

2006

Controlling and constraining the participation of the hepatitis C-affected community in Australia: A critical discourse analysis of the first national hepatitis C strategy and selected news media texts

Judith D. Pugh
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**CONTROLLING AND CONSTRAINING THE PARTICIPATION OF
THE HEPATITIS C-AFFECTED COMMUNITY IN AUSTRALIA: A
CRITICAL DISCOURSE ANALYSIS OF THE FIRST NATIONAL
HEPATITIS C STRATEGY AND SELECTED NEWS MEDIA TEXTS**

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**This thesis is presented in fulfilment of the requirements for the
degree of Doctor of Philosophy**

**Faculty of Education and Arts
Edith Cowan University**

2006

USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

The construction of texts that place hepatitis C-positive persons at social risk (Candlin, 1989, p. ix), informs this study of the ways in which public health policy makers and journalists in Australia communicate about hepatitis C. The institutions of public health and the news media form part of the cultural context within which persons construct their illness narratives. The privileged perspectives and framing of public health policy and news media discourses; the discursive practices associated with the institutions of public health and the media around hepatitis C and hepatitis C-positive persons, the “objects” of knowledge (Foucault, 1969/2002, p. 81); and the subject and social positions available to hepatitis C-positive people and spokespersons of non-government organisations (NGOs) representing the hepatitis C-affected community are examined. The place afforded the voices of individuals living with hepatitis C in these forums to discuss topics of public concern is considered.

I argue that the rhetoric of “partnership” in the first national hepatitis C strategy, the *National Hepatitis C Strategy 1999–2000 to 2003–2004*, produced by the then Commonwealth Department of Health and Aged Care, controls and constrains participation by the so-called hepatitis C-affected community. The influence of professional experts is maintained through the formal social networks of the *Strategy*’s development, implementation, monitoring, and evaluation. The inclusion of NGOs, including peer-based injecting drug user groups—on the periphery of such networks—in these processes was found insufficient to counterbalance the influence of the biomedical and bureaucratic representatives in the partnership. Moreover, NGOs are to conform to professional practices of the public health sector and help produce “Responsible IDUs”, thereby perpetuating the dominant health paradigm with its treatment imperative to contain the disease.

Just as the complex that constitutes the partnership of the *Strategy* adopted the professional voice, pushing the lay voice to the margin, so news media discourse reflects the dominance of the biomedical perspective, and demonstrates inequality of power relations between experts and the hepatitis C-affected community. News media representations of hepatitis C both reproduce and construct biomedical discursive formations, contributing to the way that people affected by hepatitis C, and others, make

sense of their world. The meanings that arise from such conceptualisations were examined in a survey of media coverage of hepatitis C by three major Australian news services from 1996 to 2003 (prior to the launch of the *Strategy* and during its initial four years). Quantitative content analysis combined with qualitative critical discourse analysis (Fairclough, 1989) extends Krug's (1997) work on the construction of speaking positions in news stories, and considers the attribution of agency for, and causality in relation to, the hepatitis C epidemic.

A major concern of this study is the impact of hepatitis C NGOs on the discursive practices in the development of public health policy, and those of news media texts. There is scope for NGOs to critique such texts to shift the discursive practices of public health and the media to construct a less skewed perspective on hepatitis C, and effect social change.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) Incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education.
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ACKNOWLEDGEMENTS

My thanks go to those who participated in interviews for this study. Their accounts of living with chronic hepatitis C heightened my awareness of the absence of lay voices in the first national hepatitis C strategy, and the limited perspectives represented in public health policy discourse and news media discourse. I am most appreciative of the encouragement of the former Manager of the Hepatitis Council of WA (Inc), Ms Larina Bromley.

I gratefully acknowledge my supervisor, Dr Rod Giblett, for his perceptiveness. His academic guidance, critique, and scrupulous editing helped hone my analytic focus particularly when it seemed likely that I might be sidetracked. I also appreciate the patience and humour with which my associate supervisor, Dr Trevor Cullen, read drafts. His thoughtful and specific comments helped me make revisions to improve the clarity of my writing. Both challenged me to critically reflect on my writing, and expressed their confidence in my ability to bring this project to completion.

This study would not have been initiated if not for my friend, Angelita Martini, who urged me to apply for a postgraduate research scholarship. She then enthusiastically supported me throughout the long process with many a long telephone conversation.

Thanks also to my family, George, Kassandra, and Skevos, for their support and encouragement, and confidence in my academic abilities. Their patience and understanding for the times that I was busy and sequestered from them is most appreciated.

I also wish to acknowledge the importance of the postgraduate room in the School of Communications and Contemporary Arts, which made my experiences as a doctoral student less lonely, and created a venue for feedback, fun, and support. My thanks to fellow postgraduate students, Panizza Allmark, Alex Bradley, Renae Desai, James Hall, Kay Hearn, David Marsh, Steven McKiernan, Ruchireak Permvattana, Taryn Ricketts, Scott Smith, Glen Spoor, and Juha Tolonen, for their good company, tips that eased my life as a student, and useful feedback on my research.

This research was supported by an Edith Cowan University Postgraduate Research Scholarship, for which I am indebted.

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CHAPTER ONE

INTRODUCTION

People are more than a cluster of cells, a body system, or a diagnostic case to be treated or understood from a narrow viewpoint...[P]eople are cultural beings with broad and divergent views of life, of living, and of experiencing. Accordingly, health and illness states are embedded in the cultural values, religious beliefs, economic conditions, and social environments of human expressions.

– Leininger, 1985, p. 2

Hepatitis C is a common blood borne virus in Australia with an overall prevalence of 1% (the number of people living with hepatitis C in 2001 was 210,00). Of these it is estimated that at least 80% of prevalent hepatitis C infections were through injecting drug use (Australian National Council on AIDS and Related Diseases, 2002, pp. 1 & 24). Biomedical and other research reports about hepatitis C often begin with this statistical mystique that obscures the human stories of people living with hepatitis C.

In his address to the 1997 First National Hepatitis C Conference, held in Sydney, Professor Stephen Leeder is more florid. In an edited version of his address, he prefaces his rundown of epidemiological data on hepatitis C, and the issues involved in responding to the “challenge” that hepatitis C poses to public health in Australia, as follows:

The alarm bells now ringing for hepatitis C signal a new episode in our battle against infectious diseases. Having lived through a decade-and-a-half of HIV/AIDS, which we might call the equivalent of World War I, we now depressingly face another world war, this time against hepatitis C. Remarkably, it has grown or, at the very least, come to light, during a decade characterised by global vigilance for blood-borne viruses. It calls for new and mysterious weapons. Unlike the best known of its alphabetical cousins, hepatitis A and B, we are naked in the face of its assault. We are devoid of our usual armour: we have no vaccine...We

may be facing the ‘mother of all infectious diseases’. (Orr & Leeder, 1998, p. 191)

Leeder employs such rhetoric to persuade his audience of the need for governments to adequately resource public health initiatives to address hepatitis C. He considers “partnership”—defined as “the equal participation of stakeholders in disease prevention and control” (p. 193)—as the central, or most important part, of public health strategies. Like Hulse (1997), Leeder stresses that any partnership with community groups representing those affected by hepatitis C must include active participation by community groups that specifically represent current and past injecting drug users (IDUs) (Orr & Leeder, 1998, p. 193).

Leeder’s (Orr & Leeder, 1998) choice of war metaphors to describe hepatitis C—including his adaptation of the phrase “the mother of all battles” coined by former President of Iraq, Saddam Hussein, during the first Gulf War—is not surprising. Since the development of cellular pathology and technologies for seeing micro-organisms in the 1880s, medicine has a well-established history of employing military metaphors to represent infectious agents, disease, pathology, symptomatology, and the treatment of diseases from syphilis and tuberculosis (post World War I) through to cancer (post World War II) and HIV/AIDS (1980s) (Giblett, n.d.; Sontag, 1988/2001, pp. 97; 104–107). War metaphors also abound in published lay illness narratives, with “the body as battlefield” (Frank, 1991 cited in Giblett, n.d.), and patient and doctors fighting as allies (Giblett, n.d.). The notion of doctors and patients as allies fighting a disease is congruent with Leeder’s (Orr & Leeder, 1998, p. 193) call for a partnership between the hepatitis C-affected community and the public health and medical communities to meet the challenge of hepatitis C. However, public health’s rhetorical use of the “gross military metaphor” when speaking about the health of populations is implicated in the stigmatisation of particular diseases and affected individuals (Sontag, 1988/2001, pp. 99–100). While Leeder (Orr & Leeder, 1998) is sensitive to the social marginalisation of IDUs, and lists the removal of hepatitis C stigma “to encourage sufferers to seek support and treatment” (p. 195) as one of the primary aims for public health, his conference address does not portray the lived experiences—including emotions of shame, guilt, anger, pride, and so forth—of individuals living with hepatitis C.

Some years ago, I recorded and produced the audio CD *Living With Hep C* (Pugh, 1998) for the community-based support group, the Hepatitis Council of WA

(Inc) (HCWA). Following is an excerpt from this CD of stories of people living with hepatitis C:

Mark [name changed]: Hepatitis C is a blood borne virus...It's a very long-term virus. Often it isn't discovered or isn't noticed until many years after someone's contracted it, and maybe through some other reason why it's found.

Evelyn [name changed]: Hepatitis C, it's a bug in your blood, which causes deterioration of the liver. Thus far incurable.

Debbie [name changed]: I believe that prior to 1980, no 1990 sorry, they couldn't actually identify hepatitis C antibodies...It would've been called non-A non-B or something like that. I feel I'm lucky that they can actually identify it...I was quite concerned because I didn't really understand what it meant because none of the doctors had told me what is meant really.

Rick [name changed]: Hep C is so silent...Just the fact that I've got a liver disease is pretty scary...There seems to be a lot of misinformation about hep C...It makes me feel a little bit prejudged in one respect that I've got this liver disease that I'm in some way dirty. I think there's a certain aspect of society that believes that if you have any, any sort of hepatitis or any disease that might be blood borne that you are dirty, or not to be sort of approached or certainly not approached too closely...It's been easier for me to treat it with silence.

Linda [name changed]: Most of it is fear, fear of not knowing.

Cathy [name changed]: Hep C is the single biggest threat perhaps that's out there about injecting drug use and you have to be so careful.

Evelyn: If the doctor seems to you to treat you as just some *thing* that he's in control of, say, "Thank you very much" and don't come back.

Mark: Rather than being a terrible thing I felt like it was an answer, a beginning...When I discovered I had hep C it started me on a road to sort of discovery about how I could come to terms with this illness...Re-invent or start a whole new attitude about who I am and what I mean to myself, what life's all about.

