NOVEMBER 2001

Report of the enquiry into hepatitis C related discrimination

ANTI-DISCRIMINATION BOARD OF NEW SOUTH WALES

Foreword

In the course of human history there is always change. Some times the changes are small, incremental, predictable, almost unnoticeable; sometimes they are vast, unexpected, and herald great transformations. The latter are 'sea-changes'.

In calling our report into hepatitis C related discrimination *C-change*, what we are essentially calling for is a major transformation in public policy — one which refuses to accept that discrimination is the inevitable companion of hepatitis C infection and one which asserts that the level of hepatitis C related discrimination which this Enquiry has identified cannot be tolerated any longer.

Concepts of health and illness, well-being and disease are cultural constructs — they vary with time and place, with ideology and belief. Over the course of history our views about health and illness have changed. We have moved, or so most of us would like to believe, away from a paradigm where the causes of illness, being unknown, were ascribed to divine judgement or intervention, to a paradigm where we have started to understand the biological, physical and psychosocial origins of our personal and community maladies.

However, every now and again, along comes some new infection, some new threat to public and personal health, something where the origins are initially uncertain and obscure. In such circumstances it often appears that it does not take long for us to revert to a more primitive reaction to these new challenges and, in particular, for us to exhibit an irrational degree of prejudice and discrimination against those who suffer from the new infection. This is particularly manifest when the new infection is somehow linked with aspects of personal behaviour which depart from the prevailing contemporary norm.

This was first evidenced in the reaction in western societies to the appearance of certain sexually transmitted infections in the fifteenth century.[1] It made an interesting appearance in Sydney at the turn of the last century when an outbreak of the bubonic plague in that city led to an outburst of hysterical over-reactions, many of them aimed directly at the city's Chinese community.[2] Most recently it has been exposed in terms of reactions to the appearance of HIV/AIDS.[3]

In 1992, the Anti-Discrimination Board conducted an enquiry into HIV and AIDS related discrimination. In its report, entitled Discrimination — the Other Epidemic, the Board stated:

> Australia has a proud reputation as a nation in which all people receive a fair go. However the impact of HIV and AIDS has severely challenged that tradition. Many people in our community do not receive a fair go. They have been subject to prejudice, discrimination, vilification and even violence because they are infected with HIV, or because it is assumed they are infected. Some of them have been forced out of their employment and accommodation; some have been denied basic health care. Their rights to privacy and confidentiality have been almost routinely violated...For many people, HIV and AIDS related prejudice and discrimination are so extensive that they simply accept them as part of life, feeling powerless to do anything about them.[4]

Readers of this Report will find that analysis depressingly familiar — a mere substitution of hepatitis C for HIV and AIDS will suffice to show how little has changed and how much still needs to be done.

In relation to a key issue in the discussion of what motivates hepatitis C related discrimination we must address the social constructs of drug use and abuse. As with social constructs of health and illness, community attitudes towards drug use change over time.[5]

Sir Arthur Conan Doyle could write eloquently about Sherlock Holmes making decisions about which syringes he would use to inject which drugs of which particular strength and potency without his Victorian audiences demurring. Notable poets and authors of that era extolled the virtues of a variety of now illegal

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[1] Cartwright, F. 1972 *Diseases and history*, Dorset Press, USA, chapter 3; Willis, C. 1996 *Plagues*, Harper Collins, London.
[2] Curson, P. and McCracken, K. (nd) *Plague in Sydney — The anatomy of an epidemic*, University of New South Wales Press, Sydney.
[3] Rosenberg, C. 1988 Disease and social order in America: Perceptions and expectations, in Free, E. and Fox, D. *AIDS — The burdens of history*, University of California Press, Berkley; Aggleton, P. and Homans, H. 1988 *Social aspects of AIDS*, The Falmer Press, London; Lupton, D. 1994 *Moral threats and dangerous desires*, Taylor and Francis, London.
[4] Anti-Discrimination Board of New South Wales 1992 *Discrimination — the other epidemic*, Anti-Discrimination Board, Sydney, page 1.
[5] An excellent analysis of this in relation to both licit and illicit drugs is to be found in Senate Standing Committee on Social Welfare 1977 *Drug problems in Australia — an intoxicated society?* AGPS, Canberra.

substances.[6] A great Prime Minister like Gladstone would regularly resort to a small dose of laudanum (a tincture of opium) to see him through his daily routine, while the famous social reformer William Wilberforce carried out all his great works, such as leading the crusade to abolish the slave trade, despite a 45 year addiction to opium. The British Empire even went to war against China to prevent its government from suppressing the opium trade.[7] Such drug taking today is both criminalised by the law and demonised by politicians.

By contrast, King James I could write *A Counterblast to Tobacco*[8] denouncing its moral and physical vices, and he undertook vigorous steps to prohibit its use,[9] whereas today governments depend upon it as a source of revenue and politicians accept tobacco company hospitality at sporting events.

The political history of cannabis use demonstrates how factors such as racial discrimination have been crucial in developing public policy towards the use of some substances, once commonplace, now criminalised.[10]

In other words, views about what constitutes illicit drug taking behaviour vary over time and with shifts in government policy. Despite the fact that tobacco constitutes the greatest single threat to public health in Australia and causes infinitely more deaths and suffering than the use of illicit substances, it remains legal.[11] Similarly it is worth noting that all major reports into the legal, social and economic costs of illicit drug use in Australia have called for major legislative reforms in this area.[12]

The illegal status of much of this drug use finds expression in terms of negative health outcomes for many people with hepatitis C. This Report shows clearly that the perception of people with hepatitis C as somehow deviant and automatically engaged in illegal or criminal behaviour lies at the root of internalised justifications for treating people in a discriminatory fashion. Were this nexus to be severed, either by means of legislative change or by changes in perceptions, attitudes and responses, then most of the problems identified in this Report would be more easily resolved.

If issues such as what constitutes health or what substances are regarded as illicit are so dependent upon changing cultural and historical circumstances, can we not anticipate that it is genuinely possible to break the nexus between certain types of ill health and the discrimination which accompanies them?

In this Report we assert that such changes can occur and we offer what we think are practical suggestions for promoting those changes.

Most of our suggestions revolve around the concept of better community and professional education. We believe that increasing awareness of what hepatitis C is, how it is contracted and who contracts it, will go a long way to breaking down the stereotypes which lead to prejudice and discrimination. This in turn will improve health outcomes for both individuals and the community in general.

However we also believe that governments have an important role to play. Again, the history of HIV is instructive. To create the 'enabling environment' in which each of the Australian National Strategies in relation to HIV/AIDS have flourished required legislative action on the part of governments — in particular the repeal of laws which discriminated against homosexuals. What this law reform did was to send out a clear public signal that a particular type of discrimination was no longer acceptable and was formally rejected by those charged with national and State leadership in the making of laws and public policy. In this respect, law reform underpinned the great thesis of Martin Luther King that laws against discrimination cannot change the hearts of men but they can restrain the behaviour of the heartless.

