

# *chapter* 1

## Introduction



# 1.1 Context

## Why conduct an enquiry into hepatitis C related discrimination?

**The NSW Parliament's Standing Committee on Social Issues (the Parliamentary Committee), undertook a landmark inquiry into hepatitis C in NSW during 1997–1998. The Parliamentary Committee's report, *Hepatitis C: The neglected epidemic*, was released in November 1998.<sup>1</sup> During the course of the inquiry, the Parliamentary Committee heard considerable evidence about the discrimination and stigmatisation people living with hepatitis C had experienced.<sup>2</sup>**

The report states that:

The Committee has come to appreciate that, particularly in relation to the issue of discrimination, hepatitis C is a medical condition, not a political issue or a moral question of right and wrong.<sup>3</sup>

The Parliamentary Committee noted the limited research into hepatitis C (HCV) related discrimination and the absence of government strategies designed to prevent and eliminate such discrimination. A recent review of international and Australian literature related to living with hepatitis C also highlights the lack of research into hepatitis C related discrimination. The reviewers conclude:

There are a number of significant gaps in the literature to date. For example, discrimination and stigmatisation of people living with hepatitis C is mentioned in the context of diagnosis and disclosure and interactions with health care professionals, however, no systematic exploration of this phenomena has been published.<sup>4</sup>

In recognition of the seriousness of the issue of hepatitis C related discrimination, the dearth of research, and the need for improved strategies to prevent and eliminate such discrimination, the Parliamentary Committee recommended that the Anti-Discrimination Board of NSW (ADB) undertake a statewide inquiry into hepatitis C related discrimination to examine the nature and extent of hepatitis C related discrimination, and recommend legal and administrative changes across a wide range of activities.<sup>5</sup> Following representations to the NSW Government by the ADB, funding was provided by the Attorney General's Department to enable the ADB to undertake this Enquiry.

The purpose of this Enquiry is to ensure we have a more comprehensive understanding of hepatitis C related discrimination. Improved understanding of the extent and nature of discrimination will enable better targeted education strategies, both strategies designed to make people aware of their rights and those designed to prevent hepatitis C related discrimination.

The Parliamentary Committee's report, *Hepatitis C: The neglected epidemic*, examines a wide range of issues including: the people at risk of contracting hepatitis C and the extent of infection among particular groups; diagnosis, treatment and management of hepatitis C; the social and economic impact of hepatitis C; and hepatitis C prevention strategies in a variety of key settings such as health care and custodial settings.

This Enquiry does not propose to duplicate the issues adequately and appropriately addressed within the broad ranging terms of reference for that inquiry. This Enquiry aims to respond to the need for an improved understanding of the nature and extent of such discrimination.

## Policy and strategic frameworks

Since the Parliamentary Committee released its report there have been significant strategic developments in responding to hepatitis C, at both national and State levels. Of particular importance are the National

<sup>1</sup>Parliament of NSW Legislative Council, Standing Committee on Social Issues, *Hepatitis C: The neglected epidemic*, Report Number 16, November 1998.

<sup>2</sup>*Hepatitis C: The neglected epidemic*, pages 108–119.

<sup>3</sup>*Hepatitis C: The neglected epidemic*, at page 119.

<sup>4</sup>Hopwood, M. and Southgate, E. (under review) Living with hepatitis C: a sociological review, *Australian Journal of Social Issues*.

<sup>5</sup>*Hepatitis C: The neglected epidemic*, Recommendation 21 at page 118. The Committee noted the studies which have documented incidents of discrimination in Burrows, D. and Basset, B. 1996 *Meeting the needs of people in Australia living with hepatitis C*, National Hepatitis C Council's Education Reference Group; and Crofts, N., Louie, R. and Loff, B. 1997 The next plague: Stigmatisation and discrimination related to hepatitis C virus infection in Australia, *Health and Human Rights* Vol. 2, No. 2 at page 89.

*Hepatitis C Strategy 1999–2000 to 2003–2004*<sup>6</sup> and the *NSW Hepatitis C Strategy 2000–2003*.<sup>7</sup> Both strategies provide a framework and direction for the prevention, treatment, management and surveillance of hepatitis C, and the care and support of those with the disease. They also acknowledge the importance of reducing the stigma and discrimination associated with hepatitis C.

The *National Hepatitis C Strategy* identifies four priority areas for action, which are:

- reducing hepatitis C transmission in the community
- treatment of hepatitis C infection
- health maintenance, care and support for people living with hepatitis C
- preventing discrimination, and reducing stigma and isolation.