The concerns of the people interviewed for this CD remain relevant today. In January 2002, I went to a movie at an outdoor Perth cinema. There I unexpectedly met up with Brian [name changed], a doctor I had worked with some years ago in the intensive care unit of a major teaching hospital. We shook hands and he asked, "Where are you working now?" I replied, "At the Hep C Council." "Ughh!" Brian responded. He grinned and deliberately wiped his hand top and palm, back and forth on his shirtfront in an exaggerated joking manner, as though wiping off hep C germs. I knew in my own mind that Brian did not believe that he could get hepatitis C from shaking hands. But I was disappointed at his reaction. To me, his reaction implied that I was *tainted* from working with people who have hepatitis C, and that these individuals were dirty.

Hepatitis C is defined and shaped by culture, particularly the shared beliefs and attitudes that characterise groups such as health care professionals, public health professionals, and the news media. There is no doubt that social meaning attaches to a diagnosis of hepatitis C. How meanings of hepatitis C are constructed, though, is not clear. The purpose of this study is to investigate conceptualisations of hepatitis C primarily in public health policy documents and the media, and explore the meanings that arise from such conceptualisations. The remainder of this chapter provides the research question, a discussion of the background or context and significance of this study, and a review of related literature.

Research Question

How is hepatitis C culturally constructed in Australia by the institution of public health and the news media?

Background (Context) and Significance

In the early 1990s, little was known about hepatitis C, and there was uncertainty about the disease. Since that time much has been done to study the virus, and the symptoms of the disease, and to study treatments to determine which therapeutic regimes are the most successful. The basic sciences provide information about the molecular basis of hepatitis C, its viral structure, and cell-mediated responses. Technologies such as recombinant DNA technologies, electron microscopy, and molecular virology have given doctors and scientists the means to look beyond the surfaces and depths of the patient's body visible to the naked eye to the cellular level, showing the virion structure and genomic structure of hepatitis C. As was the case for HIV/AIDS, the identification of the hepatitis C virus in 1989 "created opportunities for monetary rewards (for example, in revenue from patents on testing kits)", and the development of antiviral drugs (Treichler, 1987, p. 282).

Uncertainty remains, as Thompson and Locarnini (2001, p. 15) point out: "[The] challenging nature of the hepatitis C virus (HCV) has limited our understanding of the biology of this fastidious agent". Clinical sciences inform medical practitioners about clinical care, treatment, and alternative therapies, and the outcomes of infection.

Epidemiologists trace the “natural history” of the disease—the temporal trajectory of the disease.

Hepatitis C predominantly affects the liver, giving rise to symptoms of the disease. Doctors have calculated the critical time frame for hepatitis C in years. Doctors measure liver enzymes, for example, to detect any deviation from the norm and/or to monitor changes associated with hepatitis. It is recommended that qualifying patients receive treatment to get rid of the hepatitis C virus infection, and/or to minimise liver damage as

There is risk of fibrosis or cirrhosis—anywhere between 25 and 40%...So what is cirrhosis? If we chop it [the liver] out we see a knobbly, irregular liver. It doesn't look like the sort of thing you want sitting in you. A normal liver—if you go to the butcher's shop, your liver doesn't look any different to that (be it a lamb liver or a cow liver). When livers get all fibrous and scarred that's when you start to get all the problems that come with liver disease. The liver tries to repair itself. When it's trying to repair itself, that's the process that ultimately results in the cancer developing...Then all the problems with bloating up with fluid and the vomiting of blood come from the scarring and pressure changes that this causes. Some people can be quite okay for a period of time with it but, as a rule, most people end up cirrhotic to some degree. (Olynyk, 2002)

The hepatitis C virus is a leading cause of liver disease in Australia, including cirrhosis and primary liver cancer, and the main reason that people require liver transplants (Olynyk, 2002). “Epidemic” is defined in the *Dorland's Pocket Medical Dictionary* (1977, p. 246) as a disease that is “widely diffused and rapidly spreading”. It is in this sense that biomedical and public health texts commonly refer to hepatitis C: “The epidemic has been defined by rapid and widespread transmission” (Commonwealth Dept of Health and Aged Care, 2000a, p. 29).

Hepatitis C is constituted as a problem for medicine in Australia that requires detection, surveillance, management, and treatment. State/territory health departments and national organisations gather statistics about the hepatitis C epidemic, collect information about the treatments used, and set out treatment schedules for the medical profession. Health departments in some Australian states/territories have implemented educational programs to train general practitioners (GPs) who are “willing and able to be up-skilled in management of HCV [hepatitis C] and working with IDU [injecting drug users]” (Blacklock, 1999, p. xv). Aims or objectives of such programs include the following:

To facilitate coordination between GPs and the specialist clinics. (Vella & Baird, 1999, p. 89)

To establish closer links between prevention, surveillance, treatment and care services to facilitate control of HCV. (Dore, Pritchard-Jones & Goldstone, 1999, p. 77)

To reduce attendances at [hospital] clinics by improving the capacity to manage HCV positive patients in primary care. (Totten & Watson, 1999, p. 93)

The state/territory health departments establish program or project committees and specify activities through their terms of reference, and fund the programs and infrastructure. In Western Australia (WA), at least, medical information has been disseminated in a planned manner compared with, for example, South Australia—which Hepworth and Krug (1999, p. 242) describe as ad hoc. The Department of Health in WA has implemented education strategies targeting health care workers with

seminars for general practitioners, dentists and other health care workers on HCV. [It also involved] funding major teaching hospitals to provide education programs to general practitioners involved in ‘shared care’ programs in conjunction with the National GP Education Program. (Sexual Health Program, 1998, p. 9)

Evaluation of the hepatitis C Shared Care Project in WA included investigating the “extent of compliance by doctors with the patient monitoring protocol, prescribed at the start of therapy” (Totten & Watson, 1999, p. 92).

Such state or territory-based programs sit within national public health programs, which include surveillance programs, programs concerned with the regulation of medicines, and standardised treatment protocols (as will be discussed in Chapter Nine). Hepatitis C is just one of a number of diseases or health problems for which the then Commonwealth Department of Health and Aged Care (the Department) has developed a national population health strategy. The role the Department plays is outlined in the inaugural national hepatitis C strategy as follows:

The Commonwealth [Government] has a leadership role, and the Department of Health and Aged Care continues to be the principal Commonwealth agency responsible for promoting best practice and coordinating the national response to hepatitis C. The Population Health Division, within the Department...has primary carriage of the National Hepatitis C Strategy. (Commonwealth Dept Health & Aged Care, 2000a, p. 55)

Hepatitis C was considered a key national issue requiring coordination of the national strategic response by the National Public Health Partnership (NPHP):

The National Public Health Partnership (NPHP), established in late 1996 by the Australian Health Ministers' Conference, enables closer collaboration and coordination between State, Territory and Commonwealth governments across a range of public health functions and infrastructure areas. (NPHP Secretariat, 2000, p. 34)

The Department has specific responsibilities including: formulating and coordinating policy; disseminating public information; funding state and territory services (including public hospital services); commissioning and funding research and training; and developing population health standards; and contributing to international initiatives, particularly in relation to basic biomedical research and hepatitis C treatments (p. 55–56).

In relation to HIV/AIDS, Treichler (1987, p. 287) says that many voices should “contribute to the construction of official definitions”. This view applies equally to hepatitis C. Recognising this, the Department funds organisations such as the Australian Hepatitis Council (AHC). Incorporated in 1997, the AHC is funded to develop education resources for people with, and affected by, hepatitis C. Its membership comprises all Australian state and territory hepatitis C councils, which are non-government organisations (NGOs) representing people living with hepatitis C. The AHC can be considered an “authoritative” public institution that has the capacity to “to speak the truth” about hepatitis C (Danaher, Schirato & Webb, 2000, p. 37). While the AHC incorporates a social perspective on hepatitis C by paying special attention to people’s experiences of living with hepatitis C, it operates within a public health policy arena that, for the most part, frames hepatitis C as a problem from a medical and scientific perspective on disease, predominantly that of an infectious disease (Hepworth & Krug, 1997, p. 4). In terms of public health policy decision-making, such framing profoundly influences the estimation of the costs of hepatitis C to the Australian community, and the type(s) of evidence that are sought (Brown and Croft’s (1998, p. 384) modelling and estimates of the health care costs of hepatitis C infection among injecting drug users (IDUs), for example, considers only “the direct medical costs of ambulatory visits and in-patient hospital admissions over the course of the disease”).

Framing public health policy from a medical and scientific perspective also sees public health adopt a political role that resembles that which Foucault (1973, p. 34) attributes to medicine in the nineteenth century:

It assumes a normative posture, which authorizes it not only to distribute advice as to a healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he [*sic*] lives.

Characteristically, the imperative in the medical literature about hepatitis C is concerned with the behaviour of hepatitis C positive persons as it *ought* to be (Hepworth & Krug, 1999), though researchers in epidemiology have called for behavioural research to describe the actual behaviours involved in the spread of hepatitis C among IDUs (Crofts, Jolley, Kaldor, van Beek & Wodak, 1997, p. 697). The end to which such behavioural research is likely to be put is of interest.

Considering government bureaucracies of the twentieth century, Fairclough (1989, p. 212) argues that the “means-end rationality” of a bureaucracy effects control both within the bureaucracy and over people, with people “often [regarded as] objects to be ordered, checked, registered, shifted, and so forth”. Such bureaucracies may be out of touch with the lived experiences of hepatitis C-affected individuals. There has been little examination of the nexus between hepatitis C public health policy and practice whereas the impact of the broad, structural context of drug policy has been the subject of critique. Duff (2004, pp. 389-391), for example, focuses on drug policy to effect individual behaviour change. He calls for an alternative conception of harm minimisation that is framed by Foucault’s (1985) interpretation of the “practices of the self” and “ethics of the self”. Drug policy framed from this perspective would acknowledge the culture of drug use and the pleasures, as well as the harms and risks of drug use, to foster responsibility and moderation in drug use. By comparison, Moore and Dietze (2005) seek to re-frame drug policy so that the focus shifts from the individual to the environment to create “enabling environments”. An enabling environment framework sees the removal of barriers to harm reduction for street-based IDUs, (including providing long-term public housing, extending needle and syringe programs (NSPs), and altering policing strategies), so that the individual can change risky drug use practices.

