon-free treatments have been used, the

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44 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, pp 5–6.

45 Professor Alex Thompson, Director, Department of Gastroenterology, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 7.

46 Burnet Institute, *Submission 66,* p. 7.

47 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, pp 7–8.

48 Ms Sharon Caris, Executive Director, Haemophilia Foundation Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 5.

dropout rate 'is basically zero' and any dropouts that do occur are 'not related to side effects'.[49]

4.32 The Burnet Institute stated that these new treatments will reduce the number of new hepatitis C infections by 90 per cent and reduce hepatitis C related deaths by 90 per cent by 2030.[50]

Listing on the Pharmaceutical Benefits Scheme

4.33 In Australia, government subsidies for medicine costs are provided under the Pharmaceutical Benefits Scheme (PBS). Access to reduced cost medicines under the PBS is available for Australian residents and visitors from countries with a reciprocal health care agreement with Australia.

4.34 Decisions about whether a particular medicine or medicinal preparation will be subsidised under the PBS are made by the Minister for Health based on the recommendations of the Pharmaceutical Benefits Advisory Committee (PBAC). In formulating its recommendations, PBAC is required to consider the effectiveness and cost of therapy involving the use of the new medicine or medicinal preparation in question, including comparing the effectiveness and cost of that therapy with that of alternative therapies.

4.35 During the Inquiry, a number of new hepatitis C medications were simultaneously being assessed for listing on the Pharmaceutical Benefits Scheme for the second time.

4.36 Total expenditure under the PBS is uncapped, meaning the overall cost of the PBS increases as new medications are added and as usage increases.[51] In 2012–13, around 750 medicines available in more than 1970 forms were subsidised by the PBS,[52] at a cost to the Australian Government of $7.1 billion.[53]

4.37 In an answer to a question on notice, the Department of Health advised the Senate Community Affairs Committee that the cost per person for a course of sofosbuvir was estimated to be 'substantially higher than treatments already available on the [PBS], with a total cost to the Australian Government exceeding $1 billion over five years.' In contrast,

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49 Professor Alex Thompson, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 18.

50 Burnet Institute, *Submission 66*, p. 3.

51 Department of Health, 'About the PBS', viewed 30 January 2015, <http://www.pbs.gov.au>.

52 Steering Committee for the Review of Government Service Provision, *Report on Government Services 2014*, vol. E, Health, Productivity Commission, p. E. 69.

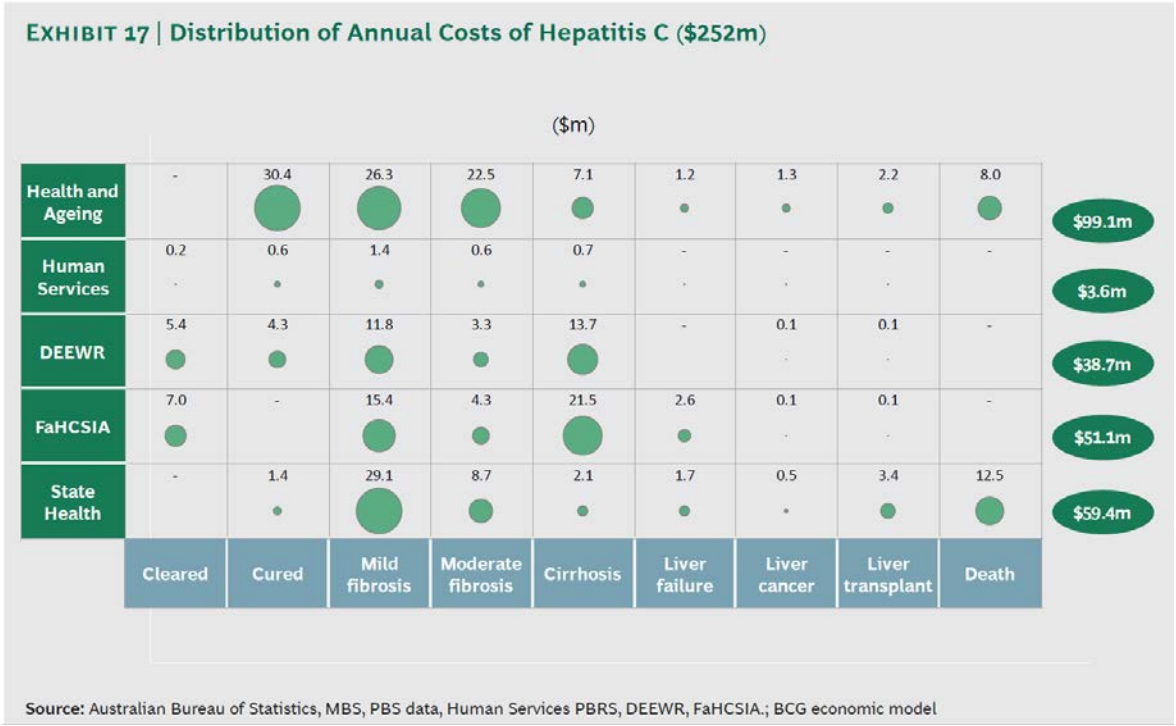
53 Steering Committee for the Review of Government Service Provision, *Report on Government Services 2014*, vol. E, Health, Productivity Commission, p. 11.8.

the cost to the PBS of existing drugs to treat hepatitis C totalled $72.5 million in 2013-2014.[54]

4.38 The Boston Consulting Group Report *The Economic Impact of Hepatitis C in Australia*[55] commissioned by the pharmaceutical company Janssen examined the broader costs of treating hepatitis C through the context of new treatments available overseas.

4.39 The listing of these new medications was first considered by the PBAC in July 2014, and was then reconsidered by the PBAC in March 2015. On 24 April 2015, the PBAC released its recommendation to the Minister for Health that two of these new generation treatments be listed on the PBS.

Figure 4.1 Distribution of Annual Costs of Hepatitis C ($ million)



Source *Boston Consulting Group, The Economic Impact of Hepatitis C in Australia*

Prioritising Access

4.40 A number of organisations discussed the priority that should be afforded to different categories of people with hepatitis C should new treatments become available in Australia. Professor Thompson suggested that if restrictions were put in place, then prisoners, one of the groups at highest

54 Department of Health, *Answer to Question on Notice, Senate Community Affairs Legislation Committee, Supplementary Budget Estimates 2014–15*, no. SQ14-001138, viewed 13 January 2015, <http://www.aph.gov.au>.

55 Boston Consulting Group, *The Economic Impact of Hepatitis C in Australia*, August 2012, <http://www.hepatitisaustralia.com>.

risk of hepatitis C infection, should be considered as a high-priority population for treatment.

4.41 In contrast, Hepatitis Australia was of the view that access to new treatment should not be restricted to certain groups of people.[56] Hepatitis Australia recommended that as these new medications offer positive outcomes regardless of the stage of liver disease experienced, all people with chronic hepatitis C should be given equal access to new treatments.[57] Hepatitis Australia stated:

> 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.[58]

4.42 Similarly, Hepatitis NSW recommended that new treatments should be made available to 'all people living with hepatitis C, and not restricted on the basis of liver disease stage or previous treatment experience'.[59] Professor Hellard also commented that limitations on access to treatment should not be set:

> … if somebody needs to have treatment because they have severe liver disease, they should be given it—and also those who want to be treated. So, if my 25-year-old daughter, who might want to have children, is hepatitis C infected, she could be treated—or my son or whoever it might be. We should not be setting limits. People will talk about the costs, but this is affordable and Australia can afford it.[60]

4.43 Although the prioritisation debate was also reflected in the different approaches by state and territory health departments, they agreed that the decision to commence treatment should be a clinical decision. For example, ACT Health advocated that effective treatment should be accessible to all people with hepatitis C:

> Effective treatments should be accessible on the PBS for all genotypes of [hepatitis C]. It appears discriminatory when effective treatments for some genotypes of [hepatitis C] are accessible through the [PBS] but access to effective treatments for other genotypes is withheld.

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56 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 28.

57 Hepatitis Australia, *Submission 84,* p. 5.

58 Hepatitis Australia, *Submission 84,* p. 5.

59 Hepatitis NSW, *Submission 91*, p. 3.

60 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 6.

> The decision about whether to treat an individual with chronic [hepatitis C] should rest with the clinician. The PBS should not specify restrictions on accessing medications, such as the duration of infection or the level of liver damage.[61]

4.44 The Government of Western Australia similarly commented that the decision to commence treatment for hepatitis C should remain a clinical decision focussing on the 'capacity to benefit'.[62]

Waiting for New Treatments

4.45 Throughout the Inquiry, it became evident that large numbers of people living with hepatitis C are being advised by healthcare professionals to delay current PBS-listed treatments until the PBAC considers the listing of these new treatments for a second time.[63] A number of participants used the analogy of a 'warehouse' of patients waiting for new treatments to be made available.[64]

4.46 Ms Saroj Nazareth, a nurse practitioner specialising in hepatology at Royal Perth Hospital, stated that treatment rates have significantly decreased as 'a lot of patients have been waiting for the newer treatments to arrive'.[65] In light of this, and if new treatments are listed on the PBS, the number of people undertaking treatment is 'poised to escalate'.[66]

Models of Care

4.47 Only accredited GPs have a role in managing treatment prescribed within specialist liver clinics. As current treatments are listed subsidised by the Pharmaceutical Benefits Scheme (PBS) under Section 100 of the *National Health Act 1953* as Highly Specialised Drugs (HSDs). HSDs are 'medicines that treat chronic conditions and because of their clinical use or other

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61 ACT Health, *Submission 105*, p. 3.

62 Professor Tarun Weeramanthri, Department of Health, Western Australia, *Committee Hansard*, Perth, 10 March 2015, p. 14.

63 Glenda Clementson, *Submission 40,* p. 2; Hepatitis Victoria, *Submission 59*, p. 9; Merck Sharp & Dohme (Australia) Pty Limited, *Submission 80*, p. 2; Hepatitis NSW, *Submission 91*, p. 16; Hepatitis ACT, *Submission 56*, p. 3; Mr Frank Farmer, Executive Director, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 2; Mr Rodney Hatch, Prisons Education Officer, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 4; Mrs Saroj Nazareth, Private Capacity, *Committee Hansard*, Perth, 10 March 2015, p. 29; Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 22.

64 Hepatitis ACT, *Submission 56*, p. 3; Mr Frank Farmer, Executive Director, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 2; Mr Rodney Hatch, Prisons Education Officer, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 4;

65 Mrs Saroj Nazareth, Private Capacity, *Committee Hansard*, Perth, 10 March 2015, p. 29.

66 National Drug and Alcohol Research Centre, *Submission 55*, p. 5.

special features, they are restricted to being prescribed in public and private hospitals with appropriate specialist facilities'.[67]

Primary and Tertiary Healthcare Settings

4.48 To enable more people to access hepatitis C treatment, Hepatitis Australia advocated that Australia move treatment and care for hepatitis C from hospital-based clinics into community-based primary care. Hepatitis Australia stated:

> 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.[68]

4.49 In light of possible access to new medicines, Hepatitis ACT stated that 'access to treatment through different models of care' is also required.[69]

4.50 The Australasian Society for HIV Medicine also commented that:

> It will be necessary to ensure that treatments are available at acceptable and appropriate services to the priority populations by improving access through primary care, alcohol and drug services, Aboriginal medical services, needle and syringe programs, mental health services and in custodial settings.[70]

4.51 The Australian Research Centre in Sex, Health and Society commented that new models of care should 'focus on the needs of the individual rather than the specialist'.[71]

4.52 The Queensland Nurses' Union (QNU) was also of the view that new treatments 'will increase rates of treatment significantly [and]… there needs to be a proportionately large response to meet the needs of the public and remove barriers to treatment by utilising primary health care settings'.[72] QNU was consequently supportive of an expanded role for nurse-led and GP-led models of care, commenting that as new treatments have a 'high safety profile', and that these treatments can be delivered to patients through alternative models, allowing for more complex cases to be efficiently managed at tertiary health services.[73]

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67 Pharmacy Guild of Australia, *Submission 106*, p. 8.

68 Hepatitis Australia, *Submission 84,* p. 7.

69 Hepatitis ACT, *Submission 56*, p. 2.

70 Australasian Society for HIV Medicine, *Submission 58*, p. 6.

71 The Australian Research Centre in Sex, Health and Society, *Submission 19*, p. 6.

72 Queensland Nurses Union, *Submission 32*, p. 3.

73 Queensland Nurses Union, *Submission 32*, p. 4.

4.53 Mr Ross Williams, appearing in a private capacity, stated to the Committee that '[t]he best information, the best treatment, is available from hospital clinics'. However, he added:

> … given the size and the scope of the hepatitis C problem, we simply cannot inundate [hospital clinics] with people who have hepatitis C. They are very busy already with people who have other liver related problems, plus those who have advanced hepatitis C related problems. If we can get treatment and support information out into the wider system, that will take an intolerable pressure off very hard-working institutions.[74]

4.54 Hepatitis Australia commented that there would be no specific need for specialist liver clinics to manage patients undertaking new treatments, freeing up places for complex cases or those with comorbidities. Hepatitis Australia stated:

> The new direct-acting antivirals have a very low risk profile. Their safety profile is very good. Their side effects are quite minimal. In terms of actual provision of safe care, there is no reason for them to be delivered in a liver clinic, unless the patient is someone with complex conditions or comorbidities that need specialist care. We need to really change that around. Liver clinics should be the province of people who really need that specialist care, not the routine care.[75]

4.55 Similarly, the Government of Western Australia stated:

> As new hepatitis C treatments are emerging, it is likely that there will be a greater role for primary care in the delivery of hepatitis C treatment, and this sector needs to be prepared for this. GP-initiated treatment, supported by approved Section 100 prescriber status by the Pharmaceutical Benefits Scheme, is essential to improved access to hepatitis treatment.[76]

4.56 The following paragraphs examine the evidence received about the potential for increased hepatitis C care in a primary care setting.[77]

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74 Mr Ross Williams, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 46. See also Mr Frank Carlus, Private Capacity, *Committee Hansard*, Melbourne, 21 January 2015, p. 41.

75 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 13.

76 Government of WA, *Submission 12*, p. 6.

77 Primary health care providers include general practitioners, nurses (including general practice nurses, community nurses and nurse practitioners), allied health professionals, midwives, pharmacists, dentists, and Aboriginal health workers. See Australasian Society for HIV Medicine, *Submission 58*, p. 7.

General Practitioners

4.57 As briefly discussed above, GPs have a limited role in providing healthcare for their patients undergoing treatment for hepatitis C. Current pegylated interferon and ribavirin drugs are subsidised by the PBS under section 100 of the *National Health Act 1953* as highly specialised drugs (HSDs). To prescribe these drugs as pharmaceutical benefit items, medical practitioners are required to be affiliated with specialist hospital units.[78]

4.58 A GP or non-specialist hospital doctor may only prescribe listed-HSDs to provide maintenance therapy under the guidance of the treating specialist.[79] These GPs must also complete accredited training programs which are established by each state and territory jurisdiction. [80]

4.59 GPs trained in the management and treatment of hepatitis C can only prescribe maintenance treatments already initiated by those medical practitioners located in specialist hospital units.[81] Currently there is a network of over 100 GPs around Australia who have completed advanced training in hepatitis C diagnosis and treatment and are accredited to prescribe therapy for the maintenance treatment of hepatitis C.[82] These GPs are required to undertake regular continuing medical education in order to maintain their accreditation.