The National Strategy emphasises that action to prevent discrimination and reduce stigma and isolation is essential if the Strategy's objectives as a whole are to be achieved. The stigma and discrimination experienced by many people living with hepatitis C, and those at risk of infection, often discourages people from testing. This in turn reduces the extent to which people will access health care services to maximise their health, and receive information and support to reduce the risk of transmission to others. The Strategy recognises that eliminating hepatitis C related discrimination plays a critical role in supporting efforts to reduce hepatitis C transmission and maximise the health of people with hepatitis C.<sup>8</sup>

While preventing discrimination and thereby protecting people's human rights has obvious merit in its own right, 'there is increasing recognition that public health often provides an added and compelling justification for safe guarding human rights...'<sup>9</sup>

The *NSW Hepatitis C Strategy* also recognises that discrimination has a personal and social impact that needs to be addressed. The NSW Strategy notes that hepatitis C discrimination is covered under the *Anti-Discrimination Act 1997 (NSW)* (ADA), but acknowledges that the discrimination people experience is not always about people's hepatitis C status, but rather because of actual, past or assumed injecting drug use.

Discrimination against people who inject drugs, and who are attempting to access services, is an issue that needs to be addressed. They are often discriminated against not because of their HCV status, but because of their drug use, and may therefore be denied care for their illness. All health professionals, including GPs, nurses, accident and emergency staff and medical specialists must be targeted for education.<sup>10</sup>

The guiding principles and strategies outlined in both the national and NSW hepatitis C strategies indicate a commitment on the part of both federal and NSW governments to address the issue of hepatitis C related discrimination. Such leadership is vital. Nonetheless, given the extent of discrimination demonstrated by the evidence to this Enquiry, significant legislative, administrative and policy changes and education initiatives are needed if a reduction in hepatitis C related discrimination and stigmatisation is to be achieved.

## Legislative context — federal and NSW anti-discrimination law

Generally, federal and NSW anti-discrimination laws prohibit discrimination against a person on the basis of their hepatitis C status, in specific areas of public life. Hepatitis C is covered by the disability discrimination provisions of both federal and NSW anti-discrimination legislation.

The ADA and the *Disability Discrimination Act 1992 (Cth)* (DDA) prohibit discrimination on the ground of disability in areas such as employment, education, accommodation and the provision of goods and services.<sup>11</sup> Under both Acts, 'disability' is defined to include the presence in the body of organisms causing, or capable of causing, disease or illness.<sup>12</sup> This definition encompasses hepatitis C. Both Acts also cover assumed, past and future disabilities, in addition to actually having hepatitis C.<sup>13</sup> That is, where someone does not have hepatitis C, but is discriminated against because they are thought to have hepatitis C, have had hepatitis C in

<sup>6</sup>*National Hepatitis C Strategy 1999–2000 to 2003–2004*, Commonwealth Department of Health and Aged Care (CDHAC), Canberra 2000. The Strategy also provides a history of Australia's response to hepatitis C at page 9.

<sup>7</sup>*New South Wales Hepatitis C Strategy 2000–2003*, NSW Health Department, 2000. The Strategy also provides a history of NSW's strategic response to hepatitis C at page 14.

<sup>8</sup>*National Hepatitis C Strategy* at page 2.

<sup>9</sup>*HIV/AIDS and Human Rights International Guidelines*, Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, United Nations New York and Geneva, January 1998.

<sup>10</sup>*NSW Hepatitis C Strategy*, at page 8.

<sup>11</sup>DDA, Part 2 and ADA, Part 4A.

<sup>12</sup>DDA, section 4 and ADA, section 4.

<sup>13</sup>DDA, section 4 and ADA, section 49A.

the past or may have hepatitis C in the future, anti-discrimination laws may apply.

The ADA and the DDA cover direct and indirect discrimination.<sup>14</sup> Generally, direct discrimination occurs where a person with a disability is treated less favourably, in similar circumstances, than a person who does not have a disability. Indirect discrimination on the ground of disability occurs where an unreasonable requirement or condition is imposed that is harder for a person with a disability to comply with, than someone who does not have a disability.

Where a person alleges they have been discriminated against on the basis of their actual, assumed, past or future hepatitis C status, they may be entitled to proceed under either federal or NSW anti-discrimination laws. However, in some circumstances it may be necessary to lodge a complaint under federal rather than NSW laws, or vice versa. For example, where a person alleges they have been discriminated against on the basis of their hepatitis C status in employment and they are a Commonwealth employee, a complaint would need to be made under the DDA and not the ADA.