Notwithstanding current hepatitis C-related policy and programs, hepatitis C, and the hepatitis C-affected community, was largely “unacknowledged by the media, senior health bureaucrats and most importantly by our politicians” for a considerable period of time (Hulse, 1997, p. 175). Yet examination of understandings of hepatitis C in the media, and the formation of hepatitis C-related policy, since the identification of the virus in 1989 and with the growth in biomedical and epidemiological knowledge, highlighted by Hepworth and Krug (1997, p. 4), is limited. The critique in this thesis of public health policy and media discourses will contribute to ways of understanding representations of people living with chronic hepatitis C in Australia. This topic and thesis is likely to be of interest to those diagnosed with the virus as well as health care professionals, scientists, community-based workers, policy-makers, and journalists.

Review of Related Literature

At the time that Faye (2000) developed an inductive, substantive theory—a grounded theory—to explain the social and psychological experiences of hepatitis C positive individuals in Western Australia (WA) I was senior project officer at the HCWA. I was interested in Faye’s research, both for its findings and its methodology, as the topic related to my own work at the HCWA developing information resources for those living with the virus, and for the “general community”.

There was little in the literature about the social and psychological aspects of living with hepatitis C, and what existed was not research-based, when Faye (2000) commenced her doctoral research in 1996. Working as a volunteer counsellor at the HCWA during her study, Faye believed that this lack of knowledge impacted on her practice. Members of the Hepatitis C Social Research Programme within the School of Health Science at Deakin University made a similar observation: “Very little attention has been given to investigating the social impact of this condition or to the broader social and cultural contexts of prevention, care, support and treatment” (Deakin University, 2001). Hepworth and Krug (1999, p. 238) conclude that virological and medical research on hepatitis C dominates the literature, with hepatitis C considered as a physical condition.

The initial broad search of the literature from 1990 to 2002, undertaken for this study, also uncovered little evidence of the lived experiences of those with hepatitis C within the health sciences. In a search of Expanded Academic ASAP International (a

database that covers the social sciences and the sciences), for example, the overwhelming majority of the 1,226 citations of research published in refereed publications categorised by the keywords “Hepatitis C” refer to biomedical research in fields such as viral studies, treatment, studies of the efficacy of antivirals, occupational exposure, and epidemiological studies. Limiting this search to research published in refereed publications that includes “Hepatitis C” and “Narratives” in title, citation, or abstract, elicited only three citations (and no citations for “Hepatitis C” and “Illness Narratives”). It was similar for databases that index clinical articles such as Medline (which indexes journals in the fields of biomedicine, nursing, and addiction) and CINAHL (which covers the fields of nursing, biomedicine, complementary medicine, consumer health and allied health).

Focusing specifically on Australia, the database APAIS-Health (Australian Public Affairs Information Service), which covers “literature on the legal, social, economic and ethical aspects of health and medicine in Australia” (National Library of Australia, 1995-2004), has no records of research categorised by combining keywords “Hepatitis C” and “Illness Narratives”, nor “Hepatitis C” and “Lived Experience”. There were, however, 38 records found in a search of APAIS-Health for “Hepatitis C”, in any field, from 1990 to 2002. These articles are published in peer-reviewed journals in the fields of public health (N=24), medicine (N=6), drugs and alcohol (N= 5), youth studies (N=1), and other (N=2). Most of the public health articles retrieved in this search were published in the *Australian and New Zealand Journal of Public Health*. The research focus of these articles is on the epidemiology of hepatitis C, particularly the prevalence, incidence, and transmission of hepatitis C within a population, including selected populations of injecting drug users and prisoners, and risk factors for transmission. Research published in medical journals—mainly the *Medical Journal of Australia (MJA)*—also have an epidemiological focus such as the distribution of the virus within specific populations in Australia. A small number of studies survey levels of knowledge about, and attitudes to, hepatitis C in specific populations such as high school students (Lindsay, Smith & Rosenthal, 1999), and a smaller number consider the impact of hepatitis C infection on the quality of life of persons living with hepatitis C (Miller, Hiller & Shaw, 2001). A search of APAIS-Health for “Hepatitis C” and “Public Health” from 1990 to 2002 furnishes the same range of research articles. In all, there is scant evidence of research investigating Australia’s hepatitis C public health policy from an alternative perspective to that of epidemiological research.

While there continues to be a gap in the available experiential knowledge of people living with hepatitis C in Australia, and the way in which meaning is constructed, research in this area is emerging. This is evident in the categories of research listed by the clearinghouse of the Consortium for Social Policy Research on HIV, Hepatitis C and Related Diseases, for the period 2001 to 2005, which include:

- Hepatitis C;
- Treatment, care and support;
- HIV and hepatitis C prevention;
- Illicit drug use;
- Discrimination;
- Living with hepatitis C.
- Indigenous;
- Gay men;
- Youth; and
- CALD [Culturally and Linguistically Diverse]. (National Centre in HIV Social Research, 2005)

Research articles listed by this clearinghouse reflect the adoption of perspectives from broader fields of study from the social sciences in the framing of research, including gender studies. A small number of studies adopt methodological perspectives intended at recovering the experiences, or voices, of people living with hepatitis C, particularly when illuminating their experiences of discriminatory attitudes and practices of health care professionals (see Crockett & Gifford, 2004; Day, Jayasuriya & Stone, 2004; Temple-Smith, Gifford & Stoové, 2004). Other studies, such as Hopwood and Treloar's (2004) survey of patient's experiences of being diagnosed hepatitis C positive—published in the Royal Australasian College of Physicians' *Internal Medicine Journal*—seek a “Yes/No” response to questionnaire items from respondents rather than in-depth responses, and summarise data using descriptive statistics.

The following review of the literature, for the period 1990 to 2002, (and noting additions since), outlines the research undertaken in Australia that explores the lived experiences of persons living with hepatitis C and/or the social and cultural context of living with hepatitis C, including public health policy and news media reporting, which form part of the context of living with hepatitis C.

Experiences of Living with Hepatitis C

Research framed from the perspective of those living with hepatitis C in Australia is scant. However, since this study commenced it has received increased attention from researchers from a number of fields including health sciences, public health (including epidemiologists) and social sciences. Those who take an interest in the health and social experiences of people living with hepatitis C demonstrate concern for issues such as who defines hepatitis C in Australia; the hepatitis C-positive person's interactions with health care professionals (particularly, at the time of testing and diagnosis); disclosure (especially within relationships and the workplace); discrimination and stigma (again, predominantly in relation to social interactions with health care providers and the association of hepatitis C with injecting drug use); and the impact of chronic illness. Gender differences in the perceptions of people living with hepatitis C also receive consideration. Researchers examine the experiences of people living with hepatitis C from different paradigms, such as feminist and gender studies in Crockett and Gifford's (2004) examination of women living with hepatitis C in Australia. Increasingly, such research employs qualitative research methods, particularly semi-structured in-depth interviews of affected persons. Most of these studies lend weight to the proposition that hepatitis C, though usually invisible to the eye is, to use Kleinman's (1988) term, a "culturally marked illness".

In a small scale, qualitative study, Krug (1995) investigated the discourses, formations, and interpretations active around hepatitis C in South Australia from 1991 to 1994. Krug set out to determine "who establishes the meanings of HCV, and how are these meanings taken up in the lived experiences of people as part of themselves" (p. 300). To do so, he collected various data: observation data at hepatitis C support groups; conversations with hepatitis C-positive people and doctors; interviews; newspapers reports and television documentaries; and written materials distributed by the hepatitis C support group (p. 301). Krug draws connections between cultural texts—such as newspapers and television documentaries, and written texts of hepatitis C support groups—and discourses existing at the time of his research but offers "no final interpretation of people's stories or of cultural texts" (p. 301). Writing in the "demonstrative mode" (Connelly & Clandinin, 1990, p. 11), Krug (1995) illustrates his argument with excerpts from the data. Having sought personal stories to capture "lived experience", he presents the case of one interviewee, which is a composite based on

interviews with a number of people, to illustrate the “common experience” of a hepatitis C diagnosis (p. 311–312).

According to Krug (1995, p. 304), physicians, scientists, and hepatitis C-positive persons in South Australia faced an “absence of meaning” around hepatitis C in the early 1990s. Nonetheless, hepatitis C has both medical and social consequences—which may be unforeseen—that “necessitate people’s constructions of it into meaningful narratives, stories, beliefs, and plans for action” (p. 303). Hepworth and Krug (1999) examine the social and cultural context of the experiences of six hepatitis C-positive individuals. The aspect they focus on is the participants’ experiences of being diagnosed with hepatitis C. Hepworth and Krug identify four major sites in people’s lives that are disrupted and transformed by a diagnosis of hepatitis C: the value of the relationship of self to others; the emotional self; self-stories and identity; and self-scrutiny and relationships (p. 240). In the absence of meanings and cultural forms that give social significance to people infected with hepatitis C, Hepworth and Krug postulate that persons living with hepatitis C will fuse their experiences with expert discourses such as medicine (p. 244). Uncertainty was an important issue for those Krug (1995, p. 307) spoke with: having “gain[ed] a great deal of information about their bodies through the medical process, patients are drawn further and further from themselves”. Krug believes that people living with hepatitis C turn to, and return to, the medical formation of their “diseased” (with hepatitis C) lives. Rather than “reclaiming” their body-self-stories (Frank, 1995, pp. 64–65), Krug (1995, p. 306) suggests that persons living with chronic hepatitis C surrender their narrative to that of the medical profession. According to Krug, scientific and medical discourses are the dominant discourses vying to define the stories of patients. However, the form(s) of self-stories merit further study (Hepworth & Krug, 1999, p. 239). Frank’s (1995, p. 32) work on illness narratives suggests that even in the face of contingency, those living with hepatitis C can be expected to construct their self-stories, their narratives of the illness. What people seek, the course that they set out upon, and the way in which they come to “own” their illness (p. 50), as opposed to letting medicine represent it, warrants exploration. In this regard, it is important to consider the construction of narratives—including the subject positions taken up in narratives—rather than fragment long stretches of talk into thematic categories focusing on the content or information conveyed as, for example, Gifford and O’Brien (2001, p. 10) and Hepworth and Krug (1999) have done.

In her grounded theory, Faye (2000) constructs a normative narrative of hepatitis C built from individual hepatitis C narratives (from interviews and field notes of counselling sessions with non-injecting drug users, past-IDUs and current-IDUs). The dominant metaphor in Faye's study is a legal-penal one. The basic social psychological problem common to participants in this study—labelled “Being condemned”—comprises two stages that reinforce this metaphor: “Stage 1: The conviction” and “Stage 2: The sentence and penalties” (Faye & Irurita, 2003, p. 94). This metaphor is akin to the nineteenth century view noted by Sontag (1977/2001, p. 43) in which the “disease fits the patients’ character, as the punishment fits the sinner” rather than “expresses” character. The association of hepatitis C with injecting drug use (Hopwood & Treloar, 2004; Krug & Hepworth, 1999, p. 104)—despite injecting drug users coming from all walks of life and forming a heterogenous grouping (Campora, 1999, MacDonald, Sullivan, Locke, Wodak & Kaldor, 1998)—is telling in this regard.