4.60 Associate Professor Joseph Torresi commented that GPs who wanted to treat hepatitis C would require upskilling 'so that they understand the disease but also the new treatments'.[83]

4.61 The Royal Australian College of General Practitioners noted that although the number of accredited GPs to dispense HSDs under section 100 of the *National Health Act 1953* remains 'quite small', there is 'potential for GPs to become more involved in treating high volumes of patients safely and appropriately, so that we can lower costs of treatment and cut transmission rates'.[84]

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78 Department of Health, Pharmaceutical Benefits Scheme, *Section 100 – Highly Specialised Drugs*, accessed 15 May 2015, <http://www.pbs.gov.au>.

79 Department of Health, Pharmaceutical Benefits Scheme, *Section 100 – Highly Specialised Drugs*, accessed 15 May 2015, <http://www.pbs.gov.au>.

80 Dr Anthony Hobbs, Principal Medical Adviser, Therapeutic Goods Administration, *Committee Hansard*, Canberra, 20 March 2015, p. 66.

81 Australasian Society for HIV Medicine, *Submission 58*, p. 10.

82 Australasian Society for HIV Medicine, *Submission 58*, p. 10

83 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, pp 13–14. See also Dr Tuck Meng Soo, Private Capacity, *Committee Hansard*, Canberra, 20 March 2015, p. 43.

84 Dr Larissa Roeske, Chair, Sexual Health Medicine Network, Royal Australian College of General Practitioners, *Committee Hansard,* Canberra, 20 March 2015, p. 13.

4.62 A number of witnesses expressed a desire for adequately resourced and trained GPs to have a greater role in treatment delivery.[85]

4.63 The Australasian Society for HIV Medicine advocated for GP treatment delivery similar to how HIV has been treated and stated:

> Appropriately trained general practitioners have successfully managed and treated HIV with antivirals for decades and the majority of people living with HIV see a GP prescriber for their HIV treatment. The Australian approach to HIV management, with the focus of care being in primary care, has resulted in the arguably some of the best outcomes in the world in term of retention in care and optimal control of HIV. This model will undoubtedly reflect similar levels of effectiveness and acceptability for other blood-borne viruses including hepatitis C.[86]

4.64 The Australasian Society for HIV Medicine similarly stated that 'the inclusion and support of general practice in hepatitis C testing, management and treatment is essential to increase treatment uptake for hepatitis C and free up tertiary services for more complex management issues'.[87] In evidence to the Committee, the Australasian Society for HIV Medicine noted findings from the *Community Prescriber Hepatitis C Treatment Initiation Pilot Final Evaluation Report* published in September 2013, which supported the initiation of hepatitis C therapy in primary care as an effective, safe treatment option and demonstrates both patient and practitioner satisfaction with the model.[88]

4.65 Dr Tuck Meng Soo, an accredited GP prescriber, commented on the delivery of treatment by GPs in regard to HIV. Dr Tuck Meng Soo stated:

> …when HIV started becoming recognised as a problem in Australia, a coalition of consumers and GPs went to government and said: 'We do not want this disease to be taken over by hospitals; we want to be able to access treatment in communities; we want to work with doctors who want to work with it.' So a system was devised where GPs who wanted to work in this area could get extra training to be able to manage people with HIV, and

85 Peter Tanczos, *Submission 6*, p. 2; Frank Carlus, *Submission 10*, p. 2; Ms Melanie Eagle, Hepatitis Victoria, *Committee Hansard*, Melbourne, 21 January 2015, p. 3. See also Mr Frank Carlus, *Committee Hansard*, Melbourne, 21 January 2015, p. 41

86 Australasian Society for HIV Medicine, *Submission 58*, p. 10.

87 Australasian Society for HIV Medicine, *Submission 58*, p. 7.

88 Australasian Society for HIV Medicine, *The Community Prescriber Hepatitis C Treatment Initiation Pilot Final Evaluation Report* (incorporating the Kirby and Centre for Social Research in Health Evaluation Reports). Darlinghurst, NSW: ASHM, September 2013, referred to in Australasian Society for HIV Medicine, *Submission 58*, p. 10.

> doctors like me undergo a certain amount of education every year to keep my registration up. And I do not see any reason why the same system could not apply to hepatitis C. After all, if you have 230,000 people with hepatitis C in Australia, the specialist units in Australia could not possibly treat all of them.[89]

4.66 Hepatitis Victoria commented that the GP model of care could be extended to hepatitis C. Hepatitis Victoria stated:

> Treatments must be available at locations appropriate and accessible to all those affected by hepatitis C, which is predominately within the primary care sector, including GP clinics, youth health services, sexual health services, community health services, alcohol and drug services, Aboriginal medical services, needle and syringe programs and custodial settings. Allowing treatment to be accessed by all will result in significant personal and public health benefits.[90]

4.67 The Victorian Department of Health and Human Services recommended a number of reforms in the transition from tertiary to primary care models, including:

- The removal of restrictions on the section 100 Highly Specialised Drugs program for hepatitis C so that treatment can be initiated and maintained by accredited community-based general practitioners. This will increase access to treatment, reduce waiting times to care, and avoid costly hospital admissions. Where cases are complex, care can occur under the supervision of hospital-based specialists
- The removal of the public/private dispensing demarcation for hepatitis C, as for HIV
- An integrated curriculum for general practitioners who wish to become section 100 prescribers for hepatitis B, C and HIV, in order to increase incentives and reduce the education and training burden
- A national standard for community-based (general practice) models of care to treat hepatitis C.[91]

4.68 Hepatitis NSW also called for funded programs to expand the number of GPs 'who are able to prescribe new hepatitis C drugs, assuming that section 100 restrictions remain in place in this area even with new drugs approved'.[92]

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89 Dr Tuck Meng Soo, Private Capacity, *Committee Hansard*, Canberra, 20 March 2015, pp 45-46.

90 Hepatitis Victoria, *Submission 59*, p. 10.

91 Victorian Department of Health and Human Services, *Submission 96*, p. 2.

92 Hepatitis NSW, *Submission 91*, p. 28.

4.69 A limited number of people are already undergoing treatment for hepatitis C in primary settings. In New South Wales, a 'modest' number of general practitioners are accredited to prescribe treatment in a shared-care arrangement with a specialist.[93] Adjunct Associate Professor Levinia Crooks from the Australasian Society for HIV Medicine informed the Committee that she is aware of primary care practitioners with significant experience, having treated up to 150 hepatitis C patients. She noted that primary care providers 'do not want to place any of their patients in jeopardy and are quite able to notice when a patient needs to receive a higher level of care and refer them on for that purpose'.[94]

4.70 Despite the limited number of GPs deciding to become accredited, NSW Health stated that this model was 'an effective, safe treatment option for some patients', further commenting, that 'if implemented at scale, this approach has the potential to significantly increase access to hepatitis C treatment'.[95]

4.71 The *NSW Hepatitis C Strategy 2014-2020* considered that the limited numbers of GPs seeking accreditation under the shared-care arrangements with a specialist available in the State may be a result of several factors, including:

> … competing clinical demands, patient choice, dissatisfaction with shared care protocols and the complexity of care not being adequately supported under the Medicare Benefits Schedule to justify the ongoing training and prescribing accreditation requirements for general practitioners.[96]

Regional and Remote Access to Care

4.72 Expanding the role for GPs in initiating and managing treatment services presents a significant opportunity for regional and remote areas. Dr David Learoyd, a rural GP, stated:

> On several occasions I have attended special seminars to train GPs about Hepatitis C treatment. Despite this, I have not been able to prescribe treatment for Hepatitis C to my patients… So the patients in my town have to travel over 200 km return trip to see a specialist, and to have treatment [and] this is a huge barrier to access to adequate effective treatment.[97]

93 NSW Government, *NSW Hepatitis C Strategy 2014–2020*, p. 27.

94 Adjunct Associate Professor Levinia Crooks, Chief Executive Officer, Australasian Society for HIV Medicine, *Committee Hansard*, Sydney, 22 January 2015, pp 10–11.

95 NSW Health, *Submission 94*, p. 5.

96 NSW Government, *NSW Hepatitis C Strategy 2014–2020*, p. 30.

97 David Learoyd, *Submission 50*, p. 1.

4.73 The Australasian Society for HIV Medicine commented that 'in rural communities there is a greater need for interested GPs to be involved in hepatitis C care due to the scarcity of tertiary and specialist services'.[98]

Nurse-led care

4.74 South Australia, New South Wales, Victoria and Western Australia have commenced delivery of hepatitis C treatments through nurse-led models of care. A nurse-led model of care requires a specialist and an advanced practice nurse to coordinate and facilitate the delivery of health care for the patient, and collaborate with and manage communication between members of a multidisciplinary team regarding the patient's management plan.[99]

4.75 Hepatology nurses, in collaboration with a medical specialist, are involved in testing and diagnosing hepatitis C, as well as educating, supporting and clinically managing patients during treatment.[100]

4.76 Hepatology nurses currently work in metropolitan, regional and rural settings in: tertiary care, primary care including general practice, sexual health clinics, mental health clinics, alcohol and other drugs services, multicultural health services and community health centres, custodial settings, antenatal services and Aboriginal medical services.[101]

4.77 The Australian Hepatology Association (AHA), which represents hepatology nurses, stated that the role of hepatology nurses should be 'significantly enhanced' to utilise its 'cost-effectiveness of delivery and flexible, adaptive, specialist nursing care'.[102] The AHA highlighted treatment models for other chronic diseases to demonstrate how specialist nurses have contributed to improved outcomes. The AHA stated:

> As we have seen in the management of other chronic diseases, such as diabetes and cardiovascular disease, enhancing the role of specialist nurses expands access to care, provides safe and efficient care, improves communication within the multidisciplinary team and improves patient outcomes through the delivery of tailored patient education and support.[103]

98 Australasian Society for HIV Medicine, *Submission 58*, p. 7.

99 Australasian Hepatology Association, *Submission 23*, pp 1-2.

100 Australasian Hepatology Association, *Submission 23*, p. 1.

101 Australasian Hepatology Association, *Submission 23*, p. 1.

102 Ms Megan Phelps, Australian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 9.

103 Ms Megan Phelps, Australian Hepatology Association, *Committee Hansard*, Melbourne, 21 January 2015, p. 9.

4.78 The AHA also commented about the development of nurse-led models internationally which has led to better patient-care outcomes:

> The development of nurse-led clinics is expanding around the world due to their established benefits including increased patient satisfaction, longer consultation times and timely access to specialists services across a range of chronic diseases. Nurse-led services do not simply replace the doctor with a nurse but provide an opportunity for patients to access the skills of a specialist nurse which enhances the quality of care through the provision of extensive patient education and support.[104]

4.79 Adjunct Associate Professor Levinia Crooks from the Australasian Society for HIV Medicine agreed that nurses could provide care for hepatitis C in a primary care setting. Not only do nurses already provide 'a considerable amount of care in the tertiary setting', nurses that provide care in a primary care setting could 'act as a very good liaison, assisting when a person needs to be moved from one level of care to another'.[105]

4.80 Commenting on its nurse-led model of care, the Government of Western Australia stated:

> A recent evaluation of this program found that the waiting time to start treatment and support services available to patients undergoing hepatitis C treatment in regions with a nurse-supported shared care hepatitis C program, seemed to be as good, if not better, than the service provided through metropolitan treatment centres. The majority of patients who participated in the evaluation expressed high levels of satisfaction with the services available and preferred to access treatment locally.
>
> There is no reason why such a nurse supported program could not operate in other regions, nor in settings other than general practice (as demonstrated in drug and alcohol services, or trialled in other settings, for example, in needle and syringe exchanges or through other community based agencies providing services to people with hepatitis C).[106]

4.81 The Government of Western Australia estimates that an additional $1.7 million per annum is required to provide a state-wide nurse-supported hepatitis shared care program in WA. Further, 'increasing the already very low number of patients treated would

104 Australasian Hepatology Association, *Submission 23*, pp 1-2.

105 Adjunct Associate Professor Levinia Crooks, Australian Society for HIV Medicine, *Committee Hansard*, Sydney, 22 January 2015, pp 10–11.

106 Government of Western Australia, *Submission 12*, p. 7.

generate significant long-term health-care cost-savings, meaning this model would ultimately pay for itself'.[107]

4.82 HepatitisWA also advocated for an expanded nurse-led primary care model and referenced the key successes of such a system operating at a hepatitis C clinic in New Zealand where its clients:

- became better informed about hepatitis C;
- made positive lifestyle changes;
- were more likely to consider starting treatment; and
- experienced less discrimination than in other health care settings.[108]

4.83 In addition to describing the benefits of a nurse-led model of care, inquiry participants also pointed out some of the challenges such a model would encounter:

- current nursing salaries—in particular, nurses are not supported to 'go out into the community and treat people with hepatitis C';[109]
- concern about the ability of nurses to provide hepatitis C treatment;[110] and
- the number of nurses available to provide treatment would need to significantly increase.[111]

4.84 Hepatitis Australia advised that although there 'are certainly some very good nurse-led models of care' these models are 'not the norm'. Professor Margaret Hellard advised that the evidence on the best models of care 'is poor', with few published reports on the subject (although she added there 'are a lot of quality anecdotal reports'). Professor Hellard and Professor Alex Thompson, will soon start two trials to assess the feasibility of nurse-led models of care. Professor Hellard was optimistic about the likely results and stated:

> In my view we are doing that to prove something which we think inherently will be successful, but you have to sometimes provide evidence for people who want scientific evidence. They have certainly been shown anecdotally—like various ones—to be successful, but there is not a great review that you will find if you

107 Government of Western Australia, *Submission 12*, p. 7; See also Australasian Hepatology Association, *Submission 23*, p. 2.

108 HepatitisWA, *Submission 9*, p. 3.

109 Professor Alex Thompson, St. Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p 13.

110 Professor Alex Thompson, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p 13.

111 Associate Professor Joseph Torresi, Australasian Society for Infectious Diseases, *Committee Hansard*, Melbourne, 21 January 2015, p 13.

are looking at the literature or asking anybody to show you that, as such.[112]

Concluding Comment

Testing

4.85 Taking into consideration the high rate of hepatitis C diagnosis at approximately 80 per cent, the Committee supports the priority actions relating to testing identified in the *Fourth National Hepatitis C Strategy*. A focus on improving testing among priority populations may further increase the rate of diagnosis.

4.86 The Committee believes the *Fourth National Hepatitis C Strategy* would benefit from the inclusion of more specific targets in relation to testing for hepatitis C. Further, reporting on progress towards these targets would enable regular evaluation of progress towards the goal of increasing testing and improving the hepatitis C diagnosis rate.