Throughout this Report we have attempted to develop practical solutions and recommendations which can be adopted by government, service providers, community organisations, professional associations and individuals. In relation to those recommendations addressed to government or public sector agencies, the Anti-Discrimination Board will be following up over time to see to what extent they have been acted upon and with what commitment and success.

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[6]Hayter, A. 1968 *Opium and the romantic imagination*, University of California Press, Berkeley; de Quincey, T. *Confessions of an opium eater*, Penguin edition, London, 1971.Coleridge wrote his classic *Kubla Khan* under the influence of some narcotic and 'a couple of years after he had finished writing *The Ancient Mariner*...was consuming over half a gallon of laudanum a week', Beeching, J. 1975 *The Chinese Opium Wars*, Hutchison, London.

[7]Beeching, J. 1975 *The Chinese Opium Wars*, Hutchison, London.

[8](1604) 'A custom loathsome to the eye, hateful to the nose, harmful to the brain, dangerous to the lungs, and in the black stinking fume thereof, nearest resembling the horrible Stygian smoke of the pit that is bottomless.'

[9]Standing Committee on Social Welfare 1977 *Drug problems in Australia — an intoxicated society?* AGPS, Canberra, page 80.

[10]Fox, R. and Matthews, I. 1992 *Drugs policy*, Federation Press, Sydney; Bloomquist, E.R. 1968 *Marijuana*, Glencoe Press, Beverley Hills.

[11]Australian Institute of Health and Welfare 2000 *Australia's Health 2000*, AIHW, Canberra.

[12]These range from the Report of the Senate Standing Committee on Social Welfare in 1977 through the report of the Victorian Premier's Drug Advisory Council (the Pennington Report) in 1996 to the recommendations of the New South Wales Drug Summit of 1999.

C-change is the product of a great deal of work by many people. On behalf of the Anti-Discrimination Board I would like to thank all of those people who contributed. The many individuals who presented submissions either in writing or in person gave this Enquiry its unique insight and flavour. The members of the Statutory Board who sat throughout the Enquiry, and contributed their time and expertise, were most capably supported by numerous officers of that Board. The efforts of the members of the Steering Committee who provided ongoing advice and counsel are much appreciated. So indeed is the support of the Attorney General, Hon Bob Debus MP and the Director General of his Department, Mr Laurie Glanfield AM who provided the funding for our work to take place. Most of all, however, our thanks go to Julia Cabassi who heroically guided this enquiry, shaped its operations and effectively wrote the final Report — her effort has been monumental.

At the end of the day this Report is a clarion call for a sea change to take place, or rather for many of them to take place. They must take place in our understanding of the origins, natural history and transmission of what is simply another virus. They must take place in our willingness to discuss openly questions of personal behaviour and health outcomes. They must take place in our education systems, from kindergartens to learned colleges. They must take place in our legislative arrangements, in our courts and in policing and custodial practices. Above all, however, they must take place in the ways in which we respond to and treat each other, in the ways in which we extend respect to our fellows and recognise ourselves in them.

Unlawful and unjustified discrimination is a hallmark of ignorance and illustrates a lack of moral decency. We should perhaps remember that great teaching "inasmuch as you have done it to one of these, the least of my brethren, you have done it unto me."[13] We could, any one of us, be there.

Chris Puplick

President

[13] Matthew 25:40

Case study

"I've been living with hepatitis C for about 17 years, but I only found out about it in March last year. And the way I found out about it wasn't that great. I'd been feeling very unwell, on and off for probably about six years. I do a fairly high pressure job and I'd just get really run down and go to the doctor and they'd say, 'Oh you've had some sort of virus — have a couple of days off work — back you go', and back I would go...finally by February last year, I'd got to the point where I couldn't get out of bed in the morning...I'd been telling my doctor for a good six months before my diagnosis about my symptoms and she just kept saying, 'You'll be alright, you've just had a virus'.

So finally, I knew I just couldn't keep going and I went back to her and asked her if she would run some blood tests, which she did. They came back and my LFTs [liver function tests] were elevated...this took my mind back to 1985 — I'd been using heroin, I wasn't very well. I had a fantastic GP at the time. But of course, hepatitis C wasn't known about back then, so she kept running these tests and saying 'You haven't got hepatitis A, you haven't got hepatitis B, but you have some kind of hepatitis'. So my mind immediately went back to then.

So I asked this doctor if she would run some more tests and I asked specifically if she would run a hepatitis C test. She said, 'You wouldn't have that'. And it was really difficult for me, but I had to say, 'Actually, I think it is possible that I may have that, because I'd been an intravenous drug user 15 years earlier'. And her head just went down and she didn't say anything. Then she said, 'Okay, we'll order the test'. A week later, she calls me in, and she said, 'I've got some very bad news...you have hepatitis C', which was a terrible shock...I started to cry and she didn't have a tissue in the room so she kind of got up and left the room for a couple of minutes and she came back with one tissue and a little brochure that had been produced in 1991.

I had quite a lot of questions — I felt so sick, I didn't want to feel the way I was feeling. So I started to ask some questions about what could be done...she just looked at me and said, 'I'm sorry but I really can't tell you anything about it because I don't see hepatitis C in my surgery'. I pulled myself together a bit more and I kept trying to ask questions...I sat there for a little bit longer and said, 'Surely there's something that can be done about this'. And so she kind of pfaffed around and found a medical directory and she said, 'Oh I think maybe there's a clinic at the Nepean Hospital'. She made a phone call and she said, 'They probably just want you to go in for liver biopsy'. And that was the end of the session.

I walked out, I was dreadfully upset. I've got the tissue — I'm trying to hide the brochure to get out of the crowded waiting room and I got home and read the brochure — which I'm sure in 1991 was probably a very good document, but it scared the be-jesus out of me, because it basically presented a fairly grim prognosis for people with hep C...the information wasn't up to date at all...so I spent the entire day feeling incredibly distraught.

But I was lucky — it was the 27th of March 2000 and it was the day the NSW Government launched its education campaign on hep C, so the gods were smiling on me. I'm sitting there tear-stained, feeling so sick and this wonderful, wonderful news item came on that told me all about hepatitis C, told me that there were treatments available, showed me that there were other people living with this disease. And also that there were people that had been treated in a very similar manner to the way I had, speaking about their experiences of discrimination. So that cheered me up too — I thought, 'Oh well, I'm not the only person that's being treated like a little bit of scum'.

I got in touch with the hospital and they were fantastic — they took me in, they gave me a lot of support. They gave me a list of GPs in my local area that would be prepared to treat me and not dismiss me in the way my own doctor had. But it still took me a good few months to shift my feelings of self-loathing and blaming myself for the situation I was in...it's been a real struggle.

In the relatively short time that I've known about my illness, I've come across a lot of other people that have hepatitis C who have similar stories. I think the thing that upsets me the most is this kind of shame and blame stuff that goes on with hepatitis C. In my support group at the hospital — people will often express the sentiment that their illness is some kind of payment for their sins. I think that's terrible, because I think that means that people have such an appalling image of themselves that they're going to be prepared to put up with some really shabby treatment from other people. They expect other people to think less of them, not to have any compassion for their situation. They're terribly frightened of anyone finding out and judging them. It's a really terrible situation.

