

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.

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:

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

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

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

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 experience of this group of people in living with hepatitis C:

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 Withheld, *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

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:

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.

...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

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

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

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 Caris, Haemophilia 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

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

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

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

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 supportive 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.