4.87 The Committee heard that the use of rapid point of care testing (RPOCT) enabled people at risk of hepatitis C transmission to be tested in approximately 30 minutes, and that testing could be performed by non-clinical staff, such as peer workers or in community pharmacy settings.

4.88 Taking into consideration evidence received, the Committee believes the RPOCT may have benefits in reaching Australians at a higher risk of hepatitis C infection. The Committee understands that RPOCT is not currently available as a testing method in Australia, and believes that the Department of Health should consider ways in which the deployment of RPOCT in Australia could assist in increasing voluntary hepatitis C testing.

Pharmaceutical Benefits Scheme Listing of New Medicines

4.89 The Committee received evidence about the Pharmaceutical Benefits Advisory Committee process. While it is relatively straight forward to determine the cost of current hepatitis C treatment, it is difficult to reliably determine the broader costs and potential long term savings that may be achieved through the approval of new hepatitis C treatments. Additional current costs of providing hepatitis C treatment may include hospital services, and lost productivity.

112 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 13.

4.90 Additionally, there was some concern about the time taken to approve new hepatitis C treatments that had previously been approved in other international jurisdictions, noting that this may have broader cost implications in regard to continued reliance on the current treatments.

4.91 The broader issue of the Pharmaceutical Benefits Advisory Committee process, including a broader measurement of costs, and treatment approval times may warrant further investigation by the Department of Health.

The Role of Primary Care

4.92 Evidence provided to the Committee suggests that more can be done to treat hepatitis C in primary health care settings. While many general practitioners may not be able to prescribe the treatments currently available to treat hepatitis C, there is still a role for general practitioners in recommending testing, providing patient support, and encouraging treatment uptake. Current caps by a number of health care facilities on the number of patients seeking treatment, also suggests that an expanded role for general practitioners should be considered.

Access to New Treatments

4.93 The Committee heard that the development of new treatments for hepatitis C would enable treatment to be more easily provided in primary care settings, and through nurse-led models. The Committee believes that the Department of Health should review the ways in which hepatitis C treatment is delivered if new methods of treatment become available in Australia. In addition, the Committee believes, the Department of Health should also consider improved treatment delivery methods for people living with hepatitis C in regional and remote Australia, and amongst Aboriginal and Torres Strait Islanders.

PBS Listing of New Medicines

4.94 The Committee understands that the process for listing new treatments for hepatitis C on the Pharmaceutical Benefits Scheme has been ongoing throughout the inquiry. As the listing and approval process is not yet complete, the Committee makes no further comment or recommendations relating to these treatments.

Recommendation 3

4.95 **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

4.96 **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

4.97 **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

5.1 This chapter includes evidence received by the Committee regarding current and potential hepatitis C prevention and treatment strategies for groups identified as being at a high-risk of acquiring an infection. According to the Australian Government's *Fourth National Hepatitis C Strategy* these groups include: injecting drug users, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds and people in custodial settings. [1] Although each group will be addressed separately, it is important to note that individuals can belong to multiple high-risk groups.

5.2 Hepatitis C prevention strategies, testing and treatment options are also discussed in regard to specific high-risk populations.

Injecting Drug Users

5.3 It is estimated that 90 per cent of all new hepatitis C infections, and 80 per cent of existing infections, are caused by sharing or reuse of injecting equipment.[2] This section discusses hepatitis C among injecting drug users generally; issues that are particular to specific settings, such as injecting drug use in prisons, are discussed in the dedicated sections that follow.

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1 This report uses the terms used for the priority populations listed in the *Fourth National Hepatitis C Strategy*. Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 13; sex workers were also identified in the *Fourth National Hepatitis C Strategy*, however the Inquiry did not focus on this particular priority population.

2 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 3; see also, Australasian Society for Infectious Diseases, *Submission 11*, p. 8.

Prevention Strategies

5.4 Needle and syringe programs (NSPs) are an established means for helping to prevent the transmission of blood-borne viruses among injecting drug users, and a large number of individuals and organisations commended their public health value.[3] Between 2000 and 2009, NSPs have directly averted 97,000 new hepatitis C infections,[4] saving approximately $1.28 billion.[5]

5.5 Hepatitis NSW described NSPs as 'the most effective means to prevent hep C transmission'.[6] In 2009, an Australian Government report concluded that NSPs are demonstrated to be a cost-saving strategy, providing a minimum of $4 in return (through healthcare costs savings in the short term and considering direct costs only) for every $1 invested.[7] Further, the commissioned report found that when indirect costs were incorporated into the modelling, (including productivity gains and losses, patient costs and benefits), NSPs represent a $27 saving for each dollar invested.[8]

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3 Kirstie Monson, *Submission 37*, p. 1; Anglicare Tasmania, the Tasmanian Council on AIDS, Hepatitis and Related Diseases, Tasmanian Aboriginal Centre, *Submission 41*, p. 25; Aboriginal Health and Medical Research Council of New South Wales; *Submission 45*, p. 5; Chris Lawrence, *Submission 47,* p. 3; Women's Health Victoria, *Submission 52*, p. 6; Penington Institute, *Submission 54*, p. 3; National Drug and Alcohol Research Centre, *Submission 55*, p. 1; Australasian Society for HIV Medicine, *Submission 58*, p. 8; Hepatitis Victoria, *Submission 59*, p. 17; Fiona Patten MLC, *Submission 71*, p. 2; Name Withheld, *Submission 72,* p. 2; Burnet Institute, *Submission 66*, p. 8; National Association of People with HIV Australia, *Submission 69*, p. 3; Cancer Council Australia, *Submission 79*, p. 1; Scarlet Alliance, *Submission 81*, p. 3; Hepatitis Australia, *Submission 84,* p. 9; cohealth, *Submission 87*, p. 2; Hepatitis NSW, *Submission 91*, p. 35; NSW Health, *Submission 94*, p. 8; Tasmanian Government, *Submission 97*, p. 9; Australian College of Nursing, *Submission 100*, p. 11; Pharmacy Guild of Australia, *Submission 106*, p. 12; Mr Frank Farmer, Executive Director, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 1; Professor Tarun Weeramanthri, Executive Director, Public Health and Clinical Services, Department of Health, Western Australia, *Committee Hansard*, Perth, 10 March 2015, p. 9.

4 Australasian Society for Infectious Diseases, *Submission 11*, p. 8; Victorian alcohol and Drug Association, *Submission 31*, p. 4; Northern Territory AIDS and Hepatitis Council, *Submission 42*, p. 2; Penington Institute, *Submission 54*, p. 3; Australasian Society for HIV Medicine, *Submission 58*, p. 8; Burnet Institute, *Submission 66*, p. 8; Hepatitis Australia, *Submission 84,* p. 9; Hepatitis NSW, *Submission 91*, p. 36. See also National Centre in HIV Epidemiology and Clinical Research, *Return on investment 2: Evaluating the cost-effectiveness of needle and syringe programs in Australia*, 2009; cited in Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 15.

5 Northern Territory AIDS and Hepatitis Council, *Submission 42*, p. 2.

6 Mr Stuart Loveday, Chief Executive Officer, Hepatitis NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 24.

7 Australian Government, 'Return on Investment 2: Evaluating the Cost Effectiveness of NSPs in Australia', 2009, viewed 15 April 2015. <http://www.health.gov.au>.

8 Australian Government, 'Return on Investment 2: Evaluating the Cost Effectiveness of NSPs in Australia', 2009, viewed 15 April 2015. <http://www.health.gov.au>.

5.6 However, the Australasian Society for Infectious Disease noted that the rate of people reusing needle and syringes has remained stable (25 to 28 per cent over the past five years), and advocated that 'this indicates [that] a more concerted effort is essential to reduce the sharing of injecting equipment'.[9]

5.7 Australia has a national network of primary and secondary 'bricks and mortar' outlets, mobile and outreach services and vending or distribution machines together which assist to prevent the transmission of blood borne viruses and the reduction of other drug related harms.[10] There are 3000 NSP outlets in Australia which are located in specifically designed primary outlets, existing health or community facilities and also in pharmacies. Thirty million clean syringes are distributed each year.[11]

5.8 Table 5.1 shows how many NSPs operate in each jurisdiction, and the total units dispensed for the financial years 2012-13 and 2013-14.

Table 5.1 Needle and Syringe Programs operating in Australia for the Financial Years 2012-13 and 2013-14

	Primary outlets	Secondary outlets	Vending machines	Participating pharmacies	Total units dispensed
Australian Capital Territory	2	10	6	29	734 095[(a)]
New South Wales	31	387	221	512	12 276 897[(b)]
Northern Territory	3	10	0	14	380 000[(c)]
Queensland	18	0	56	584	9 958 305[(d)]
South Australia	4	78	4	202	3 000 000[(e)]
Tasmania	6	20	0	90	1 000 000[(f)]
Victoria	20	208	4	353	10 838 300[(f)]
Western Australia	6	0	7	500	4 891 387[(h)]

Source *Penington Institute*, Submission 54, *pp 9-10.*
(a) FY 2012-13; (b) FY 2013-14; (c) approximate annual; (d) FY 2013-14; (e) approximate annual; (f) approximate annual; (g) FY 2013-14; (h) 2013.

9 Australasian Society for Infectious Diseases, *Submission 11*, p. 3.

10 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 10.

11 Professor Chris Baggoley, Chief Medical Officer, Department of Health, *Committee Hansard*, Sydney, 22 January 2015, p. 31.

5.9 The Department of Health advised that in the decade from 2000 to 2009, Australian jurisdictions invested $243 million in NSPs with a historical average of around $9.5 million per annum.[12]

5.10 A number of organisations and individuals recommended building upon these successes and expanding the capacity of Australia's NSP programs further.[13] The Australian Injecting and Illicit Drug Users League (AIVL) commented that the current service models for NSPs were not sufficiently scaled 'to address the unique circumstances and challenges by the HCV epidemic among people who inject drugs'.[14] AIVL further commented:

> If we want to focus on getting hep C prevention right, we quite literally need… to increase our distribution of and access to new injecting equipment… If we do hepatitis C prevention properly, pathways to hepatitis C assessment and treatment will follow because people will feel engaged, valued and respected.[15]

5.11 The National Drug and Alcohol Research Centre stated that 'increasing the provision of sterile injecting equipment to reach 90 per cent of all injection episodes' would lead to hepatitis C infections being 'substantially reduced with …significant cost savings'.[16] The Centre noted third-party research which found that distribution of sterile injecting equipment is limited by supply rather than demand, and that if NSP distribution doubled, the annual incidence of hepatitis C would reduce by 50 per cent.[17] To achieve such an increase, the National Drug and Alcohol Research Centre proposed removing legislative barriers to peer

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12 Mr Graeme Barden, Assistant Secretary, Health Protection Policy Branch, Department of Health, *Committee Hansard*, Sydney, 22 January 2015, p. 4; See also, Department of Health, *Submission 20.1*, p. 1.

13 Mr Frank Farmer, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 1; Penington Institute, *Submission 54*, p. 3; Australasian Society for HIV Medicine, *Submission 58*, p. 8; Australian Injecting and Illicit Drug Users League, *Submission 85,* pp 10-11; Ms Annie Madden, Executive Officer, Australian Injecting and Illicit Drug Users League, *Committee Hansard*, Canberra, 20 March 2015, p. 25; National Drug and Alcohol Research Centre, *Submission 55*, p. 1; Burnet Institute, *Submission 66*, p. 8; Hepatitis Australia, *Submission 84,* p. 8; cohealth, *Submission 87*, p. 8; Victorian Department of Health and Human Services, *Submission 96*, p. 3; Hepatitis NSW, *Submission 91*, p. 36.

14 Australian Injecting and Illicit Drug Users League, *Submission 85,* pp 10-11.

15 Ms Annie Madden, Australian Injecting and Illicit Drug Users League, *Committee Hansard*, Canberra, 20 March 2015, p. 25.

16 National Drug and Alcohol Research Centre, *Submission 55*, p. 1.

17 JA Kwon, J Iversen, L Maher, MG Law and DP Wilson, (2009), 'The Impact of Needle and Syringe Programs on HIV and HCV Transmissions in Injecting Drug Users in Australia: A Model-Based Analysis', *Journal of Acquired Immune Deficiency Syndromes,* 51(4), 462-469; referred to in National Drug and Alcohol Research Centre, *Submission 55*, p. 2.

distribution of sterile injecting equipment,[18] and placing NSPs in Australian prisons.[19]

5.12 The Burnet Institute also supportive of increasing the number of NSPs, opening hours and capacity in the NSP workforce. The Burnet Institute stated:

> If NSPs are to be effective, high-level coverage is vital: a clean needle and syringe needs to be available for every injecting episode. This will require more NSP outlets, increased NSP hours, greater availability of vending machines and increased capacity in the NSP workforce.[20]

5.13 Hepatitis Australia similarly supported increasing the number of NSPs, stating 'the evidence is that the investment in NSPs is not yet at an optimal level for [hepatitis C] prevention and that greater investment in NSPs will result in greater returns'.[21]

5.14 The Victorian Department of Health and Human Services recommended increasing the access to NSPs in community controlled settings in rural and regional Australia.[22]

5.15 Hepatitis NSW expressed a similar view and commented:

> NSPs are most effective in preventing hepatitis C transmission when they are easily accessible – geographically, in time, via different methods (including primary and secondary NSPs and vending machines) and, most importantly, by a wide range of priority population groups.
>
> While many (although not all) metropolitan areas now have a variety of different NSP services (including 24 hour services and/or automatic dispensing machines), coverage is not as comprehensive in rural and regional Australia.[23]

5.16 HepatitisWA stated that NSPs present opportunities other than a location to collect sterile equipment, stating 'an NSP is not just somewhere where someone comes and gets their equipment. There is a lot more that happens'. HepatitisWA emphasised that such services can build relationships with their clients, allowing more open conversations about

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18 National Drug and Alcohol Research Centre, *Submission 55*, p. 2; See also Professor John de Wit, Director, Centre for Social Research in Health, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 26.