The fear of being discriminated against is incredibly powerful. It really makes you feel like you're so alone with your illness. I think there's very good reasons why people don't want to disclose the fact that they have hepatitis C and no doubt this Enquiry has heard many examples — so the fear is real. But I think it's a very important thing that people can overcome that a little bit because you need support when you're ill. It's very difficult not to disclose your illness when you can't walk properly. I'd sort of try and get out from my desk and people would say, 'Why are you limping? Why are you so pale and puffy looking? Why have you got your head down on your desk after lunch?' It's very difficult if you're trying to get on with your life not to tell people. I've had some bad experiences with people's attitudes to hepatitis C, but I've found that since I have been able to feel a little bit braver and disclose more about my illness, that I've actually had a lot of positive feedback and a lot of support from people that I think I otherwise wouldn't have had. So I think that that silence that surrounds hepatitis C can be a real burden.

And I think that people living with hepatitis C perhaps are in a position to change people's attitudes and to make a contribution to fighting this discrimination ourselves...It would just be nice to think that attitudes have shifted enough for people to be able to summon the courage to be able to do that.[1]

[1] **Individual oral submission, Sydney hearing, 2 August 2001.**

Contents

Terms of reference

The terms of reference for the Anti-Discrimination Board's Enquiry into Hepatitis C Related Discrimination are to investigate the extent and nature of discrimination against people who have, or are thought to have, hepatitis C in New South Wales and to make recommendations for combating and eliminating this discrimination and its effects.

List of abbreviations

ACON — AIDS Council of NSW

ADA — Anti-Discrimination Act 1977 (NSW)

ADB — Anti-Discrimination Board of NSW

ADT — Administrative Decisions Tribunal

AHC — Australian Hepatitis Council

AHS — Area Health Service

AIDS — aquired immunodeficiency sydnrome

AIVL — Australian Intravenous League

AMS — Aboriginal Medical Service

ANCAHRD — Australian National Council on AIDS, Hepatitis C and Related Diseases

ARCSHS — Australian Research Centre in Sex Health and Society

ASHM — Australasian Society for HIV Medicine

CDHAC — Commonwealth Department of Health and Aged Care

CHS — Corrections Health Service

DCS — Department of Corrective Services

DDA — Disability Discrimination Act 1992 (Commonwealth)

GPs — general practitioners

HALC — HIV/AIDS Legal Centre

HCC Act — Health Care Complaints Act 1993

HCC NSW — Hepatitis C Council of NSW

HCCC — Health Care Complaints Commission

HCV — hepatitis C virus

HCWs — health care workers

HIV — human immunodeficiency virus

HREOC — Human Rights and Equal Opportunity Commission

IRA — Industrial Relations Act 1996 (NSW)

IRC — Industrial Relations Commission

IDU — injecting drug use/user

IFSA — Investment and Financial Services Association

IPPs — Information Protection Principles

LFT — liver function test

LRC — Law Reform Commission

NCHECR — National Centre in HIV Epidemiology and Clinical Research

NCHSR — National Centre in HIV Social Research

NDARC — National Drug and Alcohol Research Centre

NSPs — needle and syringe programs

NSW DET — NSW Department of Education and Training

NSW Health — NSW Department of Health

NUAA — NSW Users and AIDS Association

PBS — Pharmaceutical Benefits Scheme

PCR — polymerase chain reaction test

PHA — Public Health Act 1991 (NSW)

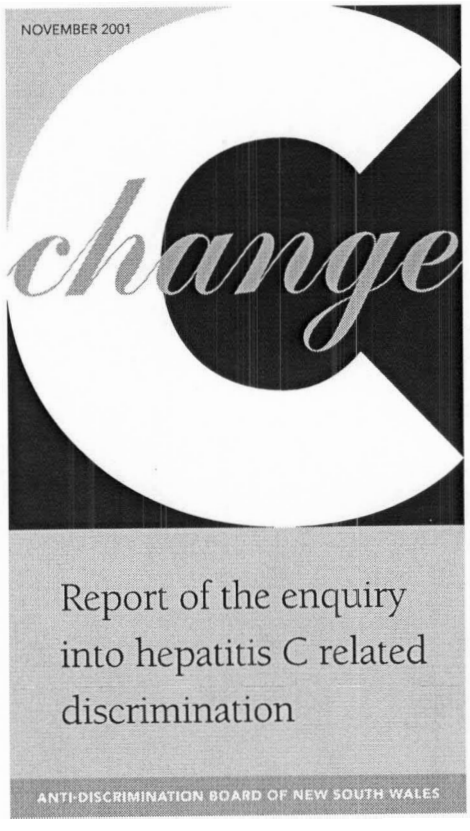
PHR — Public Health Regulations 1991 (NSW)

PPIP Act — The Privacy and Personal Information Protection Act 1998 (NSW)

OH&S — occupational health and safety

SWOP — Sex Workers Outreach Project

Executive summary



Executive Summary

Key conclusions

The evidence to this Enquiry clearly demonstrates that hepatitis C is a highly stigmatised condition and that discrimination against people with hepatitis C is rife. Such discrimination is often driven by irrational fears about hepatitis C infection, due to an inadequate understanding of how hepatitis C is transmitted. However, a perhaps more powerful driving force for discrimination than ignorance about hepatitis C transmission, is that infection is inextricably linked with illicit drug use, a highly stigmatised behaviour. Evidence to this Enquiry makes it abundantly clear that discrimination against people with hepatitis C is often motivated by stereotyped responses towards people on the basis of past, current or assumed injecting drug use.

Hepatitis C related discrimination takes many forms and occurs in many areas of public life. It is apparent from the evidence that hepatitis C related discrimination in health care settings is widespread and discrimination in employment is also commonplace. The Enquiry has heard a wide range of examples of discrimination experienced by people with hepatitis C, such as people being rejected by family and friends, ostracised in workplaces and communities, denied life insurance, and terminated from employment. So too, family and friends have been denied the right to view the body of a person known or assumed to be hepatitis C positive.

Discrimination often has a profound impact on the lives of people with hepatitis C; it frequently has damaging health, financial, social and emotional consequences both for people living with hepatitis C and for the community. The experience of discrimination acts as a deterrent to people accessing the health system, with all the consequences this brings for the health of people with hepatitis C and the community.

Specific conclusions and recommendations

Health care settings

Health care settings were the most commonly reported context for hepatitis C discrimination. Evidence to this Enquiry demonstrates that hepatitis C related discrimination in health care settings is widespread and has significant ramifications for the health and well-being of people with hepatitis C. Such discrimination undermines the relationship between people with hepatitis C and health care professionals, and can become a serious deterrent for people seeking health care. In order to effectively address hepatitis C related discrimination in health care settings a range of policy, legislative and educational responses are necessary.