The origins of hepatitis C-related illness may be associated with ambivalence centred on the infected person's sense of “self” and “not-self” (Faye, 2000, pp. 110–111; 185; 196 & 199). In relation to discourses on AIDS, Treichler (1987, p. 271) similarly asked whether an illness caused by an external disease, outside the individual's control, is preferable to an illness that is preventable or “containable through ‘self-control’.” Faye (2000, pp. 110–111) identifies two types of stigma (and subsequent discrimination) in her discussion of “penalties”, that related to injecting drug use and that relating to the infectious virus. This is the “double burden” of hepatitis C: “The physical impact of the illness and the social impact resulting from the stigma [related to injecting drug use]” (Temple-Smith, Gifford & Stoové, 2004, p. 47; see also Krug, 1995; 1997; Hepworth & Krug, 1999). Faye's (2000) introductory remarks about hepatitis C stigmatisation echo Treichler's (1987, pp. 271 & 284) aforementioned discussion of self and not-self, and accompanying semantic oppositions of “guilty and innocent”, “perpetrator and victim”. Faye (2000, p. 185) found that such constructions had an impact on social relations between people in peer support groups: “[Some] who had contracted HCV via a non-IDU mode segregate[d] themselves from, and infer[red] a comparative HCV infection innocence to those who had contracted HCV via an injecting drug use mode”.

Of note is hepatitis C-stigmatisation related to the disease's association with injecting drug use as it affects social relations with health care professionals. In the article “Balancing Perspective: The Response to Feelings of Being Condemned with the

Hepatitis C Virus”, drawn from Faye’s doctoral research, Faye and Irurita (2003, p. 101) observe that participants disclosing their hepatitis C-positive status to health care professionals were often discriminated against by service providers on the basis of known or implied injecting drug use. Recognising this, non-IDU participants disclosing their status “made an absolute point of explaining their noninjecting drug-use mode of HCV transmission” (p. 101). It is telling that the imagined or assumed stigmatisation by others towards those with hepatitis C is as detrimental as that which is actually experienced. Regarding health care professionals, Faye (2000, p. 188) quotes from Tillet (1991):

Health professionals are likely to be susceptible to the impact of the popular media...[S]cientific or medical education provides no protection from deeply held personal fears...when the individual is confronted with the objects of his or her fear.

Hepatitis C-positive individuals may also harbour negative preconceptions of hepatitis C such as “hepatitis is dirty” (p.188). Faye attributes the stigma and rejection, experienced by participants, as “influenced to some degree by a lack of understanding within the general community about the modes of HCV transmission” (p. 113). However, Faye does not extend her research to explore representations of hepatitis C in cultural texts, such as news reports, which may influence the general community and health professionals.

Evidence given to the Enquiry of the Anti-Discrimination Board of New South Wales (NSW) points to health care settings as “the most commonly reported context for hepatitis C discrimination” (Anti-Discrimination Board of NSW, 2001, p. 12). Survey research in Australia provides additional data to support this assertion. Hepatitis C-related stigma associated with injecting drug use was the “common thread” in the experiences of 25 Melbourne women interviewed by Gifford and O’Brien (2001, p. 9). In a larger study—a cross-sectional survey to elicit Australian women’s experiences of living with hepatitis C—that followed on from Gifford and O’Brien’s small qualitative study, it was found that discrimination by health care professionals added to the negative experiences of female IDUs (Gifford, O’Brien, Bammer, Banwell & Stoové, 2003). Over a third of the 606 men and women living with hepatitis C interviewed for the intake of the HepCare hepatitis C case management trial in New South Wales from 1998 to 1999 experienced discrimination by health care service providers, particularly IDUs and women (Day, Jayasuriya & Stone, 2004, p. 59). The association of hepatitis C

with injecting drug use is similarly implicated in Hopwood and Treloar's (2004) survey research, with current IDUs found to be less likely than others to receive information from their doctor at the time of diagnosis (p. 528). While Hopwood and Treloar stress the importance of social relations between doctors and hepatitis C-positive IDUs at the time of diagnosis, they do not explore why doctors do not provide adequate pre- and post-test information to patients, nor why doctors fail to refer newly diagnosed patients to support services.

Those Faye (2000) interviewed were told that hepatitis C is an infectious disease. Treichler's (1987, p. 265) work about HIV/AIDS informs us this is but one construction of hepatitis C produced within biomedical discourses. Hepatitis C is identified with injecting drug use, and those infected fear and/or experience discrimination:

Institutional and societal discrimination primarily manifests in two areas: policies and practices related to contagion fears and the possibility of transmission...[and] related fears about perceived deviant behaviour. (Ward, Coleborne & Fort, 2000, p. 143)

Not surprisingly, as well as being watchful and alert in relation to their blood, Faye's (2000) informants employed "HCV secrecy" as a "defence" so they remained "vigilant" about maintaining their secrecy (pp. 102 & 190). In so doing, it seems that they were, in Foucauldian (1977, p. 203) terms, "the principle of [their] own subjection". Hepworth and Krug (1999, p. 243) also found that a diagnosis of hepatitis C affects people's lives in terms of self-scrutiny and relationships, and that some people become "self-policing". Furthermore, those with chronic hepatitis C are encouraged by doctors to undergo continual monitoring of the disease and their health (Faye, 2000, pp. 214–217). This situation is reminiscent of Frank's (1995, p. 10) reference to "the remission society"—people who are well but not considered cured (of cancer)—with check-ups "represent[ing] the background of illness shading back into the foreground". If compliant with such medical monitoring the person living with hepatitis C could be exposed to multiple instances of discrimination.

In the recently published qualitative study "'Eyes Wide Shut': Narratives of Women Living with Hepatitis C in Australia", Crockett and Gifford's (2004) content analysis confirms that women living with hepatitis C—who have a history of injecting drug use—are prone to experience stigmatisation and discrimination by partners, family, friends and health care professionals. Crockett and Gifford compare the experiences of

25 women—past or current IDUs—from the outskirts of Melbourne, with those a small group of community health care service providers for the local government area that the women lived in for the period 1999 to 2000 (p. 122). They place their research within the context of findings on gender-related health disparities, and the gender-related risks for hepatitis C faced by female IDUs associated with drug injecting practices and the place of women in the social hierarchy of injecting networks, often subordinate to men (pp. 120–121). Like Temple-Smith, Gifford and Stoové (2004, p. 50), Crockett and Gifford (2004, p. 121) also acknowledge the propensity of women to seek health information, care and support, which may expose them to more incidents of discrimination than men. As with the participants in Faye’s (2000) study, the women interviewed by Crockett and Gifford (2004, p. 124) maintained secrecy about their hepatitis C status for fear of rejection by family and friends, and were made “to feel dirty” if known to be hepatitis C positive.

The social relations between doctors and patients are a crucial element in the diagnosis of hepatitis C (Hopwood & Treloar, 2004). Many of the women in “Eyes Wide Shut” reported that their experiences of receiving a diagnosis of hepatitis C “reinforce[d] the ‘dirty’ and ‘infectious’ meanings of the condition”, and their diagnosis was not followed up with sufficient or appropriate information or support (Crockett & Gifford, 2004, pp. 125–126). Such experiences were found to impact negatively on the likelihood of these women subsequently accessing health care services (p. 133), a finding consistent with the descriptive study of Australian women’s experiences of living with hepatitis C by Gifford et al. (2003, p. 848). Importantly, Crockett and Gifford (2004, p. 127) point out that those women diagnosed and/or treated by their long-term doctor, a doctor with expertise “in HCV and issues relating to injecting drug use”, or an outreach health care worker had a more favourable experience. This is in contrast to Gifford et al.’s (2004, p. 49) study, which found that men and women who were tested by, and received their diagnosis from, doctors in an alcohol and drug setting were more likely to have a negative experience. Crockett and Gifford’s (2004) study, which places the experiences of the 25 interviewees—women living with hepatitis C—within a specific sociocultural, economic, and policy context, emphasises misconceptions about hepatitis C amongst health care service providers and the wider community. According to the authors, the title was chosen to reflect “community misconceptions about HCV” (p. 118). The focus of “Eyes Wide Shut”, however, does not extend to representations of hepatitis C in cultural texts such as news reports, which

may be the source of misconceptions. Nor does it explore public health policy, other than to decry the continued discrimination and stigmatisation by health care professionals, despite hepatitis C having the status of a “national priority” (pp. 126 & 133).

The Import of Medical Discourse

There has been some attempt to broaden the boundaries of understandings of hepatitis C in Australia as represented in biomedical texts. The publication *Hepatitis C: An Australian Perspective*, edited by Crofts, Dore and Locarnini (2001), is one such publication that attempts to incorporate aspects of the day-to-day, lived experience of hepatitis C. The text draws together contributions predominantly by researchers in epidemiology (including viral epidemiology), molecular microbiology, molecular virology, clinical immunology, haematology, transfusion medicine, infectious diseases medicine, and hepatology. Alongside these medical and scientific writings are contributions from researchers in epidemiology and social research, which include peer-based research and education around injecting drug use, and issues of human rights and anti-discrimination.

The opening chapter of *Hepatitis C: An Australian Perspective* (Crofts, Dore & Locarnini, 2001), written by a freelance journalist and editor with an interest in public health issues, reads:

For many people, a diagnosis of hepatitis C is akin to a death sentence...It takes a long time, a great deal of support, and much information before the concept of living with hepatitis C can be incorporated into your life. (Costigan, 2001, p. 1)

In this chapter, entitled “Living with Hepatitis C: A Constant Bloody Struggle”, Costigan presents interviews with three women and two men, which she terms “personal stories”. Each story includes a brief chronology of events from the diagnosis of hepatitis C to the present day. Though mainly located in the present, there is some sense of past–present–future in each interview. Costigan’s chapter provides a sampling of the voices of those affected by, and infected with, hepatitis C. However, the medical and scientific models of disease contained in the publication in its entirety overtake these lived experiences. A glance at this publication suggests that research about hepatitis C virology, epidemiology, pathology and pathogenesis, and clinical management, dominates Australian research and public health.