19 National Drug and Alcohol Research Centre, *Submission 55,* p. 3.

20 Burnet Institute, *Submission 66*, p. 8.

21 Hepatitis Australia, *Submission 84,* p. 8.

22 Victorian Department of Health and Human Services, *Submission 96*, p. 3.

23 Hepatitis NSW, *Submission 91*, p. 36.

high-risk behaviours, prevention strategies, as well as testing and treatment options: 'So when you are talking about an NSP, we look at the whole person. Whilst our remit is to stop the transition of blood-borne viruses, it is actually about the health and wellbeing of these hard-to-reach and really vulnerable people'. [24]

5.17 This was supported by the Penington Institute, which stated that NSPs are not only 'essential to reducing risk of transmission', but also provide a 'health promotion intervention that can educate people who inject about the risks of transmission'.[25] The Australasian Society for HIV Medicine similarly noted the other important services NSPs can provide including primary healthcare, education, referrals to other services (including treatment) and increasing the safe disposal of injecting equipment. The Australasian Society for HIV Medicine promoted the importance of improving the 'capacity of NSPs to inform and educate individuals about hepatitis C and provide referrals to testing and treatment where appropriate'.[26]

5.18 The *Fourth National Hepatitis C Strategy* acknowledges that efforts to facilitate access to, and the safe use of, sterile injecting equipment can be impeded by the availability of NSP services after-hours. This is in addition to the location and geographical accessibility of NSP services, and stigma and discrimination experienced by people who have to identify as an injecting drug user when accessing health and some NSP services.[27]

Peer Education and Syringe Distribution

5.19 A number of individuals and organisations discussed the importance of peer education and the capacity of peers to access priority populations which traditional services find difficult to reach.[28] According to AIVL, peer education is 'one of the most efficacious tools we have for connecting and educating the community of people who use and inject drugs'.[29]

5.20 The role of peers in education and prevention strategies was acknowledged in the *Fourth National Hepatitis C Strategy* where it was

24 Ms Sally Rowell, Community Services Manager, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, pp 7-8.

25 Penington Institute, *Submission 54*, p. 3.

26 Australasian Society for HIV Medicine, *Submission 58*, p. 8.

27 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, pp 15–16, 25.

28 Anglicare Tasmania & Tasmanian Council on AIDS and Related Diseases & Tasmanian Aboriginal Centre, *Submission 41*, p. 27; Ms Annie Madden, Executive Officer, Australian Injecting and Illicit Drug Users League, *Committee Hansard*, Canberra, 20 March 2015, p. 26; Burnet Institute, *Submission 66*, p. 8; Scarlet Alliance, *Submission 81,* p. 3; cohealth, *Submission 87*, p. 9.

29 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 12.

identified as a national priority.[30] The Strategy further stated that models of distributing sterile equipment should be reviewed and that the involvement of peers in distribution should be considered:

> Models currently in use should be reviewed and updated to better address the known barriers and meet the changing needs of people who inject drugs in Australia. Models should consider how best to involve peers in the distribution of NSP equipment, which has shown to be cost effective. Legislative barriers restrict some of these practices at present, and should be reviewed in light of the goal of this Strategy.[31]

5.21 The AIVL commented on the unseen role of peer education and stated:

> When I think about peer education and the value of peer education, is that, when I first started injecting, there were no health workers in the room. There were not needle and syringe program workers in the room, even if they existed at that time. It was other drug users who were in the room. They were the ones who educated me about health issues, and they did. I think that is one of the things that never gets discussed enough: drug users do really care for each other; people do look after each other. People call ambulances, if they feel safe enough to do so, for overdoses. People take people to doctors and hospitals. They help engage with information and share information with each other. So we need to equip people with the capacity to do that.[32]

5.22 The AIVL stated that better equipping peer educators will encourage greater access to NSPs among new injecting drug users. Accessing these services prior to contracting hepatitis C is particularly important in light of AIVL's statement that '50 per cent of people will get hepatitis C within the first six months of starting injecting.'[33]

5.23 The Burnet Institute also discussed the impact peer education can have on this population, but cautioned that there is insufficient evidence to demonstrate that peer education alone, is sufficient to reduce transmission rates:

> Behavioural counselling and peer education interventions, when provided alone, have not been shown conclusively to significantly reduce hepatitis C transmission in [people who inject drugs]. That

30 Australian Government, *Fourth National Hepatitis C Strategy*, p. 15.

31 Australian Government, *Fourth National Hepatitis C Strategy*, p. 16.

32 Ms Annie Madden, Australian Injecting and Illicit Drug Users League, *Committee Hansard*, Canberra, 20 March 2015, p. 26.

33 Ms Annie Madden, Australian Injecting and Illicit Drug Users League, *Committee Hansard*, Canberra, 20 March 2015, p. 26.

> said, the benefits of these programs are often difficult to measure due to their small size and the complex structural and legal settings in which they occur. Behavioural counselling and peer education may have broader benefits that cannot be measured in program evaluations.[34]

5.24 However, cohealth recommended promoting peer networks for encouraging greater access to clean equipment, noting that 'the use of peer networks in communities or population cohorts where there are lower access rates, such as Aboriginal and Torres Strait Islander people, is of particular value and should be embraced'.[35]

5.25 The AIVL commended the role of peer educators as an effective strategy to disseminate new information and assisting creating understanding. AIVL stated:

> People who inject drugs are very effective when it comes to passing on information to their peers. The main problem is not encouraging people to share information but rather, making sure that the information that is in circulation is actually correct and useful. This is where the work of trained hepatitis C peer educators comes in. They are the people 'on the spot' who can not only pass on new information, but can also correct misinformation… Peer educators are the people who are best placed to engage with other drug users on hepatitis C, as they are often the only ones who are there when hepatitis C is actually transmitted - that is, when people are injecting.

5.26 A number of drug-user representative organisations have been involved in training peer educators in an effort to prevent hepatitis C transmission. However, in the view of AIVL, their capacity to provide this training 'has been severely under-resourced', advocating that if the transmission target of the *Fourth National Hepatitis C Strategy* is to be realised, resourcing for peer education programs should be increased.[36]

5.27 At present, peer needle and syringe distribution for the purpose of injecting drugs is illegal in all Australian jurisdictions.[37]

5.28 The AIVL stated that although several jurisdictions have attempted to increase the volume of distribution of needles and syringes at NSP

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34 Burnet Institute, *Submission 66*, p. 8.

35 cohealth, *Submission 87*, p. 9.

36 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 13.

37 Australian Injecting and Illicit Drug Users League, *Submission 85,* pp 13-14.

services, there has not been a corresponding effect on the rates of people reporting reuse and sharing of injecting equipment.[38]

5.29 The Scarlet Alliance also stated that peer distribution should form part of a multi-faceted prevention strategy.[39] As a result, the Scarlet Alliance 'strongly recommended' increasing the distribution of sterile injecting equipment by peers and advocated for legal reform to support peer distribution.[40]

Testing

5.30 Introducing rapid testing (or point-of-care testing) into community settings where high-risk populations are more likely to access these services, was one option put forward to encourage higher testing rates. Point of care testing is a preliminary screening test that, if a positive result is generated, would be followed up by regular clinical tests.

5.31 AIVL stated that rapid testing is likely to be used by populations who 'may not be reached through existing mainstream services':

> For people who inject drugs, hepatitis C quick testing could play an important role in improving access to … testing for people who do not use other health services other than NSP, have vein problems that make taking venous samples difficult, only access outreach based services or due to concerns about stigma, discrimination and confidentiality would prefer to access testing via peer-based quick testing service.[41]

5.32 HepatitisWA recommended that a pilot program of rapid testing be implemented for people who access NSPs. HepatitisWA explained that a key benefit of rapid testing in NSPs is that it responds to the reluctance to access conventional health services among injecting drug users. HepatitisWA referenced a 2013 pilot program in Wisconsin in the United States which resulted in 1 255 clients being tested, and of the infections found, 72% had not previously been reported.[42]

Treatment

5.33 Historically, there have been lower rates of treatment referral and uptake of people who inject drugs, or have previously injected drugs. The

38 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 13; See Australasian Society for Infectious Diseases, *Submission 11*, p. 3 for information on sharing rates.

39 Scarlet Alliance, *Submission 81,* p. 3.

40 Scarlet Alliance, *Submission 81,* p. 3.

41 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 21.

42 Hepatitis WA, *Submission 9*, p. 1.

Australasian Society for HIV Medicine stated that this is in part due to the location of treatment and management services in tertiary healthcare centres.[43]

5.34 Approximately 50 000 people are on opioid substitution treatment (OST) programs in Australia, and surveys of pharmacotherapy clients reveal a 'willingness to consider hepatitis C treatment, many people are declining treatment'.[44] The Burnet Institute reported on the findings of a Canadian study into the provision of hepatitis C treatment at OST clinics with similar findings.[45] The AVIL stated that although integrating hepatitis C treatments with OSTs 'will have appeal for some people… it is equally important to recognise that not all people… will want to undergo hepatitis C treatment'. The AVIL stated:

> The current rush to incorporate hepatitis C treatment into OST settings as a 'magic-bullet solution' to low hepatitis C treatment numbers among people with a history of injecting drug use belies the reality of the pharmacotherapy treatment experience for many people on these programs. Some people prefer to keep their drug dependency treatment separate to the management of other health conditions.[46]

5.35 Mr Sione Crawford noted that although 'new resources may help… what is really needed is redeployment of resources and thinking outside the box'. Mr Crawford advocated for the 'meaningful inclusion of the community most affected: people who inject drugs', and commented:

> A true long-term partnership approach was undertaken with the affected community in blood-borne virus prevention, HIV and hep C when the HIV epidemic first broke. That has borne fruit for us, with very low HIV rates amongst people who inject drugs, and it is because people who inject drugs got on board. This has never happened in hepatitis C treatment, and the time has come to include us meaningfully. This means involvement in planning and implementing services, and including us, with an essential and determining role, when planning services for us. [47]

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43 Australasian Society for HIV Medicine, *Submission 58*, p. 8.

44 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 27.

45 The study found that less than six percent of the hepatitis C infected population attending the service underwent treatment, with a 'cure rate' of 51 per cent for people with genotype one hepatitis C and 68 per cent for people with genotype three hepatitis C. See Burnet Institute, *Submission 66*, pp 7-8

46 Australian Injecting and Illicit Drug Users League, *Submission 85,* p. 27,

47 Mr Sione Crawford, Manager, Canberra Alliance for Harm Minimisation and Advocacy, *Committee Hansard*, Canberra, 20 March 2015, p. 26.

Aboriginal and Torres Strait Islanders

5.36 Hepatitis C rates are three times higher among Aboriginal and Torres Strait Islanders compared to non-Aboriginal and Torres Strait Islanders.[48] Infection rates are higher within certain age groups of Indigenous Australians: six times higher for the 15 to 19 year old age group; and five times higher for the 20 to 29 year old age group.[49]

5.37 As stated in Chapter 2, new diagnoses of hepatitis C have been gradually increasing in the Aboriginal and Torres Strait Islander population (from 130 per 100 000 in 2008 to 166 per 100 000 in 2012).[50] Among Aboriginal and Torres Strait Islanders who inject drugs, the rate of hepatitis C infection is estimated to be between three and 13 times higher than that of the non-Aboriginal and Torres Strait Islander injecting drug user population.[51] Aboriginal and Torres Strait Islanders also have lower rates of treatment than non-Aboriginal and Torres Strait Islanders.[52]

5.38 A range of factors contribute to the reported high rates of hepatitis C infections in Aboriginal and Torres Strait Islanders. The Aboriginal Health and Medical Research Council of NSW (AH&MRC) cited a range of health and other conditions which make Aboriginal and Torres Strait Islanders more susceptible to acquiring a hepatitis C infection, affect the disease's progression and complicate treatment. These are higher rates of hepatitis B; obesity; unsafe levels of alcohol consumption; poly drug use; exposure to blood borne viruses; higher rates of diabetes; a higher level of social and emotional wellbeing issues; and, high incarceration rates.[53]

48 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 2.

49 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 4.

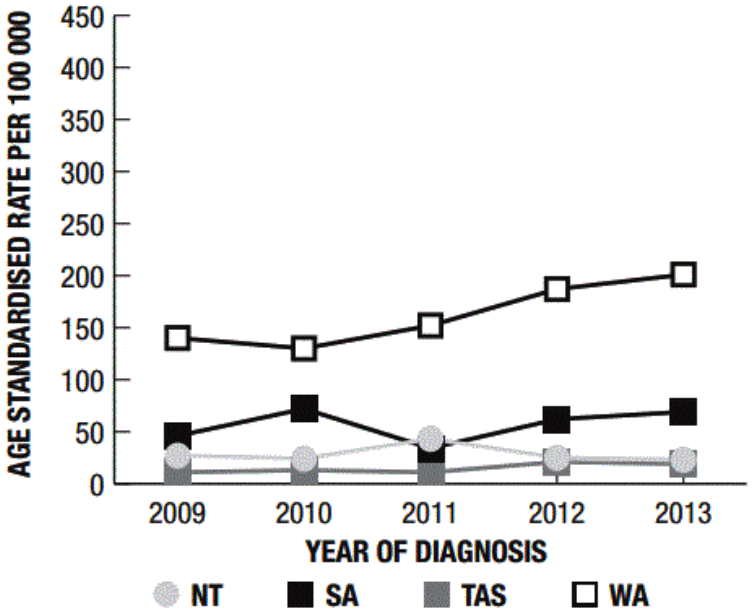
50 It is also expected that the figures for the Aboriginal and Torres Strait Islander population are likely to be under-reported, partly because Aboriginal and Torres Strait Islander status is not always included when an infection is notified. See Australian Government, *Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy 2014–2017*, July 2014, pp 4, 6.

51 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 17; see also Australasian Society for Infectious Diseases, *Submission 11*, p. 8.

52 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, pp 3, 7, 22–23.

53 Ms Sandra Bailey, Chief Executive Officer, Aboriginal Health and Medical Research Council of NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 37.

Figure 5.1 Aboriginal and Torres Strait Islander Notification rates of newly diagnosed hepatitis C infection in the Northern Territory, South Australia, Tasmania and Western Australia for the years 2009 to 2013



Source *The Kirby Institute, Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander People: Surveillance and Evaluation Report 2014*

Prevention Strategies

5.39 The AH&MRC has developed and delivered a number of campaigns specifically designed to prevent further infections among Aborignal and Torres Strait Islanders. These include a hip-hop song writing program (which won an award at the 2011 National Hepatitis Health Promotion Conference),[54] a street art based hepatitis C project (delivered in five juvenile detention centres and four community settings), and plays performed by Aboriginal theatre companies.[55]

5.40 Seven Aboriginal controlled community health services (ACCHS) operate NSPs. None of these services are directly funded for providing NSPs and the need for new injecting equipment outstrips the supply in some locations. To address this latter concern, the AH&MRC stated that 'all methods of distribution of injecting equipment should be explored, in partnership with local Aboriginal communities'. In the view of the AH&MRC, these could include distribution through ACCHSs and other Aboriginal community organisations, vending machines, self-service models and peer distribution.[56]

54 See www.loveyourliver.net.au.

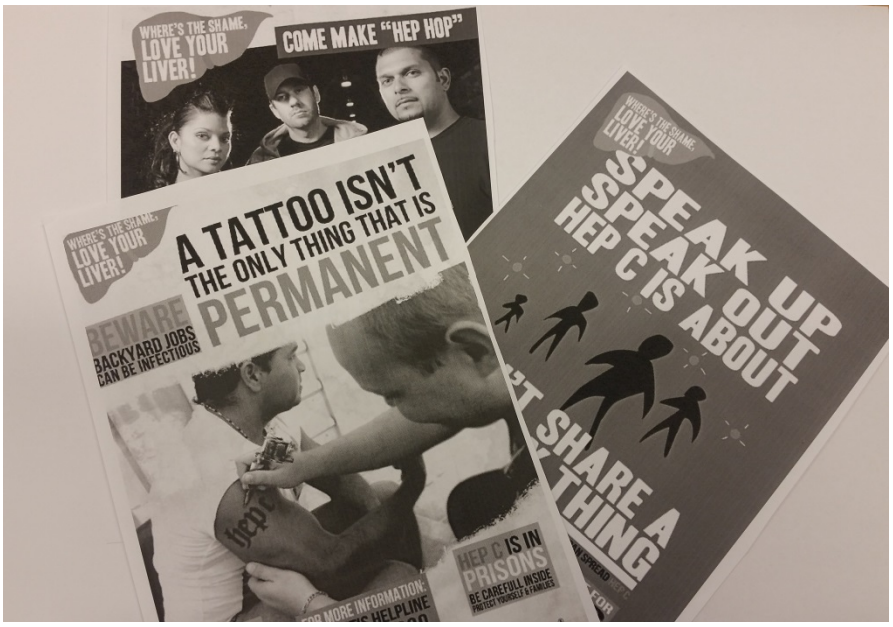
55 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 7.