The NSW Law Reform Commission (LRC) has undertaken an extensive review of the ADA and reported to the Attorney General in 1999.<sup>15</sup> The LRC's report and responses to that report are being considered by the Attorney General. The ADB has made extensive submissions, both to the LRC's review of the ADA and to the Attorney General's Department, in response to the LRC's report. Recommendations for reform of the ADA outlined in this report have also been raised by the ADB in our input to the reform process.

Despite federal and NSW anti-discrimination laws that prohibit disability discrimination in a wide variety of areas of public life, hepatitis C related complaints under both the DDA and ADA appear to be low. The Enquiry has also found that it is common for people with hepatitis C and those at risk of the virus, particularly people who have injected or do inject drugs, to be discriminated against not on the basis of their actual or assumed hepatitis C status, but rather on the basis of actual, assumed or past drug use. Coverage for assumed, actual or past drug use, under both the DDA and ADA, is currently unclear. This is considered in detail in Chapter 2, section 2.2. The limitations of anti-discrimination laws, both procedural and substantive, are considered in detail in Chapter 4.

While federal and NSW anti-discrimination laws prohibit disability discrimination in a wide variety of areas of public life, not all the evidence provided to the Enquiry falls neatly within the categories of unlawful discrimination provided by federal and NSW anti-discrimination laws. Consideration is given in this report to whether particular incidences of discrimination raised in the Enquiry may be covered by anti-discrimination law and whether amendments are necessary to enable such discrimination to be covered by anti-discrimination law.

For the purposes of this report, a broad interpretation has been given to the concept of discrimination, rather than the narrower interpretation of discrimination as that which constitutes unlawful discrimination for the purposes of anti-discrimination law. Many of the issues raised in the evidence presented to the Enquiry may not necessarily be resolved by resort to anti-discrimination law. However, people's experiences of living with hepatitis C and the impact of the disease on people's lives, reveal important insights into the stigmatisation commonly associated with hepatitis C and injecting drug use. This understanding in turn allows a more complete picture of the nature and extent of hepatitis C related discrimination. A broader approach is required to enable consideration of administrative, policy and program responses that may address such discrimination.

## 1.2 Background<sup>16</sup>

### What is hepatitis C and how is it transmitted?

The hepatitis C virus was identified in 1988 and a test to detect antibodies to the virus became available in early 1990. Hepatitis C is a blood-borne virus that affects the liver and is transmitted when the blood of a person with the virus enters another person's bloodstream.

The main mode of transmission of hepatitis C in Australia is through unsafe drug injecting practices, in particular the sharing and re-using of injecting equipment. Approximately 80% of infections are attributed to the behaviour associated with injecting drug use, another 5–10% to the transfusion of blood products (prior

<sup>14</sup>ADA section 49B and DDA section 5.

<sup>15</sup>*Review of the Anti Discrimination Act 1977 (NSW)*, New South Wales Law Reform Commission, Report 92, Sydney 1999.

<sup>16</sup>The Enquiry acknowledges that the background section of this report draws upon the excellent representation and analysis of current epidemiological and other research and Commonwealth and NSW policy and strategic frameworks contained in the Hepatitis C Council of NSW's (HCC NSW) submission to the Enquiry.

to 1990) and the remainder to other forms of blood-to-blood contact, such as non-sterile tattooing or other skin-incision procedures.<sup>17</sup> Approximately 91% of new infections are among people who inject drugs.<sup>18</sup> Since 1990 all blood has been screened for hepatitis C and the risk of transmission through blood transfusions in Australia is now very low.<sup>19</sup> There is currently no vaccine against hepatitis C.