In the background to her study, Faye (2000) reviews the biomedical literature on the hepatitis C virus regarding: hepatitis C transmission and populations at risk; hepatitis C symptoms and progression; management and treatment; and the hepatitis C epidemic. The construction of hepatitis C in these biomedical texts, though, is not detailed. Metaphors used by the medical and scientific communities, for example, are not identified. In her review of hepatitis C management, Faye hints at the clinical control over the illness but issues such as the social relations between doctors and patients implicit in texts, and power relations, are not explored.

Several papers have discussed public health communication between experts and those living with hepatitis C. In their article “Communication Ethics in Public Health”, Krug and Hepworth’s (1999) view of, and concerns regarding, discourse are congruent with those expressed by O’Sullivan, Hartley, Saunders, Montgomery and Fisk (1994, pp. 93–94):

[Discourse is] the product of social, historical and institutional formations, and meanings are produced by these institutional discourses. The theory of discourse proposes that individuality itself is the site, as it were, on which socially produced and historically established discourses are reproduced and regulated...Discourses are structured and interrelated; some are more prestigious, legitimated and hence ‘more obvious’ than others, while there are discourses that have an uphill struggle to win any recognition at all. Thus discourses are power relations.

Krug and Hepworth (1999) explore the (single) case of representatives of an IDU support group they observed at a medical and public health forum. The article derives from their personal observations, and they did not conduct interviews with those attending the forum. Krug and Hepworth reflect on the issues that the participation of this group at an international conference on hepatitis C raises for public health.

Drawing on discourse theory, symbolic interactionism, and ethnological theory, Krug and Hepworth (1999, p. 112) ask

Does their [IDU] appearance in this venue signify a contestation of discourses and so a set of emancipatory practices? Or does their appearance in this venue reveal the first steps of this group’s appropriation into mainstream practices and the resultant power and prestige?

Krug and Hepworth believe that various groups compete for the power to define hepatitis C in public health:

Having been ‘discovered’ by science, HCV [the hepatitis C virus] and the people it affects must subsequently be mapped, quantified, measured and people taught as well how to live within the definitions which scientific practices have created. The contest is, then, over who may claim authority within the discourse(s) of HCV to constitute, and so govern the identity both of the disease and of the people affected by HCV. (p. 104)

In his review of Australia’s public health response to HIV and hepatitis C, Hulse (1997, p. 174)—then Coordinator of Alcohol and Drug Education and Training in the Faculty of Medicine and Dentistry at the University of Western Australia—argues that “high-profile” medical and academics professionals took the accolade for the innovative initiatives and programs in health promotion and disease prevention to address the spread of HIV in Australia, at the expense of affected community groups and peer-based community workers.

In 1995, Krug stated that discourses about hepatitis C, including medical and scientific discourses, were not set. However, much of Krug’s work since—undertaken from a Foucauldian perspective of discourse—shows that the “formation of enunciative modalities” in the construction of knowledge of, and expression of ideas about, hepatitis C has come to approximate that of medicine in the nineteenth-century outlined by Foucault in *The Archaeology of Knowledge* (1972/2002, pp. 55-61). Further to this, the effects of resistance, or counter-power, are likely to be neutralised (Foucault, 1977, p. 219). In 1999, Krug and Hepworth observed that representatives of the aforementioned IDU support group imitate the forms and language of professionals. They found that the group was “indistinguishable from the professional groups in many aspects of the performance” (p. 112). In their estimation, this group was unlikely to change the professional discourses and probably likely to be ignored (pp. 112–114). Krug and Hepworth concluded that, in the absence of genuine dialogue, community groups stand to be controlled rather than empowered by participation in medical and public health forums (pp. 114–115). In their earlier work, Hepworth and Krug (1997) noted that knowledge arising from needs assessments that incorporates the experiences of those living with hepatitis C is made to fit within existing institutional and disciplinary structures: “Medical and scientific structures are seldom reformed to accommodate this knowledge” (p. 5). Alternatively, as Hulse (1997, p. 175) explains, governments may reject the expertise of those in the hepatitis C-affected community, preferring to seek out, and act upon, the advice of “mainstream sources”. Such mainstream advice may be based on unfounded assumptions about the injecting practices of IDUs, as Hulse

believes was the case with the treatment schedule for hepatitis C in the early 1990s (p. 175).

The examination of public health communication between experts and those living with hepatitis C is also concerned with the link between the linguistic elements of texts and social relations. Recently, Treloar and Fraser (2004) questioned the value of imagery found in health promotion materials about hepatitis C. Like Sontag (1988/2001) and Giblett (n.d.), Treloar and Fraser (2004) question representations of the human body that evoke military or war metaphors: “Health promotion messages relied heavily on fortress models of the body, that is, rigid definitions of bodily boundaries that define outside or foreign substances as hostile” (p. 377). Drawing on the work of Douglas (1994), Treloar and Fraser (2004) argue that the fortress model of the body, common to biomedicine, promulgates the stigmatisation of hepatitis C-positive individuals as blame for hepatitis C is attributed to the individuals, particularly IDUs, who do not contain their blood inside their bodies. They propose using the blood bank as a metaphor as it acknowledges that the body is not a fortress but is permeable, that exchange occurs as fluids move in and out, blood is shared as a common resource, and the operations of the blood bank represent both care of others and care of self (p. 386). This metaphor reflects the caring expressed by IDUs in interviews such as helping others inject and not exposing others to hepatitis C. However, the blood bank is considered an institution in Australian society, and cannot readily replace the fortress as a symbol of the body. The authors acknowledge that the model is fraught with problems not the least being the exclusion of groups from donating blood (p. 386). Although the blood bank is not intended to represent an “ideal of the body”(p. 386), when considered in this way it poses similar problems to the fortress model it is to replace. For example, the aseptic technique used to prevent contamination of donated blood by, and protect the donor from, microorganisms during donation reinforces “mental pictures” of inside/outside the body.

Whereas Treloar and Fraser (2004) offer a critique of the figurative language of health promotion materials, Southgate, Weatherall, Day and Dolan (2005) consider the different forms of knowledge in public health communication—expert knowledge and lay discourses. They examined the comprehension of expert information about hepatitis C infection and infectiousness among injecting drug users in Kings Cross in Sydney. IDUs’ knowledge of hepatitis C in this latter study is an amalgam of knowledge from clinical medicine and health promotion and their previous knowledge (including

common-sense knowledge and beliefs that they share with other IDUs). This may result in a divergence of meaning even when IDUs try to enter into the experts' way of seeing hepatitis C. IDUs seem to graft expert knowledge onto their existing beliefs, without always grasping the meaning of the former accurately. While the authors recommend further "examination of folk understandings of medical terms and clinical markers" (p. 6), and their research goes some way in explaining how IDUs participating in the study think, it is equally important to examine the communication of information by service providers to determine where teaching and learning processes go wrong.

Today, more is known about the hepatitis C virus and the progression of the disease, and advances have been made in its treatment. The *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b) articulates a national approach to hepatitis C in its own right (previously, it was under the auspices of the national HIV/AIDS strategy). Hepatitis C is considered a major public health problem that requires both individual and collective measures. The *Strategy* frames issues in a particular way, proposing action by the medical, scientific, and research communities and the affected community. The AHC, the peak body representing hepatitis C community groups, has also released a series of policy statements about hepatitis C. Formal ways of conceiving of, and speaking about, hepatitis C and those living with hepatitis C are now more established—creating a language that may be shared and/or reconstructed by those living with hepatitis C (Hepworth & Krug, 1999, p. 244)—and will be discussed in the chapters on public health policy discourse and news media discourse that follow.

Discourses and Images of Hepatitis C in the Australian News Media

The news media is recognised by Australian health professionals as one of the most common sources of medical and health-related information for patients (Newnham et al., 2005). The editors of the *MJA* emphasise greatly the role of media reporting of medical information to the public, describing media coverage as "an essential link between the providers and users of health care" (Van DerWeyden & Armstrong, 2005, p.188). The news media also provides a formal way in which "public institutional practices [are made] known to readers and viewers within the private sphere of family and home" (Danaher, Schirato & Webb, 2000, p. 42). Moreover, as Fairclough (1995, pp. 37–38) points out, the mass media "mediates"—transforms—communicative events

produced in the public sphere that are consumed in the private sphere. It will be argued that news media representations of hepatitis C both reproduce and construct biomedical discursive formations, which contribute to the way in which people affected by hepatitis C (and others) make sense of their world. The role that others outside the biomedical establishment play in shaping the discourse on hepatitis C is important. There is little discussion in the literature, though, about the reporting of hepatitis C in the Australian media, nor about the role of NGOs representing the affected community in reports, with the exception of Krug (1997) to which I return below.

The association of hepatitis C with “drug addicts” in the minds of the public and health professionals is recognised by researchers (Faye, 2000). In Faye’s study, awareness of hepatitis C in the general community was reported as either via the media or personal knowledge of someone with hepatitis C. Regarding participants’ responses to media portrayals of hepatitis C, Faye concludes:

The manner in which it was reported was not beneficially informative...such HCV coverage was considered to be significantly harmful emotionally, particularly if it was an HCV-positive person’s only source of HCV information. (p. 210)

Although participants in Faye’s study blame the media for “penalisation” of people who have hepatitis C, Faye does not directly gather data from the news media and analyse the coverage of hepatitis C to confirm participants’ perceptions. She does not examine the discourse of hepatitis C in media stories. An examination of the meanings that arise from such conceptualisations, absent from Faye’s research, is undertaken in this study through a survey of primary news sources for the period 1996 to 2003.

Few studies of media reporting on hepatitis C in Australia have been undertaken. Krug (1995, p. 310; 1997, p. 92) postulated that hepatitis C would become a signifier of disease or contagion as “our world is characterised, it would seem, by the necessity of policing personal boundaries with the markers of disease, filth, and social undesirability” (p. 310). Krug posited that the media would draw signifiers of hepatitis C from diseases, such as HIV/AIDS, and portrayals of “otherness”, such as drug users. The imagery around AIDS, in turn, comes from illnesses such as syphilis and cancer (Sontag, 1988/2001). However, Krug (1995, p. 309) concluded:

Although intravenous drug use is currently the major vector of transmission for hepatitis C, this has not come to dominate the representations of HCV, either in the print media or in television

coverage in Australia. In the public domain, there is no construction of the “HCV carrier” or the “HCV sufferer”.