56 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 7

5.41 Other prevention strategies proposed by the AH&MRC included: 'providing more accessible and culturally sensitive detox and drug treatment services; needle and syringe programs in prison settings more research into understanding the hepatitis C epidemic among Aboriginal people; increased funding and training for ACCHS clinicians; and a Aboriginal community led program to reduce stigma and discrimination around injecting drug use.'[57]

5.42 The AH&MRC stated that the success rates in the evaluation of its prevention programs have been due to 'the high level of Aboriginal community involvement in the design and delivery and even in the initiation of those projects and how they look'.[58]

Figure 5.2 Hepatitis C Promotional Material



Source *Aboriginal Health and Medical Research Council of New South Wales*

Role of Aboriginal Medical Services

5.43 A significant issue for Aboriginal and Torres Strait Islanders seeking hepatitis C treatment is inaccessibility of services. Accessing treatment and management services can also be impacted by a lack of experience among hepatitis C clinicians who work with Indigenous Australians.[59] To address these barriers, participants advocated that community-based

57 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 7.

58 Ms Sandra Bailey, Aboriginal Health and Medical Research Council of NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 32.

59 Ms Sandra Bailey, Aboriginal Health and Medical Research Council of NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 10.

treatments would have a significant and positive impact on the number of Indigenous Australians being tested and completing treatment.

5.44 Aboriginal Community Controlled Health Services (ACCHS, also known as Aboriginal Medical Services (AMS)), operate in over 150 communities nationally. Together, the services form a network, but each is autonomous and independent. The ACCHS range in size from small services reliant on Aboriginal health workers and nurses who provide primary care; to large multidisciplinary services.[60]

5.45 Larger ACCHS may have extensive services (provided by staff and by visiting health practitioners) which have been established at a local level to serve their community. These may include 'general practice clinics, liver health, sexual health, chronic care, social and emotional wellbeing health care, drug and alcohol services and other health programs which are highly relevant to the support and management of people with [chronic hepatitis C] and to shared care with tertiary [hepatitis C] treatment services'.[61]

5.46 The Australasian Society for HIV Medicine commented that ACCHSs 'have the ability to provide integrated multidisciplinary primary health care for people living with hepatitis C that is culturally appropriate'. As many hepatitis C patients are likely to have multiple health issues, larger ACCHSs are often well placed to provide comprehensive primary health care for these complex needs, as well as having strategies to overcome socioeconomic, geographical, system-related and other barriers to health management.[62]

5.47 In New South Wales, a number of ACCHS currently conduct hepatitis C clinics which allow patients to access a broad range of primary health care services, including visiting hepatitis C specialists.[63] Further, an ACCHS in Western Sydney also employs a GP who is an accredited s100 prescriber who operates in a shared care arrangement with a specialist in administering treatment therapies. [64]

5.48 In South Australia, one blood-borne virus specialist is funded by the state government to coordinate HIV and viral hepatitis services across ACCHS

60 Australasian Society for HIV Medicine, *Chronic HCV Models of Care: Aboriginal Community Controlled Health Services*, p. 2, viewed 15 April 2015, <http://www.ashm.org.au>.

61 Australasian Society for HIV Medicine, *Chronic HCV Models of Care: Aboriginal Community Controlled Health Services*, p. 2, viewed 15 April 2015,. <http://www.ashm.org.au>.

62 Australasian Society for HIV Medicine, *Submission 58*, p. 8.

63 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 5.

64 Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 5; Ms Sandra Bailey, Aboriginal Health and Medical Research Council of NSW, *Committee Hansard*, Sydney, 22 January 2015, pp 9–10.

within that jurisdiction. Hepatitis SA noted that while this position delivers viral hepatitis education to the Aboriginal health workforce, there is a lack of specialist knowledge. Hepatitis SA stated:

> …there can be a lack of specialist knowledge about hepatitis C amongst Aboriginal primary healthcare workers within [ACCHS], and thus a lack of information about hepatitis C prevention, testing and treatment flowing to communities. Aboriginal primary healthcare workers at [ACCHS] reported that other co-morbidities such as mental health… are often a barrier to treatment for Aboriginal people, and that what they felt was needed was a "one stop shop" in [ACCHS] so that a person can be treated for hepatitis C without being sent to an array of others services.[65]

5.49 The Victorian Department of Health and Human Services recommended the development of a national Aboriginal Health Worker competency to specifically address hepatitis C screening, treatment, care and support.[66] The Australian College of Nurses also emphasised the need for health care workers in Aboriginal health service settings to receive the appropriate knowledge and skills in sexual health, blood-borne virus prevention, treatment and care.

Culturally and Linguistically Diverse Backgrounds

5.50 The *Fourth National Hepatitis C Strategy* identified people from culturally and linguistically diverse backgrounds from countries with a high prevalence of hepatitis C as a high-risk population.[67] Hepatitis C disproportionately affects people from some of the countries that are the source of migrants to Australia, and a recent study found hepatitis C antibodies in four per cent of immigrants from Africa, 80 per cent of which had confirmed chronic hepatitis C.[68]

5.51 In addition to language and cultural barriers, Hepatitis Australia highlighted that new migrants' health, social and economic needs may present further obstacles to managing their hepatitis C infection.[69] The

65 Hepatitis SA, *Submission 33*, p. 5.

66 Victorian Department of Health and Human Services, *Submission 96,* p. 3.

67 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 18.

68 Australasian Society for Infectious Diseases, *Submission 11*, p. 4.

69 Ms Helen Tyrrell, Chief Executive Officer, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 31.

Australian Liver Association, provided the following insight into how hepatitis C may be diagnosed and managed within migrant communities:

> …about 30 per cent of the Egyptian population is infected with hepatitis C. A large proportion of them are represented in liver transplants in Australia, and they actually do not present until the late state, because of lack of awareness and by that time they have liver cancer because of comorbidities such as obesity and diabetes and so forth. That should be factored in—that it is not all about IV drug use. We should factor in the migrant population, which is a marginalised population, and awareness is quite lacking in that setting as well.[70]

5.52 Similarly, hepatology nurse, Mrs Saroj Nazareth, provided the following account of how language barriers impact an individual's understanding about hepatitis C. Mrs Nazareth stated:

> I had a patient from the Vietnamese community who we looked after for nearly a year, and it was only towards the last three months of his treatment that, because he was responding so well, he came out through his interpreter and said, 'I will be so happy when I get rid of this virus, because I can finally sit with my family and have dinner together.' That really shocked us, because for all these months he has been thinking that even by sharing cutlery he can pass the disease on to his family. So education to raise awareness is really important.[71]

5.53 A study of GPs who work in an area of Sydney with a large migrant population revealed that, of the GPs surveyed, 89 per cent identified language difficulties as the main barrier to treatment of hepatitis C among migrants. Limited culturally and linguistically diverse appropriate resources for patients was also identified as a barrier by the majority of GPs surveyed. The GPs considered that increased access to health care workers from a non-English speaking background and translated literature on hepatitis C would be the most useful improvements in treating viral hepatitis in migrants.[72]

5.54 The Australian Research Centre in Sex, Health and Society highlighted the unique challenges experienced by culturally and linguistically diverse people who are infected with hepatitis C could be overcome through the development of community-based liver clinics, where GPs have a greater

70 Professor Amany Zekry, Chair, Australian Liver Association, *Committee Hansard*, Sydney, 22 January 2015, p. 25.

71 Mrs Saroj Nazareth, Private Capacity, *Committee Hansard*, Perth, 10 March 2015, p. 30.

72 M Guirgis et al, 'General practitioners' knowledge and management of viral hepatitis in the migrant population', *Internal Medicine Journal*, vol. 42, no. 5, May 2012, pp 497, 499–500.

role in managing hepatitis C patients. Further the Centre advocated that such clinics could address the 'cultural needs of their patients', which, in its view, would include:

- interpreters;
- cross-cultural training of staff;
- recruitment of staff of similar cultural background to the likely client group; and,
- flexible delivery of care to accommodate patients difficulties in attending appointments for cultural reasons.[73]

5.55 Relationships Australia – South Australia, which runs a multicultural health program which includes support for migrants with viral hepatitis, also recommended that 'attention needs to be given to the use of interpreters as cultural taboos and language incongruities can have devastating impacts on people receiving accurate health information'.[74]

People in Custodial Settings

5.56 Professor Michael Levy AM, Clinical Director of Justice Health Services ACT described the prison environment as a 'perfect storm for hepatitis C'.[75] Other witnesses outlined why prisons were a high risk environment for hepatitis C transmission:

- the concentration of hepatitis C-infected individuals in an over-crowded setting[76];
- fights;
- unsafe barbering, tattooing and body piercing;
- the 'stultifying boredom'[77] of prison life; and
- the availability of illicit drugs and injecting equipment.[78]

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73 Australian Research Centre in Sex, Health and Society, *Submission 19*, p. 4.

74 Relationships Australia – South Australia, *Submission 95*, p. 5.

75 Professor Michael Levy AM, *Submission 2*, p. 3.

76 According to the CPSU, in mid-April 2015, NSW had an inmate population of 11 500, whilst its capacity is 11 600. Other jurisdictions are significantly over capacity in the same period: Victoria's prison population was 500 over capacity; South Australia was 200 over capacity and Western Australia is more than 1000 over capacity. See Mr Troy Stephen Wright, Senior Industrial Officer, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p. 15.

77 Professor Michael Levy, Australian National University, *Committee Hansard*, Melbourne, 21 January 2015, p. 12.

78 Professor Michael Levy, *Submission 2*, p. 4; *Committee Hansard*, Melbourne, 21 January 2015, p. 12.

5.57 Mr Rodney Hatch, who was detained in a prison in Western Australia for a period of his life, provided the following account:

> I observed prisoners injecting together, sharing a single syringe between four men. These men were willing to fatalistically accept that they were almost certainly infecting themselves and each other with bloodborne viruses. Their desire for the drug effect at that time, driven by negative emotions aroused in a prison environment, over-rode their fear of infection. They were resigned to the fate of infection in order to receive the change of mood and feeling they craved at that time. These are men who ordinarily, and given the opportunity, would take the effort to protect themselves and minimize the risk of infection by using sterile injecting equipment.[79]

5.58 The Penington Institute explained that needle access in prisons 'is run as a black-market-economy item', with needles expensive and altered to allow transport. These needles can be 'shared by up to 100 people' and present 'extraordinary' hygiene and blood-borne virus risks.[80]

Prevalence and Testing

5.59 There is no national surveillance system for hepatitis C infection in custodial facilities in Australia. In custodial settings, the general prevalence of hepatitis C infection has been estimated to be between 23 and 47 per cent.[81] Further, among women in prison, the prevalence is estimated to be over 70 per cent.[82]

5.60 The National Drug and Alcohol Research Centre stated that although the frequency of injecting drug use may reduce in prison, 33 per cent of prisoners continue to inject drugs while incarcerated, 90 per cent of whom also share injecting equipment.[83] Hepatitis NSW stated that prior to entering prison, 75 per cent of people who inject drugs reported using sterile injecting equipment each time they injected, but, while in custody,

79 Rodney Ian Hatch, *Submission 99*, p. 1.

80 Mr John Ryan, Penington Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 31. See also Dr Susan Carruthers, Research Fellow, National Drug and Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 2.

81 Hepatitis Australia, *Submission 84 – Attachment D,* p. 3; Australian College of Nursing, *Submission 100*, p. 5; See also Australian Institute of Health and Welfare (2012), *The Health of Australia's Prisoners,* Cat no PHE 170, AIHW, Canberra.

82 Hepatitis Australia, *Submission 84 – Attachment D,* p. 3; Australian College of Nursing, *Submission 100*, p. 5.

83 National Drug and Alcohol Research Centre, *Submission 55*, p. 3.

70 per cent of people who inject drugs reported sharing injecting equipment.[84]

5.61 Within these estimates of hepatitis C prevalence and drug use whilst in custody, it is not known whether the transmission of hepatitis C occurred prior to entry to prison or while in prison. Estimates on the prevalence of prison-acquired hepatitis C vary considerably and there is no detailed and consistent data on the prevalence of prison-acquired hepatitis C.

5.62 Associate Professor Mark Stoové stated that 'research in the prison space in Australia—particularly amongst people with a history of injecting drug use—is incredibly scant'.[85]

5.63 The lack of detailed, consistent data about the rate of prison-acquired hepatitis C is primarily as a result of inconsistent or absent testing of prison entrants for the virus. Jurisdictions have individual policies for testing for hepatitis C,[86] and this can complicate the statistical integrity of those limited studies. Reflecting upon the limited data collected, the CPSU stated that the 'prevalence of hepatitis C transmission in custody is not known'.[87]

5.64 In 2008, the Department of Health acknowledged that the lack of national surveillance data makes it difficult to determine the incidence of hepatitis infection within a custodial environment.[88]

5.65 Of the few studies which were referred to the Committee about the rate of prison-acquired infections, the National Drug and Alcohol Research Centre cited a study that found 'among 114 prisoners with a history of injecting drug use who tested negative for HCV antibodies [upon entry to prison], 13 subsequently tested positive, despite being continuously incarcerated.'[89]

5.66 Hepatitis ACT acknowledged that the data (on hepatitis C in a custodial setting) 'lacks a little clarity', commenting that testing in the ACT is

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84 Mr Alistair Lawrie, Policy and Media Officer, Hepatitis NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 30; See also Hepatitis NSW, *Submission 91*, p. 39.

85 Associate Professor Mark Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 9.

86 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 6; for information on testing in Western Australia, see Mr Andrew Smith, Assistant Secretary, Western Australian Prison Officers' Union, *Committee Hansard*, Canberra, 4 May 2015, p. 10.

87 Mr Troy Wright, Senior Industrial Officer, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p. 4.

88 Department of Health, *Background to Hepatitis C in Custodial Settings in Australia*, 2008, viewed April 2015, <http://www.health.gov.au>.