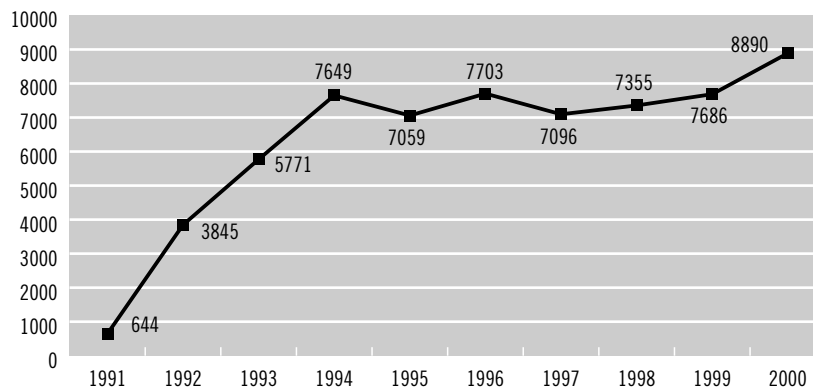
## Hepatitis C in Australia and NSW

As the most frequently reported notifiable infection in Australia, hepatitis C is a pressing public health issue. During 2000, 20,926 cases were reported, bringing the total number of notified cases of hepatitis C in Australia to more than 160,000 since the antibody test became available.<sup>20</sup> However, it is likely that many people with hepatitis C remain undiagnosed. It is estimated that 210,000 people in Australia have been exposed to the hepatitis C virus, of whom approximately 90,000 people live in NSW. Of the 11,000 new infections occurring each year, more than 40% of these are thought to occur in NSW.<sup>21</sup>

Up to December 2000, 63,698 people in NSW had been notified as having hepatitis C antibodies.<sup>22</sup> In 2000, there were 8,890 notifications of hepatitis C infections in NSW (see Graph 1), with some Area Health Services showing disproportionately high level of notifications when compared with their respective total populations (see Graphs 2 and 3). Based on current estimates, approximately 40% of people in NSW who have been exposed to hepatitis C are unaware of their status.

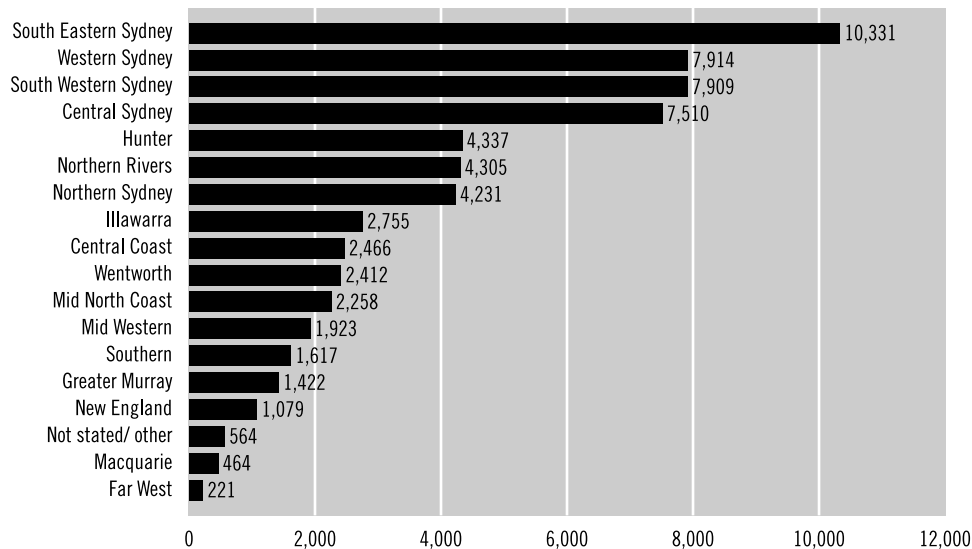
**GRAPH 1:** Hepatitis C notifications in NSW 1991 to 2000

Source: NSW Health AIDU Surveillance Section



**GRAPH 2:** Hepatitis C notifications (63,698) in NSW 1991 to 2000

Source: NSW Health AIDU Surveillance Section



<sup>17</sup> National Hepatitis C Strategy at page 4.

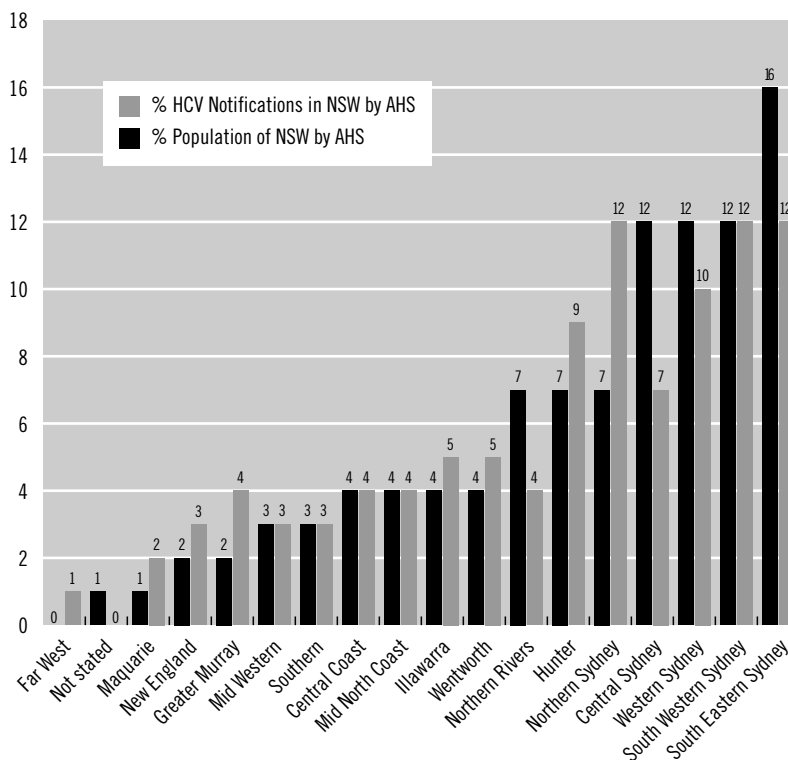
<sup>18</sup> Hepatitis C: The neglected epidemic at page 57.