A couple of years later, Krug (1997) explored the negotiation of self-identity in the face of hepatitis C, an infectious disease that appears as a marker of the boundaries of social order as an intertextual experience. In what is far from an exhaustive examination—which is not easily compared to other studies as it lacks a detailed methodological summary—Krug looked at discursive strategies in a selection of Australian television news reports, current affairs shows, and newspaper articles broadcast or published between 1994 and 1995. In keeping with his Foucauldian perspective, Krug (p. 95) found that media coverage of hepatitis C, constructs a series of speaking positions that represent discourses of the disease: firstly, an expert; secondly, the journalist; and thirdly, the thing affected by hepatitis C (a person, an institution). The disease, says Krug, is never produced. This journalistic construction “establishes the dominance of specific voices and perspectives, as well as the exclusion of others” (p. 95). People’s lived experiences are mainly told from the point of view of experts (p. 95). The individual “suffering” from hepatitis C speaks only as a preamble to expert discourses about the disease (pp. 98–103). The focus is on the “burden” hepatitis C places on the health care system, the routes of transmission, and moralising about injecting drug use (pp. 97 & 100).

This study examines the news media coverage of hepatitis C in three major Australian news services for a period of eight years: the four years prior to the launch of the first national hepatitis C strategy in 2000, and the initial four years of this public health strategy. Data analysis incorporates quantitative content analysis with qualitative critical discourse analysis to extend Krug’s (1997) work on the construction of speaking positions, and to consider the attribution of agency and causality, in news stories. A major concern of this study is the impact that hepatitis C NGOs—nominated as one of the partners in the development and implementation of the first national hepatitis C strategy—have on the discursive practices of news media producers.

Conclusion

The public health response to hepatitis C in Australia has been based on medical and scientific models of disease. The biographical, the personal and storied knowledge of hepatitis C takes a back seat. The literature reviewed here demonstrates the powerful

link between language used to represent hepatitis C and social life—particularly, social relationships between affected individuals and health care professionals, and the practices of health care professionals. It also highlights the link between perceptions of the way in which hepatitis C is spoken about (for example, in the media and by health care professionals) and the emotional life of affected individuals.

In their examination of various texts and performances in professional conferences, Krug (1995, 1997), Krug and Hepworth (1999) and Hepworth and Krug (1997; 1999) demonstrate the power struggle in the social relationships between the hepatitis C-affected community and the professional community developing in the mid to late-1990s. Their work suggests that despite the participation of groups representing the hepatitis C-affected community in “power forums” (Candlin, 1989, p. ix), and their usage of the language and forms of professional discourses, that community groups are controlled by public health rather than empowered.

Other researchers, (including Crockett & Gifford, 2004; Faye, 2000; Faye & Irurita, 2003; Gifford & O’Brien, 2001; and Temple-Smith, Gifford & Stoové, 2004), focus on the micro level of social exchanges, reporting on the stigmatising and discriminatory practices experienced by individuals living with hepatitis C, particularly those evident in the social interactions between hepatitis C-positive patients and healthcare professionals in medical encounters around the time of diagnosis.

The propensity for inequalities in communication, and the construction of texts that place hepatitis C-positive persons at social risk (Candlin, 1989, p. ix), lead me to examine the way in which public health policy-makers and journalists in Australia communicate about hepatitis C. My focus is on how the institutions of public health and the media define, through language, hepatitis C and those living with hepatitis C (constructing a role for affected individuals and the affected community). I also searched for the voices of individuals living with hepatitis C in these forums to discuss topics of public concern.

The analytic focus of this study is on the privileged perspectives and framing evident in public health policy and media discourses. I explore the practices associated with the institutions of public health and media around hepatitis C and hepatitis C-positive persons, the “objects” of knowledge (Foucault, 1969/2002, p. 81), and the subject and social positions available to people living with hepatitis C and spokespersons of NGOs representing the hepatitis C-affected community.

This thesis is broken down into four major parts Part I—Chapters One and Two—comprise the introduction and research process. Part II—Chapters Three through to Seven—comprises findings related to Australian public health policy discourse about hepatitis C. Part III, made up of Chapters Eight and Nine, presents findings related to news media discourse about hepatitis C. Concluding this study, Part IV presents a reply to the dominant narrative in public health policy and news media discourses about the hepatitis C epidemic.

Chapter One introduces Australia's hepatitis C epidemic, the public health response to the epidemic, and the origins of my interest in this area. A review of the literature, published between 1990 and 2002, frames the research question. Chapter Two provides an overview of the research approach and outlines the research process (principally Fairclough's framework for critical discourse analysis), undertaken to examine the construction(s) of hepatitis C by public health and news media institutions, and by people living with chronic hepatitis C.

Chapter Three, the first chapter on the inaugural national hepatitis C strategy, is titled "Health Policy Discourse on Hepatitis C: The Minister Speaks". This chapter analyses the then Minister for Health and Aged Care's foreword to the strategic policy document. It sets the stage for representations of the hepatitis C epidemic at the time of publication and in the future. It introduces the strategic approach based upon partnership envisaged by the Minister for managing the epidemic and the affected community, and relations between all levels of government, public health institutions, the non-government sector and the scientific, medical and research communities.

Chapters Four to Seven move on to the *Strategy* itself. Belying the non-hierarchical notion of partnership, these chapters depict the social hierarchy operating in the social relations between organisations (including public health, local and state/territory governments, scientific, medical and research communities, and hepatitis C NGOs), and individuals (including the uninfected and persons living with hepatitis C including hepatitis C-positive injecting drug users). This thesis questions whether the inclusion of representatives of the hepatitis C-affected community amongst stakeholders in the development and implementation of hepatitis C public health policy has greatly altered the dominance of the expert voice, particularly that of the medical and scientific communities.

Chapters Eight and Nine, forming the second part of the thesis, explore news coverage in Australia about hepatitis C. Producers of news media have an important role in shaping values and belief systems in the Australian community about hepatitis C by determining how to represent hepatitis C and people living with hepatitis C (and their relationship to others in the community including the audience). The production of news stories entails selection (what is included and what is excluded or absent) and framing. If hepatitis C NGOs are to control the representations of the virus and people living with hepatitis C, then it is important that they function as media sources. More important, though, is the control they effect on the perspective of news coverage of hepatitis C.

Chapter Eight, provides an overview of major news topics in, and the tone of, reporting on hepatitis C by the ABC, *The Australian* newspaper and the *Herald Sun* newspaper. A case study of a *Herald Sun* news story from the first ranked category “National Blood Supply” illustrates many of the attributes of reporting (such as the use of pejorative headlines and the attribution of agency and causality), that are repeated in other stories. It also shows the usefulness of the descriptive stage of Fairclough’s analytic framework to those responding to media coverage of hepatitis C.

In Chapter Nine, the emphasis is on the categories of news actors selected as sources in news coverage of hepatitis C, and the construction of social relations between actors that affects the balance of perspectives. Close examination of a story televised on the ABC’s *7.30 Report* bears out the unequal influence of the medical perspective in coverage of health matters, and demonstrates the hierarchical social relations in the construction of social relations between news actors drawn from the categories of “medical experts”, “hepatitis C-related support/consumer groups”, and “infected (hepatitis C sufferers) and affected individuals”. As in public health policy texts, the way that hepatitis C is spoken about, the subject positions that news actors from these three categories occupy and the audience, and the conventions used in the construction of this current affairs, perpetuate the dominance of the medical perspective and maintains traditional social relations in the partnership between medical professionals and their patients.

Chapter Ten presents the conclusions of this study. The main areas, and issues therein, for further research identified in the course of this study are outlined. In closing, implications of this study are identified, and recommendations made for hepatitis C NGOs involved in the development and critique of public health policy and news media discourse.

CHAPTER TWO

RESEARCH APPROACH

Texts are social spaces in which two fundamental social processes simultaneously occur: Cognition and representation of the world, and social interaction.

– Norman Fairclough, 1995a, p. 6

Introduction

This chapter outlines the methods of data collection, data analysis, and interpretation used in this study. The primary approach employed in qualitative data analysis was critical discourse analysis. Taking a critical stance towards myself as researcher, I also outline the position that I speak from when making sense of texts, aware that my interpretation of the data may be skewed by my experiences, assumptions, and knowledge. However, as Strauss and Corbin (1990, pp. 41–47) explain, the researcher’s own professional and personal experience and knowledge of the literature about an issue are sources of “theoretical sensitivity” that enable the researcher to see clearly and intuitively into the nature of, what may be for outsiders, a complex situation.

My research approach draws upon the “critical” perspective taken by Norman Fairclough (1989, pp. 1–5; 2003, p. 15) to social theory as my professional experiences as senior project officer of the non-government organisation (NGO) the Hepatitis Council of WA (Western Australia) (the HCWA), between June 1997 and February 2003 sensitised me to issues over which hepatitis C community groups in Australia have taken, and continue to take, action to “chang[e] the concrete conditions” (Kellner, n.d., Materialism and Dialectics, para.10) of people living with hepatitis C.

In an overview of the history of the HCWA, the inaugural chairperson notes the dearth of information about hepatitis C in the early 1990s, both among persons infected with the hepatitis C virus and medical professionals. She highlights the inertia that was perceived by those infected with the virus as characterising the response of authorities to the virus prevalent in injecting drug users: “[I was] angry at the government for what I saw as a conspiracy of silence about hepatitis C in the interests, I presumed, of saving money on testing and treatment” (Marsh, 2001, p. 1). The former federal Labor Minister for Health and Minister for Community Services and Health from 1983 to 1990 (National Archives, 2002), Dr Neal Blewett, attributes the lack of action in relation to hepatitis C at the national level, during the 1980s and early 1990s, to the legal position of IDUs: “Their activities were criminally proscribed in all States” (Blewett, 1997, p. 177).

Despite feeling angry, those who established the HCWA worked cooperatively with authorities to obtain funding, including infrastructure, “jump[ing] at the offer of our first premises from Next Step (formerly the Alcohol and Drug Authority)” (Marsh, 2001, p. 1). The HCWA’s community action focused at the outset on self help—with services initially run out of members’ lounge-rooms—while remaining critical of the failure of public authorities to provide services. The HCWA, like its counterparts in other states and territories throughout Australia, expanded its activities to include ongoing participation in the public health system in a bid to improve hepatitis C-related services. Similarly, in its “brief history”, the Hepatitis C Council of NSW (New South Wales) (2004, pp. 1–2) lists its participation as representative of the hepatitis C-affected community on various state and national committees and consultation groups.