89 F Luciani, NA Bretana, S Teutsh, J Amin, L Topp, GJ Dore, L Maher, K Dolan, AR Lloyd, (2014), 'A prospective study of hepatitis C incidence in Australian prisoners', *Addiction*, 109, 1695-1706, referred to in National Alcohol and Drug Research Centre, *Submission 55*, p. 3.

'suboptimal and that the notification criteria [leads to] … underreporting'.[90] Referring to data from the Australian Institute of Health and Welfare, Hepatitis ACT reported that Australian prisoners who are injecting drug users are 'at least eight times more likely to contract the virus while in prison than non-injecting drug users'.[91]

5.67 The Kirby Institute's *National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report* was described as 'the most reliable repeated evidence that is collected over time'.[92] In the last iteration of that study (2013),[93] the Kirby Institute reported that 31 per cent of prison entrants were hepatitis C antibody positive, representing an increase from 22 per cent in 2010. The Survey Report also found that hepatitis C antibody prevalence was higher among those with a history of injecting drug use than those who had not injected (58 per cent) and also higher among women who injected than men who injected (67 per cent versus 56 per cent).[94] The Kirby report did not reach a conclusion on the rate of prison-acquired hepatitis C.

5.68 The Western Australia Prison Officers' Union (WAPOU) stated that while testing remains voluntary, establishing prevalence data is statistically compromised. WAPOU stated:

> Speaking from Western Australian experience, it is not mandatory for any testing; it is an opt-in when prisoners come into a prison. To make a general statement that Australia-wide it is a certain percentage—where does that data come from? When prisoners enter the Western Australian system, they are not tested. We have 5,500 prisoners, and possibly a movement of between 2,000 and 3,000 are coming in and out generally during the year. How do

90 Mr John Didlick, Executive Officer, Hepatitis ACT, *Committee Hansard*, Canberra, 4 May 2015, p. 6.

91 Mr John Didlick, Hepatitis ACT, *Committee Hansard*, Canberra, 4 May 2015, p. 10.

92 Associate Professor Mark Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 9.

93 The Study is a consecutive, cross-sectional sample of prison entrants over a two week period. Participants were 794 of the 1 235 (64 per cent) prisoners entering Australian correctional centres who were offered the survey, (The Public Health Association of Australia, *Exhibit 13*: National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, 2010 and 2013: Prevalence of HIV, Hepatitis C, Hepatitis B, Sexually Transmissible Infections, and Risk Behaviours Among Australian Prison Entrants, UNSW Australia and Kirby Institute, March 2015, p. 13).

94 The Public Health Association of Australia, *Exhibit 13*: National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, 2010 and 2013: Prevalence of HIV, Hepatitis C, Hepatitis B, Sexually Transmissible Infections, and Risk Behaviours Among Australian Prison Entrants, UNSW Australia and Kirby Institute, March 2015, p. 7.

you arrive at that figure if they are not actually tested? It cannot be relative.[95]

5.69 To correct these issues with data collection and retention, the Public Health Association of Australia recommended improvements to the 'consistency and a comprehensive collection of data and reporting'.[96] The CPSU and Hepatitis Australia made similar recommendations.[97]

Prevention Strategies

5.70 Strategies to prevent the transmission of hepatitis C in prison environments must be threefold: harm minimisation, supply reduction and demand reduction strategies.[98] Much of the evidence presented during the Inquiry focussed on the introduction of an NSP into the prison environment as a specific harm-minimisation strategy.

5.71 There are currently no NSPs operating within Australian prisons. In 2013, the ACT Government announced that it intended to introduce a prison NSP. At the time of writing, stakeholder consultation was continuing.[99]

5.72 A large number of participants in the Inquiry supported the introduction of NSPs in Australian prisons.[100] The Penington Institute 'strongly

95 Mr Andrew Smith, Western Australian Prison Officers' Union, *Committee Hansard*, Canberra, 4 May 2015, p. 10.

96 Adjunct Professor Michael John Moore, Chief Executive Officer, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 25.

97 Mr Vince McDevitt, Australian Capital Territory Secretary, Community and Public Sector Union, *Committee Hansard,* Canberra, 4 May 2015, p. 25; Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard,* Canberra, 4 May 2015, p. 25.

98 Mr Troy Wright, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p. 4; Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 4; Ms Melanie Walker, Deputy Chief Executive Officer, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 11.

99 See ACT Government, *Strategic Framework for the Management of Blood-Borne Viruses in the Alexander Maconochie Centre 2013–2017*, August 2013, viewed 10 February 2015, <http://www.health.act.gov.au>

In April 2015, the ACT Government reached an agreement with the CPSU to develop a working group to progress the proposed introduction of an NSP at the ACT prison, the Alexander Maconochie Centre. According to news reports, the agreement envisages a model will be developed in 12 months, and then proceed to a ballot among correctional staff. Its introduction will only proceed if the majority of staff support the model in the ballot. (See: Canberra Times, 'Corrective services staff to vote on Alexander Maconochie Centre needle exchange program', 1 April 2015, viewed, 12 April 2015, <http://www.canberratimes.com.au/act-news/corrective-services-staff-to-vote-on-alexander-maconochie-centre-needle-exchange-program-20150401-1mcp4v.html>)

100 Hepatitis SA, *Submission 33*, p. 12; Kirstie Monson, *Submission 37*, p. 1; William Lenane, *Submission 39*, p. 1; Anglicare Tasmania, the Tasmanian Council on AIDS, Hepatitis and Related Diseases, Tasmanian Aboriginal Centre, *Submission 41*, p. 26; Northern Territory AIDS and Hepatitis Council, *Submission 42*, p. 3; Aboriginal Health and Medical Research Council of New South Wales, *Submission 45*, p. 7; Penington Institute, *Submission 54*, p. 5; Hepatitis ACT,

believes' that the State's legal duty of care to prisoners 'must include providing prisoners with access to sterile injecting equipment to prevent the spread of blood borne viruses – as is done in all Australian communities'.[101]

5.73 A number of individuals and organisations discussed the variety of different models which have been introduced internationally, and whether they could be used as models for Australia to implement.[102] The Kirby Institute noted that around 60 prisons around the world operate NSPs through various mechanisms, such as peer distribution, distribution by medical staff and vending machines.[103]

5.74 Hepatitis ACT referenced the results of an NSP located in a Spanish prison where, after ten years of the program, the prevalence of hepatitis C had decreased from 40 per cent to 26 per cent.[104] The National Drug and Research Institute commented however that these international models would need to be adapted to an Australian context, further noting that within Australia, one model will not be successful in all states and territories, or even within those jurisdictions.[105]

5.75 The National Drug Research Institute commented that prior to entering prisons, 90 per cent of all prison entrants were 'active users' of community-based NSPs, arguing that there is a high level of awareness among the cohort and a high level of desire not to contract blood-borne viruses, including hepatitis C.[106]

Submission 56, p. 3; Name Withheld, *Submission 72,* p. 2; Public Health Association of Australia, *Submission 68,* p. 6; National Association of People with HIV Australia, *Submission 69*, p. 3; Cancer Council Australia, *Submission 79*, p. 1; Scarlet Alliance, *Submission 81,* p. 4; Hepatitis Australia, *Submission 84*, p. 9; Hepatitis NSW, *Submission 91*, p. 38; Relationships Australia – South Australia, *Submission 95*, p. 7; Australian College of Nursing, *Submission 100*, p. 10; Mr Frank Farmer, Executive Director, Hepatitis WA, *Committee Hansard*, Perth, 10 March 2015, p. 2; Dr Susan Carruthers, National Drug Research Institute, *Committee Hansard*, Perth, 10 March 2015, p. 17; Associate Professor Mark Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 2.

101 Penington Institute, *Submission 54*, p. 5; National Drug and Alcohol Research Centre, *Submission 55*, p. 3. See also, Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Melbourne, 21 January 2015, p. 13.

102 Professor Michael Levy, *Submission 2*, p. 4; Professor Lisa Maher, Kirby Institute, University of New South Wales, *Committee Hansard*, Sydney, 22 January 2015, p. 3; Professor Margaret Hellard, Director, Centre for Population Health, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 12; Hepatitis ACT, *Submission 56*, p. 3.

103 Professor Lisa Maher, Kirby Institute, *Committee Hansard*, Sydney, 22 January 2015, p. 30.

104 Hepatitis ACT, *Submission 56*, p. 3.

105 Dr Susan Carruthers, National Drug and Research Institute, *Committee Hansard*, Canberra, 4 May 2015, pp 1-2.

106 Dr Susan Carruthers, National Drug and Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 7.

5.76 It was the view of both Professor Hellard and Hepatitis Australia that NSPs in prisons could reduce the risk of transmission for prisoners, but also prison staff.[107]

5.77 However, the CPSU stated that introducing NSPs in prisons represents a 'serious and tangible risk to occupational health and safety'. The CPSU stated that this risk is twofold: either a deliberate attack through the use of a needle as a weapon or an accidental needle-stick injury, and that both risks could result in a transmission of a blood borne virus.[108]

5.78 Despite these concerns, a number of individuals and organisations stated that there is no evidence internationally of injecting equipment being used as a weapon in a prison where an NSP was operating.[109]

5.79 Rodney Hatch, a former prisoner in WA stated:

> Working towards the elimination of any risk associated with prison NSPs will be greatly enhanced by the cooperative efforts and goodwill of all stakeholders.[110]

5.80 The community health organisation cohealth similarly noted that a 'harm minimisation approach' should be developed 'in a manner which is not detrimental to the safety of correctional officers'.[111] The organisation recommended the adoption of a transparent 'co-design process' where all stakeholders across the health and corrections systems with an interest in the issue including correctional services management, correctional health services management, custodial officers, health specialists, prisoners and prisoner advocates can 'establish a shared objective of translating the harm minimisation approach to drug use into the correctional setting'.[112]

5.81 Hepatitis ACT similarly noted that it would not support measures that increase the risks or harms to any one stakeholder, commenting: 'we do not believe that creating safer and healthier prisons needs to have winners

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107 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 12; Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 4.

108 Mr Troy Wright, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, pp 3-4.

109 Mr John Ryan, Penington Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 32; Penington Institute, *Submission 54*, p. 6; Dr Susan Carruthers, National Drug Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 1; Associate Professor Mark Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 3;

See also, United Nations Office on Drugs and Crime, *A handbook for starting and managing needle and syringe programmes in prisons and other closed settings*, 2014. Exhibit 8b.

110 Rodney Ian Hatch, *Submission 99*, p. 1.

111 cohealth, *Submission 87*, p. 2.

112 cohealth, *Submission 87*, p. 7.

and losers. Safer and healthier prisons are in the best interests of everyone'.[113]

5.82 Prevention strategies proposed by the CPSU included: increased resourcing to disrupt the trafficking of contraband, increased alcohol and other drug services inside prison and upon release, provision of tattooing and piercing services for inmates, the introduction of rapid testing for hepatitis C, and greater research on the current rate and methods transmission of hepatitis C in prisons across Australia.[114]

5.83 Data received indicated that 39 per cent of men and 20 per cent of women in prisons reported getting tattoos whilst in prison while 14 per cent of women reported having piercings done in prison.[115]

5.84 The CPSU also advocated that current hepatitis C education strategies in prisons are not effective, commenting:

> [Prisoners] are provided with two minutes to read a booklet. They have many more worries on their mind than reading a booklet and therefore, once they enter the domestic part of the prison, they are untrained. They are uneducated on hepatitis C, hepatitis B and HIV. We should start with education when prisoners come into the prison.[116]

5.85 A number of organisations were of the view that harm-minimisation, supply-reduction and demand-reduction strategies, if introduced in isolation of the other two strategies, would not be successful. The Public Health Association of Australia stated that it is 'not an either/or, nor is it sequential'.[117] This was echoed by Hepatitis Australia, further commenting that NSPs cannot be positioned 'as the answer'.[118]

5.86 Rather, Hepatitis Australia advised that an NSP must be part of a 'suite of interventions… this has to be looked at as a whole… it is about providing the best possible protection of health for prisoners and custodial officers, and for the community by extension'.[119] The National Drug Research Institute agreed and recommended that a 'raft of measures' is needed to prevent hepatitis C transmission in prison, including: drug and alcohol

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113 Mr John Didlick, Hepatitis ACT, *Committee Hansard*, Canberra, 4 May 2015, p. 5.

114 Community and Public Sector Union, *Submission 101*, p. 6.

115 Mr Stuart Loveday, Hepatitis NSW, *Committee Hansard*, Canberra, 4 May 2015, p. 13.

116 Mr Andrew Smith, Western Australian Prison Officers' Union, *Committee Hansard*, Canberra, 4 May 2015, p. 8.

117 Adjunct Professor Michael Moore, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 8.

118 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 8.

119 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 8.

treatment, drug-free units, needle and syringe programs, and the ability to clean needles and syringes.[120]

Treatment

5.87 Correctional settings were described as an 'ideal opportunity' to undergo treatment for hepatitis C.[121] Hepatitis ACT reported that the view of some prisoners is that the correctional setting is a 'great opportunity' to undergo treatment as 'life on the outside can be too complex or hectic to maintain a course of daily treatments or there are other priorities; or… because the treatment side effects are better dealt with in prison away from the demands of everyday life'.[122]

5.88 Despite this, in 2013 only 231 treatments for hepatitis C were conducted in Australian prisons.[123] The Australasian Society for HIV Medicine stated that, with 30 000 people entering Australian prisons each year, there is 'potential to treat 9 000 people'.[124] While hepatitis C treatment services are available in some custodial settings in Australian jurisdictions, this is not consistent nationally.[125]

5.89 There are a number of barriers to commencing treatment for hepatitis C in prison, including variable sentence length, frequent movement of prisoners between different prisons, limited communication between and within custodial settings, and the lack of specialist providers.[126] However, new interferon-free treatments, with shorter treatment periods of six to twelve weeks, create new opportunities for prisoners with shorter custodial sentences to commence and complete hepatitis C treatments.[127]

5.90 Professor Alex Thompson described prisoner movement from one prison to another as 'enormously challenging' for prison treatment clinics. Professor Thompson explained that:

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120 Dr Susan Carruthers, National Drug Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 24.

121 Dr Susan Carruthers, National Drug Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 14; Associate Professor Mark Andrew Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 14; Mr Troy Wright, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p 20-21.

122 Mr John Didlick, Hepatitis ACT, *Committee Hansard*, Canberra, 4 May 2015, p. 16.

123 Australasian Society for HIV Medicine, *Submission 58*, p. 11.

124 Australasian Society for HIV Medicine, *Submission 58*, p. 11.

125 Australian Government, *Fourth National Hepatitis C Strategy 2014–2017*, July 2014, p. 23.

126 Australasian Society for HIV Medicine, *Submission 58*, p. 11

127 Dr Susan Carruthers, National Drug Research Institute, *Committee Hansard*, Canberra, 4 May 2015, p. 14; Associate Professor Mark Stoové, Private Capacity, *Committee Hansard*, Canberra, 4 May 2015, p. 14; Australasian Society for Infectious Diseases, *Submission 11*, p. 6.