Hepatitis C testing

The Enquiry recommends that:

1. The *Public Health Act 1991* (NSW) is amended to provide that hepatitis C testing of individuals is only carried out with their informed consent, except in specific cases of mandatory and compulsory testing authorised by law.
2. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a comprehensive hepatitis C testing circular, in line with the National Hepatitis C Testing Policy, outlining that hepatitis C testing should only occur with informed consent and accompanied by appropriate pre-test information and post test counselling.
3. NSW Health disseminate the hepatitis C testing circular to all Area Health Services for implementation in health care services within their jurisdiction.
4. Area Health Services report to NSW Health on steps taken to implement the hepatitis C testing circular within 12 months of the circular's release.
5. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the hepatitis C testing circular to private sector health providers, in particular GPs, through the NSW office of

the Royal Australian College of General Practitioners and the Divisions of General Practice in NSW.

6. The Ministerial Advisory Committee on Hepatitis consider mechanisms for ensuring provision of appropriate information to doctors and people with hepatitis C upon provision by pathology laboratories of a positive hepatitis C test result, in addition to the education strategies outlined elsewhere in this report.

Confidentiality and privacy

The Enquiry recommends that:

7. Section 17 of the *Public Health Act 1991* (NSW) is amended to include hepatitis C and thereby provide a specific confidentiality provision in relation to non-disclosure of a person's hepatitis C status in the same terms the Public Health Act currently provides in relation to HIV.
8. NSW Health, in consultation with the Ministerial Advisory Committee on Hepatitis, develop a circular which provides clear guidelines on legal requirements in relation to hepatitis C and confidentiality.
9. NSW Health disseminate the circular on hepatitis C and confidentiality to all Area Health Services for implementation in health care services within their jurisdiction.
10. The Ministerial Advisory Committee on Hepatitis and NSW Health disseminate and promote the circular on hepatitis C and confidentiality to private sector health providers, in particular GPs.
11. NSW Health revise its *Privacy Code of Practice 1998* to include hepatitis C within the list of 'special information categories'.
12. Area Health Services take all necessary steps to promote compliance with privacy legislation and the *Privacy Code of Practice 1998* within their health care facilities.
13. Area Health Services provide a report to NSW Health, within 12 months of the circular's release, on steps taken to:
    - promote compliance with privacy legislation and the *Privacy Code of Practice 1998*
    - ensure implementation of the circular on hepatitis C and confidentiality.

Infection control

The Enquiry concludes that there is an urgent need to improve the implementation of standard infection control procedures, particularly in hospitals and dental surgeries. Continuing education is essential to reduce discrimination in health services and ensure the safety of both patients and health care workers.

The Enquiry recommends that:

14. Area Health Services ensure that:
    - hepatitis C education for health care workers includes standard infection control procedures, and assesses health care workers' knowledge of such procedures and their understanding of the rationale for standard infection control procedures
    - all health services within their jurisdiction have in place standard infection control procedures appropriate to their health setting and that the implementation of standard infection control procedures occurs in the context of existing quality assurance systems at service level.
15. The Australian Dental Association (NSW Branch):
    - undertake ongoing education concerning standard infection control procedures that incorporates the rationale for such procedures
    - ensure that implementation of standard infection control procedures is adequately monitored
    - link adequate systems for monitoring standard infection control procedures to the accreditation of dental workplaces.

Access to hepatitis C treatment

The Enquiry recommends that:

16. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people who currently inject drugs.
17. The NSW Ministerial Advisory Committee on Hepatitis consider and determine appropriate strategies to improve access to best practice therapy for people living in regional and rural communities.

Education and training

The Enquiry recommends that:

18. NSW Health, in conjunction with Area Health Services, ensure that health care worker hepatitis C education and training forms an integral part of Area Health Services' hepatitis C Strategies/Service Planning.
19. NSW Health ensure that adequate funding is made available to Area Health Services to address the hepatitis C education and training needs of all health care workers.
20. Area Health Services allocate adequate resources for hepatitis C education, training and workforce development that encourages continuous learning, is integrated within management systems and linked to organisational strategic outcomes.
21. Area Health Services provide hepatitis C education, training and workforce development for health care workers that:
    - enables health care workers to examine their values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C and people who have injected or do inject drugs
    - supports implementation of standard infection control procedures and confidentiality policies and procedures
    - ensures health care workers understand and comply with their obligations under anti-discrimination, privacy and related legislation.
22. The National Review of Nursing Education examine existing opportunities for continuing professional education about hepatitis C for nurses and consider options for improving such opportunities.
23. The Ministerial Advisory Committee on Hepatitis ensure that the NSW Hepatitis C Treatment and Care Plan provides minimum standards for Area Health Services in the delivery of appropriate hepatitis C education, training and workforce development for all health care workers.
24. The following principles should guide the development and delivery of hepatitis C education and training for GPs. Education initiatives should:
    - provide GPs with the opportunity to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people with hepatitis C, and people who have injected or do inject drugs
    - include information about GPs' obligations under anti-discrimination, privacy and related legislation
    - assist GPs to implement non-discriminatory policies and practices, including standard infection control and confidentiality policies, which support compliance with anti-discrimination and privacy legislation
    - integrate hepatitis C education with related disciplines
    - actively involve GPs, people with hepatitis C and those affected by hepatitis C in design and delivery.
25. Pre-service tertiary training and educational institutions develop and incorporate hepatitis C specific education, including a focus on anti-discrimination, into their curricula for people training as nurses, doctors, dentists and other health care professionals.

Employment

Submissions made to the Enquiry indicate that hepatitis C related discrimination in employment is the most common setting for discrimination, after health care settings. The Enquiry concludes that hepatitis C related discrimination in employment is extensive and takes many forms, including selection and recruitment practices which deter people from seeking employment, loss of employment and harassment in the workplace. Such discrimination often has devastating financial, social and emotional consequences.

It is clear that many employers do not understand their obligations under anti-discrimination law. Evidence indicates that many employers have an inadequate knowledge of hepatitis C transmission, the extent to which it is a risk in the workplace, and the rationale for standard infection control procedures. Hepatitis C education initiatives targeting key private and public sector employers are essential in order to address hepatitis C related discrimination in employment.

The Enquiry recommends that:

26. The WorkCover Authority of NSW update and reissue the *Code of Practice: HIV and other blood-borne pathogens in the workplace.*

27. The ADB establish an advisory committee to develop and deliver a Hepatitis C Workplace Education Strategy to ensure an effective and coordinated response to hepatitis C related discrimination in employment. The advisory committee should include representatives from the NSW WorkCover Authority, NSW Health, the NSW Labor Council, Privacy NSW, and relevant community, employer and union representatives.

28. The Hepatitis C Workplace Education Strategy should include activities that support and promote:
    - effective implementation of appropriate workplace policies in relation to non-discriminatory selection and recruitment, in compliance with anti-discrimination law
    - adequate and appropriate workplace training regarding the rights and obligations of employers and employees under anti-discrimination law
    - effective implementation of appropriate workplace policies in relation to infection control, in compliance with the WorkCover Authority of NSW's *Code of Practice: HIV and other blood-borne pathogens in the workplace*, as updated, and OH&S law
    - effective implementation of workplace policies on confidentiality and privacy, in compliance with privacy laws.