From their inception, too, personnel of hepatitis C support groups have tried to establish a media profile: “The first meeting of the group [HCWA] was held at the Health Department in mid-1992. I sent out press releases to the media inviting interested people to a public meeting” (Marsh, 2001, p. 1). Using the mass media, in particular, the national news media, has been a long sought-after component of communicating information to the community. In March 2000 the Hepatitis C Council of NSW launched the “world’s first mass media hepatitis C public awareness campaign” (Hepatitis C Council of NSW, 2004, p. 2). Since that time each state and territory hepatitis C council has run a “Hepatitis C Awareness Week”—usually an annual event—that attracts patchy media coverage. The Hepatitis C Council of Victoria (2002b, p. 1) sums up the situation:

Media coverage of the Week was much improved compared to previous years, with good articles in suburban papers and on radio Triple J and 3CR but the mainstream dailies and TV/radio channels remained elusive.

In 2001, the Australian Hepatitis Council (AHC) published the first edition of *The Australian Media Guide to Hepatitis C*. However, it was not until May 2005 that the first national media campaign was undertaken by the AHC and state and territory hepatitis C councils during “National Hepatitis C Treatment Awareness Week” (Paterson, 2005a, pp. 23–24).

The awareness I developed of issues surrounding community action by the hepatitis C-affected community stem from the readings and in-service training about community groups that I undertook during my first months of work at the Council in 1997. From reading the *Community Groups Handbook* (Pearse & Smith, 1990, pp. 66–68), for example, I was aware that authorities might hold power over community groups through the control of resources, timetables, expert knowledge, and information. Often the authorities define the problem, communicating in language familiar to bureaucrats but not necessarily to community representatives. Therefore, I presuppose that relations of power exist between the stakeholders in the espoused “partnership between people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals” (Wooldridge, 2000a, iii), and that power relations are evident in texts such as public health policy documents.

My concerns relate to my research focus of examining features of the strategic communication practices of public health organisations that have developed in response to the “hepatitis C epidemic”, particularly regarding the way(s) in which people living with hepatitis C, and NGOs representing people living with hepatitis C, are represented. Media constructions of meanings around hepatitis C and people with hepatitis C are also of interest, as are the practices of both media producers and spokespersons representing the hepatitis C-affected community in the construction of stories. Whether narratives in media coverage of hepatitis C—with respect to both story and narrative presentation (Fairclough, 1995b, pp. 91–92)—are congruent or at odds with the ways in which people living with hepatitis C make sense of their experiences is also a consideration.

Research Questions

The focus in this study is to describe, analyse, and explain how hepatitis C and those living with hepatitis C are represented in Australian public health policy and news media texts. The following research questions frame the analysis:

- How are hepatitis C and people living with hepatitis C represented and constructed in Australian public health policy and the Australian news media?
- What is the dominant narrative in texts?
- What message(s) about hepatitis C are communicated in texts?
- Whose interests are involved in constructing these messages?
- What normative ideas about hepatitis C are expressed?

Assumptions of the Study

A number of assumptions about texts influenced my approach to this research. In a critique of research from the early 1980s in the fields of applied linguistics, discourse analysis, cognitive psychology, and educational psychology, Grabe (2000) convincingly argues that both linguistic and information structuring in expository texts, in particular, guides the textual interpretations generated by the reader:

While a reader certainly brings individual sets of background knowledge and intertextual networks to text comprehension, there are nonetheless well-recognised conventions and systems that lead a reader to preferred interpretations. (p. 65)

The form of a text is, therefore, as important an aspect of analysis as is the content (Fairclough, 1995a, p. 188). I assume that the reading and interpretation of a text by each member of the audience (that is, the reader/viewer/listener) is a negotiated process that depends in part on what individuals bring to that reading such as their own knowledge (including knowledge of the rules of a language), beliefs, attitudes and prior experiences, that is, what Fairclough (1989, pp. 11 & 24) terms “members’ resources”. As Faye’s (2000, p. 210) grounded theory study of hepatitis C indicates, media coverage of hepatitis C is, for some members of the public, a primary source of information and

ideas—replete with the values and attitudes of the respective producer(s)—in the resources they bring to their reading of texts.

While reading a text is an interpretative process on the part of the reader, the media producers of that text cue and limit interpretations (Fairclough, 1989, pp. 24–25; 1995b, p. 16). My experiences underpin the assumption of this study that the structuring of a text contributes to the “preferred reading” of that text (Fairclough, 1995b, p. 122). As the producer of community education resources and editor of the newsletter for the HCWA, for instance, I worded social practices such as injecting drug use from a harm reduction perspective in keeping with the aims of the organisation. The utilitarian form of a number of the texts produced by the HCWA reflects the notion of self-help that characterised the setting up of the HCWA. Earlier ethnographic research that I conducted (Pugh, 1993, p. 55) also made me aware that texts reflect the researcher’s (that is, the producer’s) interpretation of the major dimensions of any social situation (Spradley, 1980) that they study. Similarly, the producer(s) of hepatitis C-related news texts and public health policy texts are considered as making choices when representing the hepatitis C epidemic and events (including the sequencing of events over time). They make choices when representing people affected by hepatitis C and other members of the “partnership” spoken of in the first national hepatitis C strategy (that is, medical, scientific, research and health care professionals and governments at all levels). Representations of the relationships between members of the partnership, what actors are trying to accomplish, and the activities carried out, also involve choices on the part of the text’s producer(s). In representing events, situations, relationships, and people, texts

constitute versions of reality in ways which depend on the social positions and interests and objectives of those who produce them. They do so through choices which are made at various levels in the process of producing texts. The analysis of the representational processes of a text, therefore, comes down to an account of what is made explicit or left implicit, what is foregrounded and what is backgrounded, what is thematised and what is unthematized, what process types and categories are drawn upon to represent events and so on. (Fairclough, 1995b, pp. 103-4)

In this light, the analysis in this study includes consideration of how the producer(s) of hepatitis C-related news and public health policy texts represent agency and responsibility (Fairclough, 1995b, p. 109). Hence one of the questions I asked about

texts was: Does the producer(s) represent the hepatitis C epidemic in Australia as an action with causal actor(s), or as an event without a causal actor(s)?

In this study, “representation” is used in two senses. It is used in relation to those who act or speak on behalf of others in an official way. In this respect it includes staff of hepatitis C-related NGOs and lay people who act or speak on behalf of the hepatitis C-affected community. News media texts, for example, commonly claim to represent the perspective of the “hepatitis C sufferer” by making use of a NGO spokesperson to speak for and about people living with hepatitis C and/or a hepatitis C-positive patient who speaks from personal experience. In this study, too, the federal Minister for Health acts and speaks on behalf of the Commonwealth Government and the Australian community. However, the greater part of this study is concerned with the way in which hepatitis C and people living with hepatitis C are spoken about in public health policy and news media texts. In this regard, the term “representation” refers to the depictions, descriptions or accounts, that is, re-presentations, created by the producer(s) texts when speaking about the hepatitis C virus, the hepatitis C epidemic, and those infected with or affected by hepatitis C. The choice of community representatives (that is, who is chosen to speak for people living with hepatitis C and who is *not* chosen), and the way in which their contribution is handled, is an important aspect of representation particularly with respect to the construction of identities.

Data Collection

Data was collected primarily from documents. In addition to the primary sources of data (outlined below), data was gathered from a range of documents that imparted further information on, and added to my understanding of, the subject. Data was also collected from a small number of interviews. In some instances, data—such as published speeches, conference presentations and articles in industry newsletters—was collected to validate my analysis and interpretation of primary texts. Data collection and analysis, particularly that of public health policy documents, was undertaken in tandem, with the analysis guiding subsequent data collection where appropriate (Woods, 1986, p. 120). The literature was also searched as analysis progressed to see what had been written about issues that emerged.

Data Collection: Public Health Policy

The *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b) was chosen as the specific public health policy text for study for two reasons. Firstly, the *Strategy* is the inaugural national population health strategy developed in response to the hepatitis C epidemic in Australia. Secondly, it represents the official discourse about hepatitis C in Australia, developed from a review of Australia's response to the hepatitis C epidemic commissioned by the Commonwealth Department of Health and Aged Care (Lowe & Cotton, 1999, p. 3), and incorporating consultation with "people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals" (Wooldridge, 2000a, p. iii). Hepatitis C-related NGOs received a hard copy of the document. The document is in the public domain; the full publication can be downloaded via the publications link on the homepage of the Department's website, which links to the Population Health Division of the Department. Provision is also made to provide an alternative format or a copy for persons who have difficulty downloading the document. Thirdly, as the first hepatitis C strategy, the text is a crucial link in the chain of "communicative events" about hepatitis C. It is expected that the *Strategy* will, in turn, be "transformed" and "embedded" (Fairclough, 1995b, p. 77) in subsequent public hepatitis C policy documents. At the commencement of this study, the second strategy, the *National Hepatitis C Strategy 2005 – 2008* (Commonwealth of Australia, 2005), had not been published, and the consultation draft of this second strategy was released in August 2004.

Data Collection: News Sources

Media representations of hepatitis C were sought in three main sources, the Australian Broadcasting Corporation (ABC) news sources, *The Australian* newspaper (including *The Weekend Australian*) and the *Herald Sun* (including its Sunday edition). The starting point for this search of the media is 1996, the end point of Krug's (1997) study of the media and hepatitis C. The hepatitis C virus was identified in 1989. This search of the media was completed on 31 December 2003.

The Australian, a broadsheet newspaper owned by News Limited, is Australia's main national newspaper with a weekday circulation of 133,000 and growing according to figures from the Audit Bureau of Circulations (Schulze, 2003, p. 20). Its broad stance is described as centre-right (Jackson & Doman, 2003, p. 5). Although *The Australian*

has its head office in Sydney, it operates permanent bureau in each state and territory capital (News Limited, n.d.).

Amongst the tabloid newspapers, Melbourne's *Herald Sun* prides itself on being "Australia's largest-selling daily" ("The Herald & Weekly Times Ltd", 2003). It has an average daily circulation of 557,000, effectively reaching 1.5 million readers, with similar figures for its Saturday and Sunday editions ("The Herald & Weekly Times Ltd", 2003; Simper & Doman, 2003, p. 5). Herald and Weekly Times (HWT), a division of News Limited, produce the *Herald Sun*. The broad stance of the newspaper is described as middle-ground conservative but representing "the battler" (Jackson & Doman, 2003, p. 5). Its editor-in-chief, Peter Blunden, says that the *Herald Sun* "appeals as much to the so-called top-end, intellectual sections of the community as it does to suburbia. Morning talkback radio programs in this town are based, almost entirely, on what's in our newspaper" (Simper & Doman, 2003, p. 5). Journalism professor and former journalist John Henningham reiterates the view that newspapers are providers of news and current affairs for radio and television (Simper & Doman, 2003, p. 4).