<sup>19</sup> Hepatitis C: The neglected epidemic at page 5.

<sup>20</sup> HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia — Annual Surveillance Report 2001, National Centre in HIV Epidemiology and Clinical Research (NCHECR), University of NSW, 2001, at page 11.

<sup>21</sup> Personal communication with Dr Greg Dore, NCHECR, July 2001.

**GRAPH 3:** Hepatitis C notifications in NSW 1991 to 2000 by AHS compared with (%) population at 1997 by AHS



## Testing for hepatitis C

The hepatitis C virus (HCV) was discovered in 1988 and a test to detect antibodies to the virus became available in early 1990.

When a person makes a decision to be tested for hepatitis C, a sample of blood is taken and tested to determine whether the person's body is producing antibodies to the virus (the viral RNA). This is known as an antibody test because it tests for the presence of antibodies, not for the virus itself. After exposure to the virus it can take up to six months before antibodies can be detected. This is known as the window period.

The hepatitis C RNA test, sometimes called PCR (Polymerase Chain Reaction Test), tests for the presence or absence of the virus itself. This test is generally used when assessing people for treatment and can also be used where an antibody test result is indeterminate.<sup>23</sup> There are also a number of other tests used in monitoring people's health and/or assessing people for treatment, such as tests which determine the quantity of the virus in a person's system and assess the function of the liver.

Professor Batey, in his evidence to the Enquiry, explains the difference between the antibody test and hepatitis C RNA test as follows:

The virus, once it has infected an individual, leads to some antibodies being produced, no doubt about that. But they're not particularly helpful antibodies, and in the chronically infected person, the viral RNA remains present in the host, and is now measurable. Testing is still an evolving science and there is no one test that you could do today and be absolutely sure that that would give you the complete information you thought it was going to on your patient... It demonstrates exposure, but not necessarily active infection.

Hep C RNA testing which is done by PCR technology, so those two terms are often used interchangeably to talk about the test for the virus, actually does look for the presence of the virus itself. So a person can be antibody positive, and viral RNA negative, because the virus just isn't there any more. Equally, early on in an infection, a patient can be RNA positive because the virus is there, and because the host hasn't yet mounted a proper immune response, the antibody can be negative. So no one test is absolutely able to tell you what is going on if the person, for example, has recently been exposed to positive blood.<sup>24</sup>

<sup>22</sup>NSW Health Department, unpublished data.

<sup>23</sup>National hepatitis C resource manual, CDHAC, Canberra, September 2001, page 86.

<sup>24</sup>Professor Robert Batey, Director of the Gastroenterology Unit, John Hunter Hospital Sydney hearing, 15 March 2001. Evidence quoted from the hearings of the Enquiry are taken from tape recordings of proceedings. No written transcript of the oral evidence has been produced.