29. The NSW Government provide adequate funds for the development and implementation of the Hepatitis C Workplace Education Strategy.

30. The NSW Government amend the ADA to include discrimination on the ground of profession, trade, occupation or calling.

Custodial settings

People in custodial settings should have access to health care services and programs of a standard equivalent to that available in the community. While evidence to the Enquiry indicates that discrimination on the basis of inmates' hepatitis C status does occur, the most pressing concerns raised are in relation to access to health care, health promotion and hepatitis C prevention programs and services for prisoners, regardless of whether they have hepatitis C. Impediments to the effective delivery of health care and health promotion services in custodial settings have significant and detrimental consequences for the health of all prisoners, including many hepatitis C positive inmates in the NSW correctional system.

Access to health care

The Enquiry recommends that:

31. NSW Health recognise the importance of the integration of health promotion and hepatitis C prevention within the clinical service delivery provided by the CHS, and ensure that the health promotion and hepatitis C prevention services provided by the CHS are adequately funded.

32. NSW Health ensure adequate resources are provided for the capacity building necessary to enable the effective implementation of the CHS hepatitis C continuum of care, including implementation of specific protocols incorporating health promotion, prevention, services for newly diagnosed inmates, ongoing clinical management and discharge planning.

33. The DCS and the CHS develop and implement protocols to enable effective discharge planning to maximise prisoners' access to health services post release.

34. NSW Health, in conjunction with the CHS, other relevant Area Health Services and the DCS, develop service protocols to improve prisoners' access to hospitals for day-only procedures and agreed mechanisms for linking prisoners into health services in the community, post release.

35. The NSW Ministerial Advisory Committee on Hepatitis give consideration to the emerging scientific literature that indicates that liver biopsy may not be mandatory in order to determine whether treatment is indicated and, if appropriate, enable the use of serological markers to assess liver damage, in order to maximise inmates' access to hepatitis C treatment.

36. The DCS provide the NSW Ministerial Advisory Committee on Hepatitis with the report arising from the review of the Alcohol and Other Drugs and HIV Health Promotion Units and updated information

as requested by the Committee to enable the Committee to examine whether the health promotion and hepatitis C prevention education services and programs provided by the DCS are adequate to meet demand.

37. The DCS evaluate the currency of information in the HIV/AIDS communicable diseases and health promotion policies and procedures, particularly the coverage of hepatitis C, and the extent to which these policies and procedures reflect current practice.

38. The DCS update the HIV/AIDS communicable diseases and health promotion policies and procedures, in line with the review and evaluation findings.

39. The DCS ensure the effective implementation of revised policies and procedures, with particular emphasis on education and training in relation to standard infection control procedures and a systematic approach across the correctional system to the provision of information and education to inmates about hepatitis C prevention and health promotion.

Hepatitis C prevention

The Enquiry endorses the following recommendations and/or proposals for policy or service reform considered in this Report:

40. The NSW Ministerial Advisory Committee on Hepatitis investigate and report on the appropriateness of introducing a needle and syringe exchange program, modelled on the successful European trials, into the State's correctional system and, if necessary, develop guidelines for the program's implementation.

41. The Minister for Corrective Services ensure that adequate bleach dispensing machines are available in all correctional centres enabling inmates to access bleach freely and anonymously. Bleach programs should be administered as a hepatitis C control measure and should not be linked to drug surveillance.

42. NSW Health ensure that the CHS has adequate resources to meet the treatment needs of opioid dependent inmates, particularly to ensure access to methadone, and other therapeutic options such as naltrexone and buprenorphine.

43. The Minister for Corrective Services enable tattooing to be available in hygienic conditions within the NSW correctional system. Consideration should be given to:

- trialing the availability of professional tattooists in the correctional system
- training inmates in the infection control procedures necessary for safe tattooing and supplying inmates with single use ampoules of ink and autoclaves.

44. The Minister for Corrective Services give consideration to differentiating between the punishment for the use of cannabis and injectable drugs in custodial settings.

45. The NSW Government increase the range of non-custodial and diversionary programs to reduce incarceration.

Insurance

The evidence to the Enquiry indicates:

- that people with hepatitis C are being routinely refused insurance or dissuaded from applying for insurance
- that it is common for applications for insurance to be refused without regard to medical evidence about people's individual prognoses
- such policies and/or practices are inconsistent with current natural history research and clinical evidence about hepatitis C disease progression.

The Enquiry recommends that:

46. HREOC's proposed public inquiry into insurance discrimination, depression and anxiety disorders be expanded to an inquiry into disability discrimination and insurance to enable hepatitis C related discrimination to be considered.

47. HREOC encourage the participation of key community and industry stakeholders and research bodies including the Investment and Finance Services Association, the Institute of Actuaries of Australia, the Australian Hepatitis Council, the Australian Intravenous League and the National Centre in HIV Epidemiology and Clinical Research.

Funeral Services

The evidence to the Enquiry indicates that:

- family and friends of deceased persons known or assumed to be hepatitis C positive, are routinely denied the right to view the body
- the rationale for refusal on public health grounds, cited by the funeral industry, is inconsistent with the *Public Health Act 1991* (NSW) and *Public Health Regulations 1991* (NSW).

The Enquiry recommends that:

48. In the context of any proposed changes to the *Public Health Act 1991* (NSW) and *Public Health Regulations 1991* (NSW), that specific reference to funeral industry practices in relation to the handling of bodies should be retained in the *Public Health Regulations.*

49. NSW Health, in conjunction with relevant government departments, industry bodies and consumer representation, develop and implement guidelines in relation to the funeral industry, including in relation to the handling of bodies, to ensure compliance with the *Public Health Act 1991* (NSW) and *Public Health Regulations 1991* (NSW), or such other public health legislation as may be enacted.

50. The WorkCover Authority of NSW, in conjunction with relevant government departments, industry bodies and community representation, develop a Code of Practice on infection control for NSW funeral industry workplaces pursuant to OH&S legislation.

51. The WorkCover Authority of NSW, in conjunction with relevant government departments, work with industry bodies and relevant community agencies to ensure appropriate education and workforce development within the funeral industry to enable effective implementation of the Code of Practice on infection control for NSW funeral industry workplaces.

52. The NSW Government amend the definitions of 'relative' and 'associate' in the ADA to provide coverage where a person alleges they have been discriminated against on the basis of the disability of a relative or associate who is deceased.

Autopsies

Evidence to the Enquiry indicates that:

- the NSW Institute of Forensic Medicine (Glebe Morgue) has a policy of not reconstructing the bodies of deceased persons with hepatitis C after autopsy and that in cases where viewing of the body is not arranged prior to autopsy, family and friends may be denied the right to view the body
- the policy of the NSW Institute of Forensic Medicine appears to be inconsistent with current autopsy policies and practices elsewhere in NSW and other jurisdictions.