> … to date there has not been a facility for their treatment to be transferred, so it leads to interruptions in treatment, if not cessation of treatment. It emphasises the need for a state based holistic approach, where a person can be started on treatment in their resident prison, and, if they need to move to another prison, it can be seamlessly continued.[128]

5.91 The NSW prison system was highlighted by a number of participants as delivering an improved treatment model for prisoners.[129] In NSW, a recent pilot program of hepatitis C treatment in custodial settings demonstrated 'the feasibility and effectiveness of a nurse-led model of care'. NSW Health explained:

> A NSW Health pilot of hepatitis C treatment in correctional facilities demonstrated the feasibility and effectiveness of a nurse-led model of care. Despite a high proportion of individuals who reported current illicit drug use or had a psychiatric disorder(s), almost 80% of patients were able to commence treatment with phone or teleconference involvement by specialists. The treatment success rate and safety was comparable to that in specialist settings. The effective implementation of this model requires comprehensive training and ongoing support for participating nurses as well as specialist support. NSW Health supports a continued focus and expansion of nurse-led treatment in correctional facilities.[130]

5.92 Professor Alex Thompson noted that the treatment model in NSW is being used as a model in Victoria, where St Vincent's Hospital is delivering a centralised service for the entire prison-population in Victoria, using nurse-led models of care and telemedicine. Professor Thompson stated that this model will make it possible to 'dramatically increase treatment rates'.[131]

5.93 In addition to models of care, the availability of treatment in prison is impacted by the 'availability of resources'.[132] The CPSU similarly noted

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128 Professor Alex Thompson, Director, Department of Gastroenterology, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 15.

129 Professor Michael Levy, Australian National University, *Committee Hansard*, Melbourne, 21 January 2015, p. 10; Mr Stuart Loveday, Hepatitis NSW, *Committee Hansard*, Sydney, 22 January 2015, p. 30; Professor Alex Thompson, St Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 15; NSW Health, *Submission 94*, p. 3; Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 19.

130 NSW Health, *Submission 94*, p. 4.

131 Professor Alex Thompson, St. Vincent's Hospital, *Committee Hansard*, Melbourne, 21 January 2015, p. 15.

132 Mr Stuart Loveday, Hepatitis NSW, *Committee Hansard*, Canberra, 4 May 2015, p. 19.

that the healthcare provided to prisoners is limited by resources and the prioritisation of those resources: 'when corrections departments feel the financial pinch, it is their non-custodial operations that probably get hit a bit earlier than the custodial operations'.[133] The CPSU emphasised that recent expansions in prison populations and resulting overcrowding, has increased the risk of the transmission of blood-borne viruses and placed prisoners' health services under significant pressure.[134]

Post-Release Support

5.94 The continuity of treatment for prisoners entering prison and returning to the community following prison was another key issue for this high-risk population. Professor Margaret Hellard described prisons as 'a revolving door' as a result of the average duration of time spent in prison being 'only seven months'.[135]

5.95 Professor Michael Levy stated that in the ACT's Alexander Maconochie Centre, a prisoner will not commence treatment if they are scheduled to return to the community before the treatment's end as there had been issues with as it was difficult for a patient to comply with treatment requirements after release.[136]

5.96 The Victorian Department of Health and Human Services confirmed that 'given the length of current therapy for hepatitis C and the number of shorter sentence lengths, many [clinically] eligible prisoners do not receive treatment due to issues with continuity following release'.[137] However, the Victorian Department of Health was of the view that new treatments 'represent an opportunity to markedly increase the number of prisoners receiving curative treatment for hepatitis C while in prison'.[138] Improvements in therapies as well as post-release care delivery and referral was also raised by HepatitisWA and the Public Health Association of Australia.[139]

133 Mr Troy Wright, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p. 20.

134 Mr Troy Wright, Community and Public Sector Union, *Committee Hansard*, Canberra, 4 May 2015, p. 15; Ms Catherine Davies, Assistant Branch Secretary (Victoria) CPSU-SPSF Group, *Committee Hansard*, Canberra, 4 May 2015, p. 2.

135 Professor Margaret Hellard, Burnet Institute, *Committee Hansard*, Melbourne, 21 January 2015, p. 15.

136 Professor Michael Levy, Australian National University *Committee Hansard*, Melbourne, 21 January 2015, p. 14.

137 Victorian Department of Health and Human Services, *Submission 96*, p. 3.

138 Victorian Department of Health and Human Services, *Submission 96*, p. 3.

139 Mr Frank Farmer, HepatitisWA, *Committee Hansard*, Perth, 10 March 2015, p. 7; Ms Melanie Walker, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, pp 17-18.

Access to Medicare Benefits Schedule and Pharmaceutical Benefits Scheme

5.97 A number of organisations suggested extending prisoners access to services available on the Medicare Benefits Schedule and therapies listed on the Pharmaceutical Benefits Scheme.[140] Under current arrangements where prison health is a state and territory issue, prisoners automatically lose access to Medicare and the Pharmaceutical Benefits Scheme upon entering a custodial-setting. The Department of Health explained:

> The provision of pharmaceuticals and medical treatment within a prison is state and territory responsibility. PBS medicines are not dispensed in state prisons. The cost of those drugs is met by the state and territory governments themselves.
>
> Notwithstanding these general provisions, the Commonwealth has approved access under provisions within the PBS to the Highly Specialised Drugs Program for prisoners in each state and territory. This recognises the need to provide access to medicines used to treat HIV/AIDS and hepatitis B and C in particular.[141]

5.98 Both Hepatitis Australia and the Public Health Association of Australia stated that, although they support listing new treatments on the general schedule (to encourage greater access to those medications in the general community as recommended by the PBAC), this will limit access to treatment for prisoners.[142]

5.99 In effect, costs of providing new treatments to prisoners will shift to state and territory governments and 'will undoubtedly exacerbate hepatitis C treatment access issues within prisons'. [143] The Public Health Association of Australia emphasised that when state and territory governments are 'forced to cap their corrections budget', prisoners' health services is likely to be more difficult to provide.[144]

5.100 To address this problem, Hepatitis Australia advocated that 'it may be possible to make a dual listing under section 100 and the general schedule'. [145] More broadly, Hepatitis Australia stated that these current arrangements do not facilitate 'national consistency in health care for

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140 Ms Melanie Walker, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 3.

141 Department of Health, *Submission 20.3*, p.1.

142 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 15; Ms Melanie Walker, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 19.

143 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 15.

144 Ms Melanie Walker, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 19.

145 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 15.

prisons', and recommended a review of prisoner access to Medicare and PBS-listed pharmaceuticals whilst in prison.[146]

5.101 The Public Health Association of Australia similarly suggested the introduction of 'Medicare access for prisoners and equity in treatment across Australia in terms of opioid substitution treatment, alcohol and drugs, and hepatitis C.'[147] Hepatitis NSW made a similar recommendation, which further commented that prisoner health should be placed on the agenda for the Council of Australian Governments Meeting.[148]

Concluding Comment

5.102 The Committee acknowledges the statement in the *Fourth National Hepatitis C Strategy*, that health care in Australia should be 'accessible to all based on need… Whether related to geographic location, gender, sexuality, drug use, occupation, socioeconomic status, migration status, language, religion or culture'.[149] The Committee welcomes the identification of priority demographics in the *Fourth National Hepatitis C Strategy*.

Injecting Drug Users

5.103 The Committee acknowledges the role of NSPs in reducing the transmission of hepatitis C among injecting drug users in the general community setting. Evidence received emphasises the value of providing health services for injecting drug users outside of the traditional primary and tertiary care models. The Committee believes that the introduction of rapid point of care testing, especially in community-based settings could assist in increasing the diagnosis rate of hepatitis C, as well as providing an environment where treatment options can be more easily discussed.

5.104 Offering treatment for those with a hepatitis C infection through community-based settings should continue to be encouraged, in addition to considering ways of extending these services in rural and remote areas.

Aboriginal and Torres Strait Islanders

5.105 The Committee acknowledges the information it received about the higher proportion of hepatitis C infection amongst Aboriginal and Torres Strait

146 Ms Helen Tyrrell, Hepatitis Australia, *Committee Hansard*, Canberra, 4 May 2015, p. 15.

147 Adjunct Professor Michael Moore, Public Health Association of Australia, *Committee Hansard*, Canberra, 4 May 2015, pp 24-25.

148 Mr Stuart Loveday, Hepatitis NSW, *Committee Hansard*, Canberra, 4 May 2015, p. 25.

149 Australian Government, *Fourth National Hepatitis C Strategy,* p. 10.

Islanders, and the lower treatment rate. The Committee also acknowledges the added complications many Aboriginal and Torres Strait Islanders experience in seeking treatment, including being co-infected, having high incarceration rates, and also limited access to treatment for varying reasons.

5.106 The limited data available on Aboriginal and Torres Strait Islander hepatitis C infection rates does not easily enable the identification of trends for comparison purposes across years. There is however evidence of an increase in new diagnoses of hepatitis C among Aboriginal and Torres Strait Islanders, and it is clear that to address this issue requires a national response.

5.107 The Committee welcomes developments in outreach to Aboriginal and Torres Strait Islanders living with hepatitis C, and notes the way hepatitis C testing and treatment is being offered through several Aboriginal community controlled health services. The success of these programs should be used to set the standard for hepatitis C treatment in Aboriginal and Torres Strait Islander communities.

Culturally and Linguistically Diverse Backgrounds

5.108 Stigma and discrimination about hepatitis C varies within migrant communities, and culturally specific treatment and outreach should be encouraged as best practice. To this end, there is room for more of a focus on culturally sensitive communication between medical practitioners and people from diverse backgrounds who are living with hepatitis C.

5.109 Linguistic issues and access to interpreters, especially for smaller linguistic communities is still limited in Australia. Through its inquiry, the Committee heard evidence of people with a positive diagnosis for hepatitis C keeping it a secret from their immediate family, and changing their behaviours to reduce physical contact. The Committee believes that providing adequate resources to ensure that culturally and linguistically appropriate information provision in relation to hepatitis C is a basic way of improving the lives of migrant people living with an infection.

People in Custodial Settings

5.110 The Committee heard a considerable amount of evidence on hepatitis C in custodial settings. The Committee understands that prisons are a segregated environment where there is a higher risk of hepatitis C infection than the general community.

5.111 The Committee was concerned by the limited reliable data available on hepatitis C infection and transmission rates in Australian prisons.

Estimates vary significantly; nonetheless, the rate of hepatitis C infection is higher within prisons than in the general population.

5.112 The Committee heard there was no consistent approach to determining prisoner health on incarceration. Developing a consistent national approach to determining prisoner health would assist in measuring hepatitis C in custodial settings.

5.113 The introduction of a national surveillance system for hepatitis C infection should also be a priority. Such a system would enable better responses to hepatitis C infection in prisons, as well as providing a way of treating those who wish to seek treatment.

5.114 Rapid point of care testing in the custodial setting would also assist in determining the status of prisoners upon entry, as well as checking their HCV antibody status while incarcerated.

5.115 The Committee acknowledges the challenges faced by prisoners seeking treatment. Prisoner movement between facilities, the regimented environment, long treatment regimes, and accessing treatment all make it more difficult for a prisoner seeking to undergo treatment for hepatitis C.

5.116 The Committee received a considerable amount of information on the introduction and operation of NSPs in prisons. The Committee notes recent developments in relation to NSPs in the Australian Capital Territory and believes the outcome of this debate will inform the broader debate on this matter throughout Australia.

5.117 At present, there are five national strategies for blood-borne viruses and sexually transmissible infections. The Committee considers that the development of a sixth strategy focused on custodial settings may assist in addressing the challenges of blood-borne viruses in prisons.

5.118 A further benefit of developing a dedicated strategy is that once it has been finalised, the implementation and success of the strategy can be assessed, as is the case with the existing strategies. Measuring progress will also improve Australia's national data set on prisoner health more generally, and more specifically the prevalence of prison-acquired hepatitis C.

5.119 As an initial step towards this goal, the Committee believes that the Australian Government should raise the issue of prisoner health, focussing on hepatitis C with its state and territory counterparts at the earliest opportunity, including at a future meeting of the Australian Governments Health Council. At this meeting, the Committee also believes that achieving national standards in prisoner health-delivery should be made an overall priority.

Recommendation 6

5.120 **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

5.121 **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

5.122 **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

5.123 **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

5.124 **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.**

Steve Irons MP
Chair

23 June 2015

A

Appendix A – Submissions

1	Mr Mik Raskine
2	Professor Michael Levy AM
3	Mr John McCarthy
4	Ms Kathryn Snow
5	Mr Gerald Butler
6	Mr Peter Tanczos
7	Mr Christopher J Brice
8	Kirby Institute
8.1	Kirby Institute
9	Hepatitis WA
10	Mr Frank Carlus
11	Australasian Society for Infectious Diseases
12	Western Australian Government
13	Mr Jeffrey Paterson
14	Berenice Pearcy
15	Mr Stephen Gribbin
16	Mr Mark Taranto
17	Name Withheld

18 Name Withheld

19 Australian Research Centre in Sex, Health and Society

20 Department of Health

20.1 Department of Health

20.2 Department of Health

21 Australian Institute of Health and Welfare

22 Name Withheld

23 Australasian Hepatology Association

24 Paula Gunning

25 Name Withheld

26 Name Withheld

27 Name Withheld

28 Centre for Social Research in Health

29 Name Withheld

30 Name Withheld

31 Victorian Alcohol & Drug Association

32 Queensland Nurses' Union

33 Hepatitis SA

34 Inner East Melbourne Medicare Local (IEMML) and Eastern Health (EH)

35 Tasmanian Users Health and Support League Inc

36 Hepatitis Queensland Inc.

37 Kirstie Monson

38 Name Withheld

39 William Lenane

40 Ms Glenda Clementson

41 Anglicare Tasmania, Tasmanian Council AIDS and Related Diseases and the Tasmanian Aboriginal Centre Inc

42 Northern Territory AIDS & Hepatitis Council Inc.

43 Mr A.J. Gillett

44 Miss Barbara Durward

45 Aboriginal Health & Medical Research Council of NSW

46 Karen Brereton

47 Chris Lawrence

48 Name Withheld

49 Name Withheld

50 Dr David Learoyd

51 Name Withheld

52 Women's Health Victoria

53 Ms Amanda Geikie

54 Penington Institute

55 The National Drug and Alcohol Research Centre (NDARC)

56 Hepatitis ACT

57 Ms Starlie Geikie

58 Australasian Society for HIV Medicine

59 Hepatitis Victoria

60 Gilead Sciences

61 Cairns Hepatitis Action Team

62 Janssen-Cilag Pty Ltd

63 Name Withheld

64 Name Withheld

65 Bristol-Myers Squibb Australia

66 Burnet Institute

67 Name Withheld

68 Public Health Association of Australia

69 National Association of People with HIV Australia

70 Name Withheld

71 Ms Fiona Patten MLC

72 Name Withheld

73 Nina Bailey

74 Medicines Australia

75 Viveka de Costa

76 Ms Deborah Warneke-Arnold

77 Name Withheld

78 Joel Murray

79 Cancer Council Australia

80 Merck Sharp & Dohme (Australia) Pty Limited

81 Scarlet Alliance

82 AbbVie

82.1 AbbVie

83 Haemophilia Foundation Australia

84 Hepatitis Australia

85 Australian Injecting & Illicit Drug Users League (AIVL) Inc.

86 Alliance for Sharps Safety and Needlestick Prevention in Healthcare

87 cohealth

88 Colin Beeston

89 Confidential

90 Deborah D'Arcy

91 Hepatitis NSW

92 Andrew Little

93 Name Withheld

94 NSW Health

95 Relationships Australia South Australia Ltd

96 Victorian Department of Health and Human Services

97 Tasmanian Government

98 Mr Graham James

99 Mr Rodney Ian

100 Australian College of Nursing (ACN), Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) and Drug and Alcohol Nurses of Australasia (DANA)

101 Community and Public Sector Union (CPSU)

102 Tainted Blood Product Action Group

103 Confidential

104 Liver Foundation of Western Australia

105 ACT Health

106 The Pharmacy Guild of Australia

B

Appendix B – Exhibits

1 Harm Reduction VIC
Australasian Society for HIV Medicine
Australian Injecting & Illicit Drug Users League

Harm Reduction Journal: The acceptability and feasibility of peer worker support role in community based HCV treatment for injecting drug users, 25 February 2008.