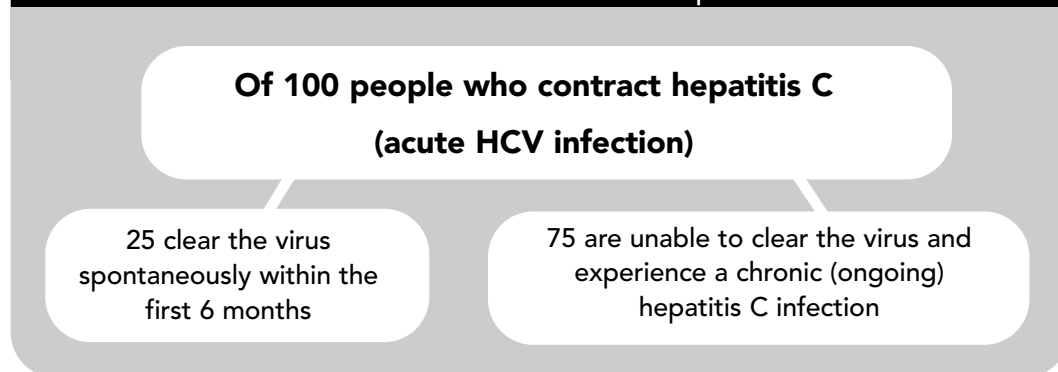
Evidence provided to the Enquiry indicates there is often a lack of understanding regarding the difference between a positive antibody test and a positive hepatitis C RNA or PCR test. This can lead to discriminatory outcomes, and reference is made elsewhere in this report to specific issues, such as insurance (section 2.6).

## The natural history of hepatitis C

The natural history of a disease is defined as its progression in the absence of any medical treatment or other intervention over a designated period of time.<sup>25</sup>

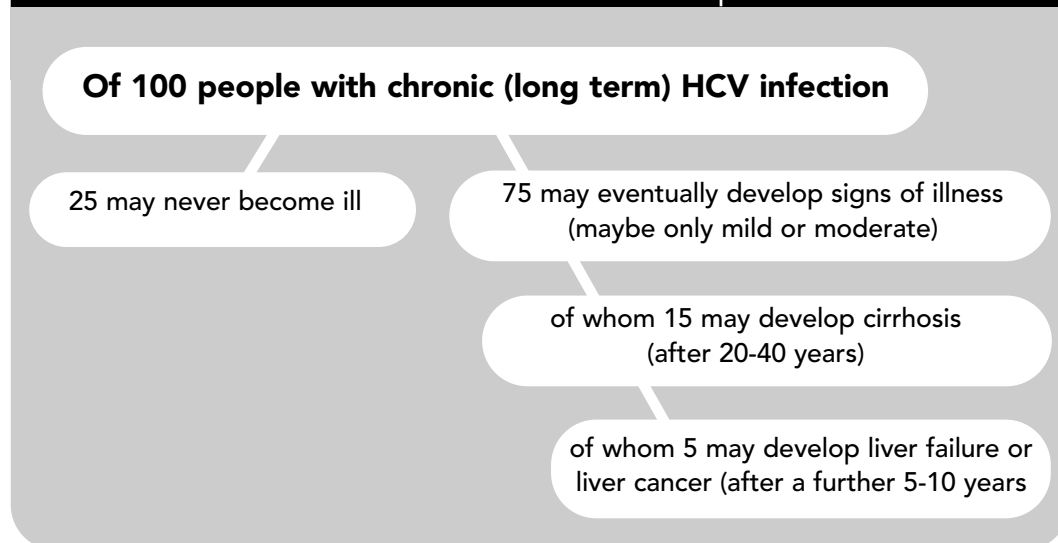
Hepatitis C is a slow-acting virus, and for the majority of people infection will not result in serious disease or death. A review of studies into the natural history of hepatitis C has found that approximately 25% of people with hepatitis C infection will clear the virus spontaneously within two to six months of infection (Figure 1); of the remaining 75%, only a small proportion will develop cirrhosis of the liver (Figure 2).<sup>26</sup>

**FIGURE 1:** current belief on outcome of acute hepatitis C virus infection



**Figure 2** indicates the likelihood of illness and severe liver disease among those who have chronic (ongoing) hepatitis C infection.<sup>27</sup>

**FIGURE 2:** current belief on outcome of chronic hepatitis C virus infection



<sup>25</sup> National hepatitis C resource manual, page 20.

<sup>26</sup> Dore, G. 2000 Natural history of hepatitis C virus infection, *Hepatitis C: informing Australia's national response*, CDHAC, Canberra.

<sup>27</sup> *Hepatitis C - What you need to know*, Edition 4, June 2001, Hepatitis C Council of NSW, Sydney, at page 7.

## 1.3 Methodology

The Enquiry has been conducted by the ADB, with hearings chaired by the President of the Board and assisted by members of the Statutory Board. The ADB has been guided in the conduct of the Enquiry by the expertise provided by the Enquiry's Steering Committee. Members of the Enquiry and Steering Committee are outlined at Appendix A.