The Enquiry recommends that:

53. Central Sydney Area Health Service determine whether the NSW Institute of Forensic Medicine's policy has been to refuse to reconstruct bodies where the deceased is known or suspected of being hepatitis C infected.

54. Central Sydney Area Health Service ensure that the Division of Laboratory Medicine, undertaking the work of the Institute of Forensic Medicine, develops and implements a policy on reconstruction of bodies which provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

55. NSW Health ensure that the proposed statewide statutory authority, the Forensic Medicine and Pathology Authority, once established, develops and implements a policy on reconstruction of bodies which:

- applies to all agencies within the jurisdiction of the Forensic Medicine and Pathology Authority
- provides that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

56. NSW Health's Draft Infection Control Policy is amended to provide that every effort is made to ensure that the viewing of bodies occurs before an autopsy takes place and, where viewing has not occurred

prior to autopsy, that the bodies of deceased persons are reconstructed to enable family and friends to view the body where requested.

Educational settings

The Enquiry concludes that:

- there is a need for a stronger and more integrated policy response to hepatitis C education in schools
- efforts need to be made to improve policies and procedures in relation to standard infection control procedures and confidentiality in NSW educational institutions
- school-based education needs to address the stigma and discrimination associated with hepatitis C and its relationship to injecting drug use.

Infection control

The Enquiry recommends that:

57. NSW Department of Education and Training's (DET) *Prevention of transmission of hepatitis* policy is amended to ensure that standard infection control procedures are applied regardless of whether a staff member or student is known to have hepatitis C and the document accurately reflects the differences between the modes of transmission for hepatitis A, B and C.
58. NSW DET support the amended policy with an implementation strategy to ensure that the policy is implemented within educational institutions.
59. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy's release.

Confidentiality

The Enquiry recommends that:

60. NSW DET develop clear and accessible privacy and confidentiality guidelines which ensure that DET complies with their obligations under the NSW PPIP Act and that appropriate strategies are in place to protect the confidentiality of staff and students with hepatitis C.
61. NSW DET support privacy and confidentiality guidelines with an implementation strategy to ensure that the policy is implemented within educational institutions.
62. Educational institutions report to NSW DET on steps taken to implement the policy within 12 months of the policy's release.

Secondary school education

The Enquiry notes that NSW DET is currently developing curriculum support materials for secondary students related to hepatitis.

63. In formulating the curriculum for secondary students related to hepatitis the Enquiry recommends that:
    - consideration is given to the *National framework for education about STIs, HIV/AIDS and blood borne viruses in secondary schools* and the *NSW Survey of High School Students 2000*
    - the curriculum enables students to examine the values, attitudes, stereotypes and myths associated with hepatitis C transmission, people who have hepatitis C and those most at risk of infection
    - the curriculum addresses discrimination against people who have hepatitis C or are thought to have hepatitis C and discusses anti-discrimination laws
    - the curriculum ensures students are taught how to be blood aware and adopt standard infection control guidelines in all situations where blood is present.

Anti-discrimination legislation

64. The NSW Government repeal the broad exception for private educational authorities in the ADA.

Accommodation

The Enquiry concludes that there is inadequate evidence to determine the extent of discrimination in accommodation against people who use drugs, have used drugs or are assumed to use drugs, particularly given the problems of proof which are commonly associated with allegations of discrimination in the private

rental market. Given that there was insufficient evidence provided to the Enquiry regarding discrimination in the provision of accommodation, no recommendations are made on this issue.

General community — family, friends, communities, media

The Enquiry concludes that people with hepatitis C are often shunned and ridiculed by their own friends, families and communities, leading to increased social isolation and a lack of adequate support. There is also evidence that serious harassment and vilification of people with hepatitis C does occur. There is a need to improve community understanding about hepatitis C. However, significant steps have been taken in recent years to address the level of community understanding about hepatitis C and there are limits to the extent to which knowledge of hepatitis C transmission alone will assist in eliminating discrimination against people with hepatitis C. The Enquiry is of the view that should a social marketing campaign be undertaken, reducing stigmatisation associated with injecting drug use should be a primary aim. However, there was insufficient evidence before the Enquiry to determine whether a social marketing campaign would be effective in addressing hepatitis C related discrimination.

The Enquiry recommends that:

65. The NSW Government amend the ADA to include vilification against people with disabilities, including hepatitis C, which covers conduct that is offensive, insulting, humiliating or intimidating.

Stigmatisation of injecting drug use

Evidence to the Enquiry indicates that the stigma associated with injecting drug use often leads to discrimination against people who have a history of drug use, currently inject drugs or are on drug treatment programs. Such discrimination is widespread and has damaging consequences, both for individuals and for the community. The Enquiry concludes that strategies designed to address discrimination against people on the basis of their past, current or assumed drug use must be an integral part of responding to hepatitis C related discrimination.

The Enquiry recommends that:

66. Education initiatives which are designed to address discrimination against people with hepatitis C in employment and health care settings must also examine and challenge stereotypes associated with injecting drugs.

67. The NSW Ministerial Advisory Committee on Hepatitis ensure that the *NSW Hepatitis C Treatment and Care Plan* provides services and programs which are appropriate for and accessible to people who inject drugs and address the specific health care needs of people who are injecting drug users.

68. The NSW Ministerial Advisory Committee on Hepatitis, in conjunction with NSW Health and Area Health Services, develop and implement strategies to improve compliance with NSW Government harm reduction strategies, and improve State and local leadership for harm reduction measures.

69. The NSW Police Service examine and implement strategies to increase compliance with NSW Police Service guidelines for support of needle and syringe exchange and methadone programs and provide a report to the NSW Ministerial Advisory Committee on Hepatitis on steps taken to improve compliance.

The Enquiry endorses the recommendation of the NSW Drug Summit that:

70. The NSW Government repeal section 11 of the *Drug Misuse and Trafficking Act 1985* dealing with use or possession of equipment for use in the administration of a prohibited drug.

Aboriginal and Torres Strait Islander people

The Enquiry concludes that Aboriginal and Torres Strait Islander people are particularly vulnerable to hepatitis C infection given the disproportionate representation of Indigenous people in the NSW prison system and the poorer standard of health of Indigenous people generally. Not all hepatitis C related health services are delivered by Aboriginal controlled health services. This underscores the need for mainstream health services to work in partnership with Aboriginal Medical Services to ensure culturally appropriate hepatitis C service delivery and education initiatives.

71. The Enquiry recommends that the following principles should guide the development and delivery of hepatitis C education and services for Aboriginal and Torres Strait Islander people:

    - partnerships between mainstream health services and Aboriginal Medical Services should be encouraged

- hepatitis C education initiatives, designed to increase compliance with anti-discrimination law, should incorporate the intersection of hepatitis C discrimination with other forms of discrimination including race discrimination
- education resources and services should be culturally appropriate.

Culturally and linguistically diverse communities

The Enquiry recommends that:

72. The NSW Ministerial Advisory Committee on Hepatitis ensure that the *NSW Hepatitis C Treatment and Care Plan* provide services, programs and educational resources which are appropriate for and accessible to people from culturally and linguistically diverse communities.