2 The Burnet Institute

Evaluation of Queensland Injector's Health Network's Mix Up Project. Completed by The Burnet Institute and VIVAIDS - The Victorian Drug User Organisation, January 2009.

3 Australian Injecting & Illicit Drug Users League

Exhibit 3 – Cover letter with list of references and articles.

a) World Health Organisation: Guidance on prevention of viral Hepatitis B and C among people who inject drugs, July 2012.

b) Australian Institute of Criminology, Prison HIV Peer Education: Report of the National Prison HIV Peer Education Project, Judith Robinson.

c) Health Education Research: Structural constraints on the training of peer educators in hepatitis C prevention, October 2011.

d) Integrating treatment: Key findings from a qualitative evaluation of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) study, Jake Rance and Carla Treloar.

e) Assessment and Treatment of Hepatitis C Virus Infection Among People Who Inject Drugs in the Opioid Substitution Setting: ETHOS Study.

f) Peer Support Models for People With a history of Injecting Drug Use Undertaking Assessment and Treatment for Hepatitis C Virus Infection, Sione Crawford and Nicky Bath.

g) Australian Drug Foundation: Prevention Research Quarterly, Current evidence evaluated, Peer education, March 2006.

4 Kirby Institute

Exhibit 4 - Incidence and risk factors for hepatitis C seroconversion in injecting drug users in Australia, Addiction 2006.

a) Opioid substitution therapy protects against hepatitis C virus acquisition in people who inject drugs: the HITS-c study, Medical Journal of Australia 2014.

5 Professor Alex Thompson

Enhanced antiviral treatment efficacy and uptake in preventing the rising burden of hepatitis C-related liver disease and costs in Australia, Journal of Gastroenterology and Hepatology 2014.

6 Mr Grenville Rose

Cost Benefit Analysis of the New Zealand National Mental Health Destigmatisation Programme ("Like-Minds Programme"), 18 February 2010.

7 Harm Reduction Victoria

Exhibit 7 - Hepatitis C Models of Access and Service Delivery for People with a History of Injecting Drug Use, October 2010.

a) Barriers to Hepatitis C Treatment for People with a History of Injecting Drug Use.

8 Hepatitis ACT

Exhibit 8 - Public Health Wales, Dried Blood Spot Testing for Hepatitis C, Hepatitis B and HIV: Information for substance misuse services, 18 April 2012.

a) Healio HCVnext, Article, Dried blood spots may be useful in HCV RNA detection, genotyping, Greenman J, et al. j Viral Hepatology 2015.

b) United Nations Office on Drugs and Crime, A handbook for starting and managing needle and syringe programmes in prisons and other closed settings: Advance Copy, 2011 consultation.

9 Pharmacy Guild of Australia

Exhibit 9 - Pharmacy Guild of Australia, brochure pinwheel titled Hepatitis C. Assess Your Risk

a) Prescription repeat cover: Hepatitis C, Get Tested. Get Treated.

b) Brochure, Hepatitis C, Get Tested. Get Treated.

c) Post Card: Hepatitis C – Think of your pharmacy as part of your treatment team

d) Pharmaceutical Society of Australia: Self Car Brochure – Hepatitis C

e) Quick Facts for Pharmacy: Hepatitis C – Get Tested. Get Treated.

f) Poster: Get Tested. Get Treated.

g) ashm brochure – Pharmacy and hepatitis C

h) Booklet: Community Pharmacy – Hepatitis C Public Health Promotion Program

10 National Drug Research Institute

Exhibit 10 - Retractable Syringes in a Swiss Prison Needle and Syringe Exchange Program: Experiences of Drug-using Inmates and Prison Staff Perceptions, 17 April 2014.

a) Reinfection with hepatitis C virus following sustained virological response in injection drug users, Journal of Gastroenterology and Hepatology, 3 December 2009.

b) Hepatitis C Virus Reinfection and Superinfection Among Treated and Untreated Participants with Recent Infection, ATAHC Study Group, 3 October 2009.

c) Advocacy and piloting the first needle and syringe exchange program in Iranian prisons, Mohammad Shahbazi, Retrovirology, March 2010.

d) High Rates of Hepatitis C Virus Reinfection and Spontaneous Clearance of Reinfection in People Who Inject Drugs: A Prospective Cohort Study, 7 November 2013.

e) International Journal of Drug Policy 14: Ten years of experience with needle and syringe exchange programmes in European prisons, 11 August 2003.

f) Hepatitis C Virus Reinfection Following Treatment Among People Who Use Drugs, Supplement Article, Bart P. Grady, 2013.

11 Mr Rodney Hatch

Poem – Dying of liver failure in a public housing flat by the South Perth foreshore.

12 Burnet Institute

Exhibit 12 – World Health Organization, United Nations Office on Drugs and Crime, and UNAIDS: Evidence for Action Technical Papers, Interventions to Address HIV in Prison, Needle and Syringe Programmes and Decontamination Strategies, Geneva, 2007.

a) Anex: With conviction: the case for controlled needle and syringe programs in Australian prisons, October 2010.

b) United Nations Office on Drugs and Crime: Needle and syringe programmes in prisons, Dr Fabienne Hariga.

13 The Public Health Association of Australia

National Prison Entrants' Bloodborne Virus and Risk Behaviour Survey Report 2004, 2007, 2010 and 2013: Prevalence of HIV, Hepatitis C, Hepatitis B, Sexually Transmissible Infections, and Risk Behaviours Among Australian Prison Entrants, UNSW Australia and Kirby Institute, March 2015.

14 Hepatitis ACT

The Health of Australia's Prisoners 2012, Australian Institute of Health and Welfare, 2013.

15 Hepatitis NSW

2009 NSW Inmate Health Survey: Key Findings Report, NSW Health, Justice Health, 2010.

16 Hepatitis NSW

Exhibit 16 - Article entitled The Australian prison needle program story: from Geoffrey Pearce to Alexander Maconochie. Hep Review, Edition 78, December 2012.

a) Book entitled: Stories from the Other Side – an exploration of injecting drug use in NSW Prisons. Produced by the NSW Users and AIDS Association (NUAA) 2013.

17 Professor Michael Levy

Article: Custodial officers in Australia are still poorly served, Michael H. Levy, Clinical Professor, Stuart A. Kinner, March 2011.

18 Confidential

19 Australian Injecting & Illicit Drug Users League and the Canberra Alliance for Harm Minimisation and Advocacy

Needle and Syringe Programs in Prisons: An International Review, May 2015.

C

Appendix C – Hearings and Witnesses

Wednesday, 21 January 2015 – Melbourne

Australasian Hepatology Association

Ms Megan Phelps, President

Dr Jacqui Richmond, Member

Australasian Society for Infectious Diseases (ASID) Inc

Associate Professor Joseph Torresi, Chair, Viral Hepatitis Special Interest Group

Burnet Institute

Professor Margaret Hellard, Head, Centre for Population Health, Burnet Institute; Head, Hepatitis Service, Infectious Diseases Unit, the Alfred Hospital

Gilead Sciences

Mr Rob Hetherington, General Manager, Australia and New Zealand

Dr Amanda Elsome, Senior Manager, Market Access, Australia and New Zealand

Haemophilia Foundation Australia

Ms Sharon Caris, Executive Director

Ms Suzanne O'Callaghan, Policy Research and Education Manager

Mr Gavin Finkelstein, President

Hepatitis Australia

Ms Helen Tyrrell, Chief Executive Officer

Hepatitis Victoria

Ms Melanie Eagle, Chief Executive Officer

Professor Michael Levy AM

Clinical Director of Justice Health Services, ACT

Merck Sharp & Dohme Australia

Dr Gary Jankelowitz, Medical Director

Ms Nicola Richards, Public Affairs and Policy Manager

Penington Institute

Mr John Ryan, Chief Executive Officer

Professor Alex Thompson

Director, Department of Gastroenterology, St Vincent's Hospital

People living with Hepatitis C

Ms Jen Anderson

Mr Frank Carlus

Mr Gavin Finkelstein

Ms Zoe Kelley

Mr Paul Kidd

Mr Ross Williams

Ms Pam Wood

Thursday, 22 January 2015 – Sydney

Department of Health

Mr Graeme Barden, Assistant Secretary, Health Protection Policy Branch
Ms Sharon Appleyard, Assistant Secretary, Primary Health Networks Branch

Professor Chris Baggoley, Chief Medical Officer

Ms Teresa Gorondi, Director, Blood Borne Viruses and Sexually Transmissible Infections Section

Dr Andrew Singer, Principal Medical Adviser, Acute Care Division

Therapeutic Goods Administration

Dr Anthony Hobbs, Principal Medical Adviser

Aboriginal Health and Medical Research Council of New South Wales Inc

Ms Sandra Bailey, Chief Executive Officer

Ms Bronwyn Briggs, Project Officer, Public Health Unit

Australasian Society for HIV Medicine

Adjunct Associate Professor Levinia Crooks, Chief Executive Officer

Australian Liver Association (part of the Gastroenterological Society of Australia)

Professor Geoff McCaughan, Chair of the Transplant Society of Australia and New Zealand

Professor Stuart Roberts, Chair of the Australian Liver Association Clinical Research Network

Professor Amany Zekry, Chair of the Australian Liver Association

Dr Mark Douglas, Senior Lecturer, Westmead Millennium Institute Infectious Diseases and Hepatitis Specialist, Westmead Hospital

Centre for Social Research in Health

Professor John de Wit, Director

Hepatitis NSW

Mr Alastair Lawrie, Policy and Media Officer

Mr Stuart Loveday, Chief Executive Officer

Kirby Institute

Professor Gregory Dore, Head, Viral Hepatitis Clinical Research Program

Professor Lisa Maher, Program Head and NHMRC Senior Research Fellow

National Aboriginal Community Controlled Health Organisation

Ms Summer Finlay, Project and Research Officer

People living with Hepatitis C

Ms Justine Doidge

Mr Damien House

Mr William Lenane

Mr David Pieper

Mr Grenville Rose

Ms Mary Sherwood

Tuesday, 10 March 2015 – Perth

Hepatitis WA

Mr Frank Farmer, Executive Director

Ms Sally Rowell, Community Services Manager

Mr Rodney Hatch, Prison Education Officer

Government of Western Australia

Professor Tarun Weeramanthri, Executive Director Public Health and Clinical Services

Ms Lisa Bastian, Program Manager, Sexual Health and Blood Borne Virus Program

National Drug Research Institute

Dr Susan Carruthers, Research Fellow and Project Leader

Liver Foundation of Western Australia

Professor Gary Jeffery, Chairman and Medical Director

Professor Luc Delriviere, Surgical Director

Ms Saroj Nazareth, hepatology nurse

Friday, 20 March 2015 – Canberra

AbbVie

Ms Kirsten O'Doherty, General Manager
Dr Johnathan Anderson, Medical Director

Mr Ross Hannah

Royal Australian College of General Practitioners

Dr Larissa Roeske, National Chair, Sexual Health Medicine Network

Hepatitis ACT

Mr John Didlick, Executive Officer

Australian Injecting and Illicit Drug Users League

Ms Annie Madden, Executive Officer

Canberra Alliance for Harm Minimization and Advocacy

Mr Sione Crawford, Manager

Community and Public Sector Union

Mr Vince McDevitt, ACT Secretary
Mr Troy Wright, Senior Industrial Officer

Community and Public Sector Union-State Public Service Federation (SPSF) Group

Ms Catherine Davies, Assistant Branch Secretary (Vic), Federal Vice President

Western Australian Prison Officers' Union

Mr Andrew Smith, Assistant Secretary

Dr Tuck Meng Soo

Pharmacy Guild of Australia

Mr Ian Todd, National Councillor and South Australian Branch Committee Member

Ms Khin Win May, National Manager – Policy & Regulation, National Secretariat

National Health and Medical Research Council

Professor Warwick Anderson, Chief Executive Officer

Dr Clive Morris, Head, Policy Group

Kirby Institute

Professor Gregory Dore, Head, Viral Hepatitis Clinical Research Program

Department of Health

Professor Chris Baggoley, Assistant Secretary, Health Protection Policy Branch

Mr Graeme Barden, Assistant Secretary, Health Protection Policy Branch

Ms Kylie Jonasson, First Assistant Secretary, Office of Health Protection

Ms Felicity McNeill, First Assistant Secretary, Pharmaceutical Benefits Division

Therapeutic Goods Administration

Dr Anthony Hobbs, Principal Medical Adviser, Therapeutic Goods Administration

Monday, 4 May 2015 – Canberra

Hepatitis Australia

Ms Helen Tyrrell, Chief Executive Director

Hepatitis ACT

Mr John Didlick, Executive Officer

Hepatitis NSW

Mr Stuart Loveday, Chief Executive Officer

Public Health Association of Australia

Adjunct Professor Michael Moore, Chief Executive Officer
Ms Melanie Walker, Deputy Chief Executive Officer

Burnet Institute

Associate Professor Mark A Stoové, Head, HIV Research; Head, Justice Health Research Program

National Drug Research Institute

Dr Susan Carruthers, Research Fellow

Community and Public Sector Union – State Public Service Federation Group

Ms Catherine Davies, Assistant Branch Secretary (Vic), Federal Vice President

Community and Public Sector Union

Mr Vince McDevitt, ACT Secretary
Mr Troy Wright, Senior Industrial Officer

Western Australian Prison Officers' Union

Mr Andrew Smith, Assistant Secretary