### Methods for data collection

The ADB has sought the widest possible input from people living with hepatitis C, community-based organisations, relevant government departments, Area Health Services, private sector institutions, and experts in the field. In February 2001, the Enquiry was advertised in *The Sydney Morning Herald*, *Daily Telegraph*, *The Australian* and various regional and community newspapers. The ADB produced a poster advertising the Enquiry and factsheets explaining how to participate. The Hepatitis C Council of NSW also produced a factsheet on the Enquiry. These resources were widely distributed by both the ADB and members of the Steering Committee. The ADB's website has also been regularly updated during the course of the Enquiry. Organisations represented on the Steering Committee have played an active role in distributing information to their clients, communities and professional networks. Media coverage during the course of the Enquiry has also contributed to public awareness of the Enquiry and the issue of hepatitis C discrimination: see Appendix B.

The Enquiry hearings provided both organisations and individuals with the opportunity to speak directly with the Enquiry panel about hepatitis C related discrimination issues. The Enquiry panel conducted a total of 13 hearings including three days of hearings in Sydney, one-day sessions in Lismore, Goulburn, Dubbo, Newcastle and Wollongong, and half-day sessions in a number of correctional centres. Informal private sessions were also conducted at locations such as the Kirketon Road Centre and the offices of the Hepatitis C Council of NSW. Each public hearing included a session open to the public, individuals, workers in the field and media, and a more informal session, closed to the public and media, to enable individuals to tell their stories in a confidential environment. Hearings, both public and private, were tape recorded and notes were also taken during the course of the proceedings.

Discrimination in health care settings is one of the strongest themes to emerge from the evidence. It is important to acknowledge that the methods of data collection may have influenced the extent of the evidence the Enquiry has heard relating to discrimination in health care settings. Health services were an important means of reaching people living with hepatitis C and health care workers who are familiar with the experiences. As a result health services such as community health centres, drug and alcohol clinics, and needle and syringe programs were important sites for the distribution of information about the Enquiry. That health care settings are a key site for discrimination against people who have or are assumed to have hepatitis C is supported by both the submissions to the Enquiry and the limited prior research which exists in this area.

A 1997 study surveyed people with hepatitis C and undertook an analysis of 37 case histories.<sup>28</sup> The study revealed 46% of discriminatory incidents against people living with hepatitis C reported by participants involved health care settings and 20% occurred at work.

The Australian Hepatitis Council's submission to the Enquiry states:

It is the experience of community hepatitis C organisations that the most commonly reported instances of discrimination occur within the health services sector.<sup>29</sup>

This view is echoed by many other submissions to the Enquiry. This issue is considered in detail in Chapter 2.

The evidence regarding the experiences of individuals received during the course of the Enquiry is treated as strictly confidential. In order to maintain people's confidentiality, some submissions have been paraphrased to ensure particular details of stories do not inadvertently breach a person's confidentiality. Direct quotes are only used in the text where there is insufficient information to enable a person to be identified. Where names appear, these are pseudonyms, designed to enhance the readability of the stories provided. In some instances where evidence has been provided by health care workers on behalf of their clients, particularly in regional areas, quotes and case studies may not include the name of the health care worker or the hearing location.

<sup>28</sup>Crofts, N. et al. *The next plague: Stigmatisation and discrimination related to hepatitis C virus infection in Australia*, at page 89.

<sup>29</sup>AHC, Submission No. 60.

The Enquiry has received extensive evidence of hepatitis C related discrimination by written and oral submissions. For details about oral and written submissions, see Appendices C and D. An overview of the evidence received and further consideration of the advantages and disadvantages of the Enquiry's methods of data collection is considered below.

## Written submissions

The Enquiry received 110 written submissions. Individual's stories are well represented in written submissions. Well over 50% of written submissions are from individuals writing about their own experiences of discrimination or the experiences of a person close to them.

People with hepatitis C often turn to organisations such as the NSW Users and AIDS Association (NUAA), the Hepatitis C Council of NSW, health services and community legal centres for referral and assistance when they experience discriminatory treatment. The Enquiry has received numerous submissions from such organisations, which are regularly in contact with individuals who have experienced discrimination. In 25 submissions from organisations, multiple individual stories of discrimination are anonymously documented.

Table 1 at right provides an overview of the types of organisations that have contributed to the Enquiry, although some organisations may fall within more than one category. A complete list of submissions from organisations, government departments, public and private sector agencies and the like is provided in Appendix D.