Anti-discrimination and other complaint mechanisms

The Enquiry concludes that:

anti-discrimination and other complaint-based systems are under-utilised by people with hepatitis C

- people with hepatitis C are often unaware of their rights under anti-discrimination law
- anti-discrimination complaint-based systems place a significant burden on individuals to enforce their rights
- people with hepatitis C face significant barriers in utilising complaint mechanisms provided by anti-discrimination and other legislation
- individual complaint-based systems are inadequate to address systemic discrimination.

The Enquiry recommends that:

73. The Hepatitis C Council and NUAA, in partnership with the ADB, design and implement an anti-discrimination advocacy program to:
    - enhance the capacity of the Hepatitis C Council of NSW and NUAA to identify discrimination or unfair treatment actionable under anti-discrimination and other relevant legislation
    - support individual access to and use of anti-discrimination and other complaint mechanisms.
74. The NSW Government provide adequate resources to the Hepatitis C Council of NSW and NUAA to develop and implement the above program and provide ongoing individual advocacy services.
75. The NSW Government amend the ADA to enable:
    - the President to initiate complaints under the ADA
    - the President to intervene in applications for original decisions and Appeal Panel matters.
76. The NSW Government amend section 118 of the ADT Act so that the Appeal Panel can refer a question of law to the Supreme Court, for an opinion of the Court, at the request of the President.
77. The NSW Attorney General's Department ensure that the ADB is provided with sufficient resources to:
    - enable the timely handling of complaints
    - take action to address systemic discrimination, such as initiating complaints and intervening in ADT proceedings.
78. The NSW Government enact specific legislation dealing with privacy of health information as recommended by the NSW Ministerial Advisory Committee on Privacy and Health Information.
79. The NSW Government ensure that the NSW Privacy Commissioner is adequately resourced to fulfil this expanded role.

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.[1] During the course of the inquiry, the Parliamentary Committee heard considerable evidence about the discrimination and stigmatisation people living with hepatitis C had experienced.[2]

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.[3]

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.[4]

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.[5] 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

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

[2] *Hepatitis C: The neglected epidemic*, pages 108–119.

[3] *Hepatitis C: The neglected epidemic*, at page 119.

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

[5] *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

Hepatitis C Strategy 1999–2000 to 2003–2004[6] and the NSW *Hepatitis C Strategy 2000–2003*.[7] 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.[8]

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...'[9]

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.[10]

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.[11] Under both Acts, 'disability' is defined to include the presence in the body of organisms causing, or capable of causing, disease or illness.[12] This definition encompasses hepatitis C. Both Acts also cover assumed, past and future disabilities, in addition to actually having hepatitis C.[13] 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

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[6] *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.

[7] *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.

[8] *National Hepatitis C Strategy* at page 2.

[9] *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.

[10] *NSW Hepatitis C Strategy*, at page 8.

[11] DDA, Part 2 and ADA, Part 4A.

[12] DDA, section 4 and ADA, section 4

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.[14] 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.[15] 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[16]

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

[14] ADA section 49B and DDA section 5.

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

[16] 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

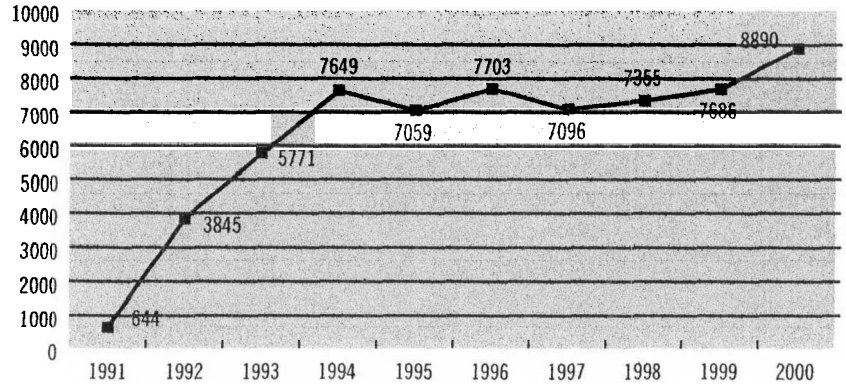
to 1990) and the remainder to other forms of blood-to-blood contact, such as non-sterile tattooing or other skin-incision procedures.[17] Approximately 91% of new infections are among people who inject drugs.[18] Since 1990 all blood has been screened for hepatitis C and the risk of transmission through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

Hepatitis C in Australia and NSW

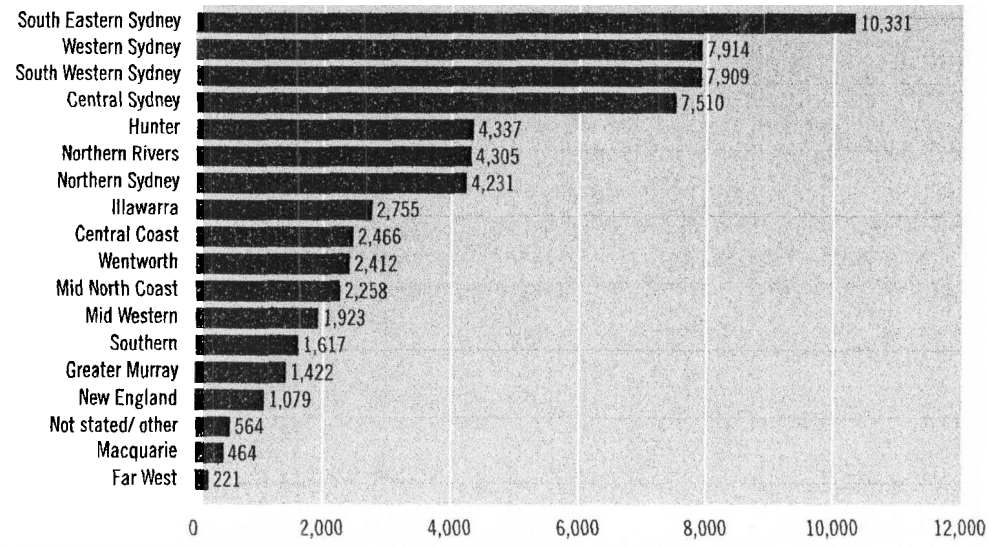
As the most frequently reported notifiable infection in Australia, hepatitis C is a pressing public health issue. During 2000, 20,926 cases were reported, bringing the total number of notified cases of hepatitis C in Australia to more than 160,000 since the antibody test became available.[20] However, 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.[21]

Up to December 2000, 63,698 people in NSW had been notified as having hepatitis C antibodies.[22] In 2000, there were 8,890 notifications of hepatitis C infections in NSW (see Graph 1), with some Area HealthServices 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