**TABLE 1: Written submissions by category**

Written submission category	Number
NSW Government departments	7
NSW Government authorities	2
Federal Government departments or authorities	1
Area Health Services	9
Health care workers (eg GPs)	6
Health care providers (eg hospitals)	2
Health promotion services	2
Individuals	62
Non-government organisations, community-based organisations	11
National professional bodies	3
State professional bodies	1
Research institutions	4
<b>TOTAL</b>	<b>110</b>

## Oral submissions

The Enquiry panel conducted 13 hearings to take oral evidence and heard from 125 people. Eighty-one (65%) of the participants in the hearings were health and community workers in the field, researchers or representatives of organisations, and 44 (35%) were individuals. However, as with written submissions, many organisations and health workers providing oral evidence presented stories relating to their clients' experiences of discrimination: see Appendix C for details of Enquiry hearing participants.

The conduct of the Enquiry hearings made abundantly clear the extent to which people living with hepatitis C fear their status being disclosed. The Enquiry was told repeatedly by health workers who are in regular contact with people living with hepatitis C, particularly those working in regional and rural areas, that despite the high levels of discrimination many of their clients experience, many were unwilling to attend even closed hearing sessions for fear that attendance may result in their hepatitis C status becoming known to others in their community or being seen as an injecting drug user.

I've talked to quite a few people about coming but unfortunately I don't think any of them will come because they're too wary of being seen as being [drug] users in the community.<sup>30</sup>

Many health workers encouraged their clients to attend, with very limited success.

A client [of mine came] along who was an ex-user, he got to the door of the hearing and found that he felt so uncomfortable that he couldn't stay.<sup>31</sup>

There's been some pretty horrendous things that have happened to clients and I think they just expect that they won't be listened to. It's not so much that they don't bother, I just don't think that they think that they're going to get a fair trial... I think people just want to get what they need to get on with their life. The general community often won't complain about being mistreated. Community health is a big enough, intimidating enough organisation, and the ADB is big and statewide — it's like a huge concept for people.<sup>32</sup>

<sup>30</sup>Health care worker, Dubbo hearing, 16 May 2001.

<sup>31</sup>Health care worker, Dubbo hearing, 16 May 2001.

<sup>32</sup>Health care worker, Goulburn hearing, 8 May 2001.

This has undoubtedly impacted upon the number of individual stories contributed to the Enquiry through the oral hearing process and is a disadvantage with public hearings as a method of evidence gathering. However, as discussed above, the Enquiry has held closed sessions in every location to maximise people's access to the Enquiry hearings. In association with community-based organisations, two closed sessions were also held specifically for individuals affected by hepatitis C related discrimination. Individual's experiences are also well represented in written submissions from individuals and organisations working with individuals affected by hepatitis C related discrimination. One of the strengths of hearings is that the Enquiry panel has the opportunity to seek clarification and explore the issues raised by participants. As a result, the quality of the evidence was enhanced through such interactions.

## Methods of analysis

The Enquiry proceeded as a qualitative, rather than quantitative, study into the nature and extent of discrimination against people living with hepatitis C. The evidence gathered has been reviewed and analysed to identify the range of discrimination issues that have been raised in evidence, the frequency with which they arose, the groups of people affected by discrimination and the contexts in which discrimination is said to occur. In the context of the evidence raised during the Enquiry, consideration has been given to whether anti-discrimination and other relevant laws require reform, whether current public and private sector policies and procedures are adequate and /or adequately implemented, and what initiatives may be necessary to eliminate hepatitis C related discrimination and its effects.

The National Centre in HIV Social Research has assisted the ADB in the Enquiry by undertaking a thematic analysis of the written and oral submissions provided to the Enquiry. For this purpose, written submissions received by the ADB were released to the NCHSR.<sup>33</sup> People were given the opportunity to The aim of this analysis is to search for themes within the submissions presented to the Enquiry that emerge as significant or important to individuals. The data for the thematic analysis consisted of notes taken at public hearings and written submissions from organisations and individuals to the Enquiry. This data were assigned codes and the information was then condensed into preliminary concepts. Frequency counts of the preliminary concepts enabled the identification of emerging themes. A theoretical framework concerned with social identity was applied to complete interpretation of the findings. The NCHSR thematic analysis is produced in full in Appendix E and references to this analysis are made throughout the report.

---

<sup>33</sup>Upon receipt of a written submission, the ADB returned a letter of acknowledgment detailing the role of the NCHSR in the Enquiry. A two-week period was granted for people making written submissions to withdraw consent for their evidence to be used in the NCHSR analysis. Where people did not provide a contact address, submissions were not provided to the NCHSR.