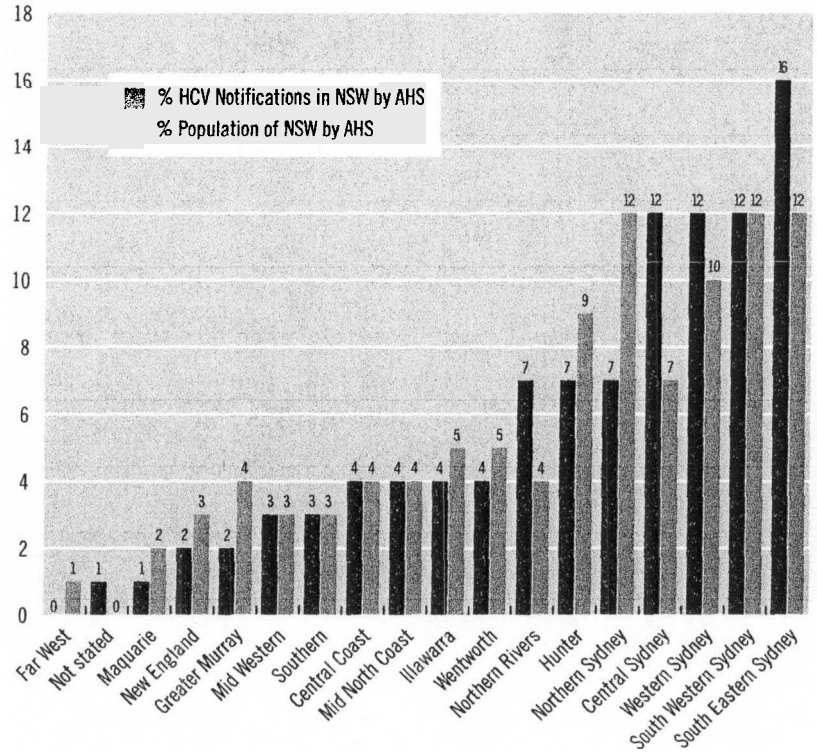


GRAPH 2: Hepatitis C notifications (63,698) in NSW 1991 to 2000
Source: NSW Health AIDU Surveillance Section



[17] *National Hepatitis C Strategy* at page 4.
[18] *Hepatitis C: The neglected epidemic* at page 57.
[19] *Hepatitis C: The neglected epidemic* at page 5.
[20] *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

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.[23] 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.[24]

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[22] NSW Health Department, unpublished data.

[23] *National hepatitis C resource manual*, CDHAC, Canberra, September 2001, page 86.

[24] Professor Robert Batey, Director of the Gastroenterology Unit, John Hunter Hospital Sydney hearing, 15 March 2001. Evidence quoted from

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.[25]

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).[26]

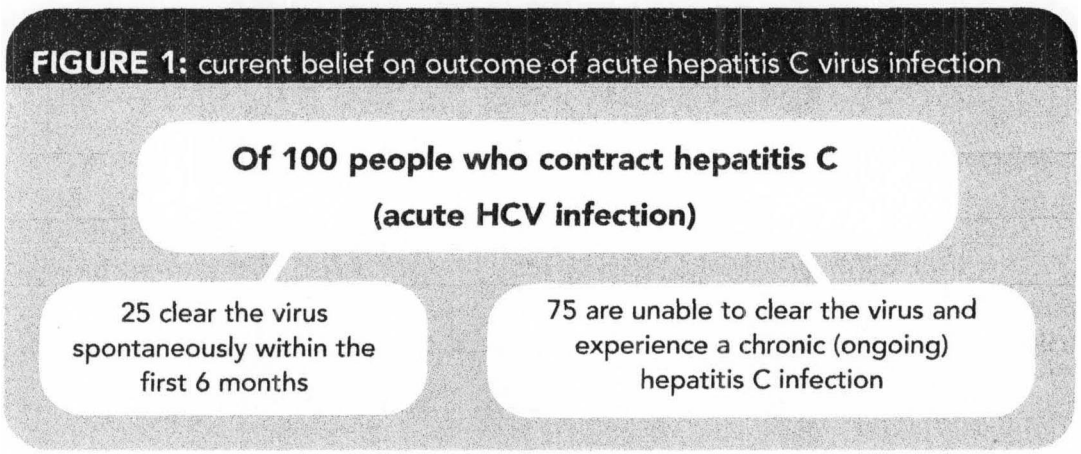
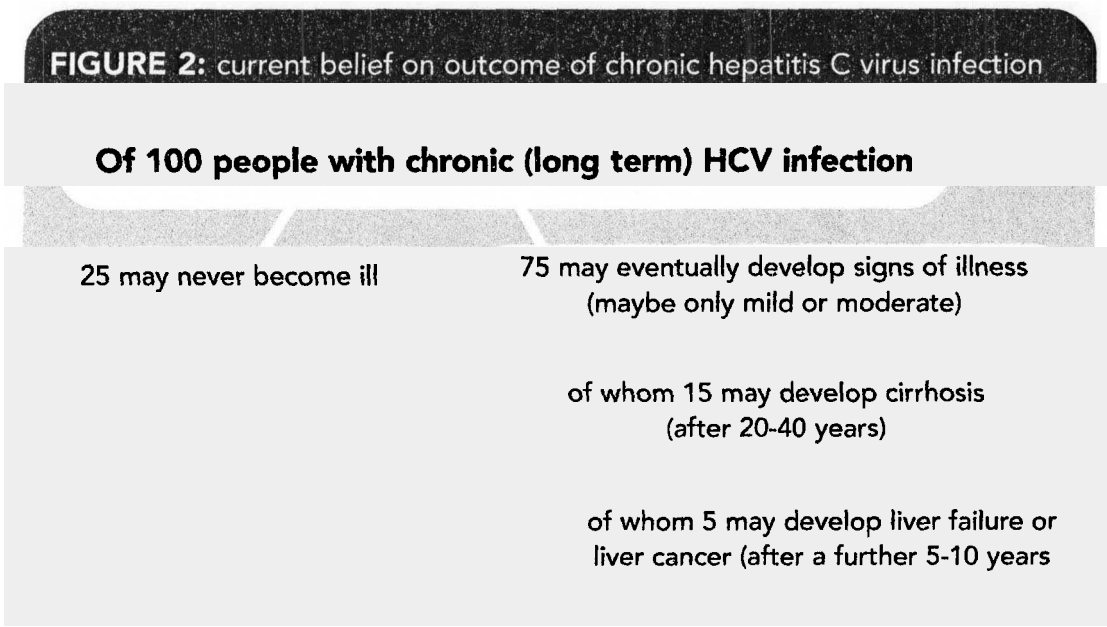


Figure 2 indicates the likelihood of illness and severe liver disease among those who have chronic (ongoing) hepatitis C infection.[27]



[25] *National hepatitis C resource manual*, page 20.

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

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.[28] 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.[29]

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.

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[28] Crofts, N. et al. The next plague: Stigmatisation and discrimination related to hepatitis C virus infection in Australia, at page 89

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
TOTAL	110

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.[30]

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.[31]

> 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.[32]

[30]Health care worker, Dubbo hearing, 16 May 2001.
[31]Health care worker, Dubbo hearing, 16 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.[33] 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.

[33]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