The ABC is Australia's national public broadcaster. ABC television has 16.6% of the prime-time audience share of free-to-air television (Jackson, 2003). Under the Australian Broadcasting Corporation Act 1983, the ABC is required to provide an independent news service. The news and current affairs divisions and other information programs are charged with providing accurate information, and balance and impartiality in stories (ABC, 2003a). The Act also stipulates editorial independence of ABC services. Publisher and editor-in-chief of the *Sydney Morning Herald*, Alan Revell, declares that the ABC is unique amongst broadcasters with regards to the credibility of its television and radio news services; it is considered a quality news service (Simper & Doman, 2003, p. 5). The ABC news and information services are intended to provide balance to this study as both the major daily national news publication and the nation's leading tabloid are owned and published by News Limited.

A search of the ABC's online search facility for "Hepatitis C" for the period 1996 to December 2003 elicited 53 stories explicitly related to hepatitis C or indirectly related to hepatitis C (as in stories about the rise in liver cancer in Australia). These 53 stories were published over the period January 1999 to December 2003. Online articles and transcripts and/or audiovisual recordings of radio and television broadcasts were obtained from a range of ABC news and information services. ABC radio broadcasts

have become more readily accessible to researchers via the Internet in the form of online transcripts of programs. With the appropriate media player program installed on a computer, and a sound card, it is possible to listen to ABC radio programs that are broadcast over the Internet using streaming audio technology. Some programs are also available online as files for downloading. This allowed a more detailed examination of the ABC coverage about hepatitis C.

An online search of the Newtext archives of *The Australian* for stories containing “Hepatitis C” for the period January 1996 to December 2003 was also performed. Fifty-three relevant news stories were retrieved from *The Australian* and *The Weekend Australian*. Articles pertaining to the AFL blood rule were excluded. An online search of the Newtext archives of the *Herald Sun* and its Sunday edition for *hepatitis C* for the same period elicited 98 news stories.

Data Collection: Interviews

Following ethics approval from the Human Research Ethics Committee of Edith Cowan University, a small number of interviews of persons living with chronic hepatitis C were collected. I started by contacting the Committees of Management of the HCWA and the Western Australian Substance Users’ Association (WASUA)—both community-based groups—about the recruitment of participants for interview. Formal letters to the committees detailed my proposed research, my background, and addressed possible ethical issues of concern (see Appendix A). I was available to speak to the committees, to give an overview of my research and answer any questions, but was not asked to do so. I placed a request for expressions of interest in *the C files* and *Yooz*, the newsletters of each organisation respectively (see Appendix B), and interested persons contacted me directly.

To participate in this study, persons had to be living with chronic hepatitis C and willing to share their stories. The participants I sought, therefore, were purposive informants. They also had to be what Morse (1989, p. 121) calls “good” informants: “Knowledgeable about the topic and experts by virtue of involvement in specific life events”. As living with hepatitis C tends to be overshadowed by more immediate drug-used related problems in persons who currently inject drugs (Faye, 2000, p. 154), I recruited persons with chronic hepatitis C, from amongst members of the HCWA and clients of the WASUA, who either were not injecting drugs at the time of the study or who had never injected drugs. Reflecting the membership of the HCWA identified in an

evaluation of its members' newsletter (Pugh, 2001), informants were Australian of Anglo-Celtic background.

Seeking "information-rich" cases, the number of participants was not set. I anticipated a small sample of less than ten, as 24 in-depth interviews formed the main body of data in Faye's (2000) grounded theory study. Sampling was to stop when redundancy in information was reached and/or available time and resources were exhausted. As the time-consuming analysis of news and public health policy texts progressed, I soon became aware that my initial plan was not feasible, and limited interviews to four persons living with hepatitis C. However, I continued to collect commentary on issues of concern to people living with hepatitis C in the publications of NGOs representing the hepatitis C-affected community.

Interviews were conducted with three females and one male aged 43 to 50 years. Two of the females were professionals, one an academic. The third female interviewed was a massage therapist—her partner and one of her sons were also hepatitis C positive—and completed antiviral treatment a month prior to the interview. The male, who had returned to working as a supervisor in a mine after a period as a natural therapist and massage therapist, completed antiviral treatment two years prior to the interview.

Interviews were conducted at a mutually agreed time and place. Two informants invited me to interview them in their homes, one in the morning and the other in the evening after she had finished work. Another preferred to be interviewed at the HCWA's premises during business hours, and another by telephone as she lived outside the metropolitan area. All interviews were tape-recorded. I offered to make a copy of transcriptions available for those informants who wanted it but all declined the offer.

Informed consent was obtained from participants in this study (see Appendix C: Disclosure Statement and Appendix D: Consent Form). Informants were told the purposes of the study, and their permission was sought to tape-record interviews. Hepatitis C is considered a "disability" under the Disability Discrimination Act 1992 and I was aware that persons with hepatitis C could experience discrimination arising from their hepatitis C-positive status. I thus took care to ensure that no identifying information appears on data or documents. The anonymity of informants was protected by the use of pseudonyms on paper documents, electronic records, and audiotapes. Participation in this research was voluntary and informants could withdraw their consent to participate at any stage. Data was kept secure, and protected from loss,

unauthorised access, modification, and misuse. Computers used throughout this study were password protected. In accordance with the Edith Cowan University's records retention and disposal schedule, data relating to this research will be retained for five years from the date of submission and then hard copies will be shredded and electronic copies erased.

Formal, unstructured interviews were conducted. So as not to fracture the narrative accounts that an informant would naturally tell if not interrupted, my starting point was to ask the informant to describe or tell me about his/her life with hepatitis C, "What it is like living with hep C?" One informant asked me if I wanted to know how she got it [the hepatitis C virus] to which I replied, "If you were going to tell someone about having hep C what would you tell them?" (Cathy, interview, April 24, 2003, line 3). From this point on she spoke about issues and experiences of importance to her. I made every effort to pay attention to the language that an informant used to index his/her world, to listen to words with interest and to ask myself, "Why is he/she using that word?" Verbal probes were used to encourage informants to elaborate or explain. Where unsure, I asked informants: "What do you mean when you say...?" (Riessman, 1993, p. 32).

Data Analysis

As I worked as the senior project officer for the HCWA for the first two years of this study, I monitored and reflected upon the effect that my own background (including my nursing background) and knowledge of hepatitis C had on this research. I was aware that to some extent I was an "insider". As such I had preconceptions and a personal bias, and so had to work at viewing the "familiar" as though alien. This was aided by employing distinct procedures for analysing the data, and by regularly discussing my analyses and interpretations of texts with my supervisor and/or associate supervisor. I also presented findings to academic staff and postgraduate students in forums such as the Media and Culture Society Research Group at Edith Cowan University. Where analysis procedures facilitated the breaking down of the data, memos that I regularly wrote about the analysis, my thesis writing (which was undertaken concurrently with analysis and drew upon progressive memos), and discussing analyses with academic staff and postgraduate research students greatly assisted my ongoing reading of the literature, conceptualisation, and the construction of the thesis of this study. The following data analysis procedures were undertaken: quantitative content analysis of

news texts; critical discourse analysis of public health policy and news texts; and narrative analysis of interviews. An outline of each of these follows.

Quantitative Content Analysis of News Stories About Hepatitis C

This study combines quantitative content analysis, in order to systematically gain an overview of a relatively large number of news texts about hepatitis C, with qualitative discourse analysis to obtain insight into both the form and content of news and public health policy texts. The critical discourse analysis undertaken goes beyond a count of participants and categories of participants in texts to consider “how participant identities and relations are constructed” in texts (Fairclough, 1995b, p. 39).

The term “text” is used in its broad sense to refer to written texts, such as newspaper articles and policy documents, as well as spoken and/or visual texts (including aural elements), such as television and radio news broadcasts and speeches (and transcriptions of these) (Fairclough, 1995b, p. 17; 2003, p. 3; Parker, 1992, p. 7). Language—in its widest sense—is considered in the analysis, including the visual images of texts such as television broadcasts, and the visual design features of written texts (Fairclough, 1995b, pp. 17 & 33; 2003, p. 3).

Analysis of data collected from the three news sources, *The Australian*, the *Herald Sun* and ABC news services reflects a blending of methods. A quantitative content analysis in the manner of Lupton and McLean (1998) was undertaken to identify the major topic categories around hepatitis C and the major actors in news stories. This was augmented by a closer analysis of the discourse focusing on the way in which representations of hepatitis C and of people with hepatitis C are achieved linguistically in particular texts.

Initially a record was made of each news item including the date, source (print, radio, television, online news service), and the type of item (interview, news item, feature/main/top story, opinion, editorial). The major news sources and/or actors were identified, grouped into categories and frequencies calculated for each news item. Thus the key actors selected as informants, and the types of actors, in coverage of hepatitis C were identified. The headlines and lead paragraphs of each news story transcript were then open coded to identify the major topic categories. If an ABC show’s host introduced the story (a lead-in), then this lead-in, along with the reporter’s introductory paragraph, was coded. The headline sums up the story in one line. In print news, the first or lead paragraph “hooks” the reader. The lead paragraph contains the essence of

the story and states the significance of a news event, that is, the “what” and “who” of a story (Fairclough, 1989, p. 137; Whitaker, Ramsey & Smith, 2000, pp. 141 & 143; White, 1996, p. 186). The shorter lead-in to broadcast news gives the most important fact in a story and gains the listener’s or viewer’s attention (Whitaker, Ramsey & Smith, 2000, pp. 217 & 219). It was expected that the leads in both print and broadcast news would contain key words (Whitaker, Ramsey & Smith, 2000; White, 1996).

Major topic categories were recorded for each news item in a memo created in QSR N6 (enabling me to readily locate data). Up to five topic categories were recorded for each news item. Labels were assigned to phenomena, including codes drawn from the news story itself. Some categories concur with the library headings of *The Australian* and the *Herald Sun* newspapers. Incidents that pertained to the same phenomenon were coded under one conceptual label. The frequencies of topic categories were calculated. To check the internal consistency of coding, the researcher re-coded a selection of data at intervals throughout the study. Intra-coder agreement was above 95%. A selection of news items coded for major topic categories by a second person not associated with this research found that there was agreement on codes for the same block of data. This double coding, both intra- and intercoding, provided a reliability check of codes (Miles & Huberman, 1984, pp. 60 & 63). Critical discourse analysis of sample news items was then undertaken to reveal how representations of hepatitis C and of people living with hepatitis C are constructed, including the construction of social relations between news actors and the subject positions set up for them and the audience.

Critical Discourse Analysis of Public Health Policy and News Texts

Various definitions of “discourse” and approaches to “discourse analysis” exist. This section presents and discusses the approach to discourse analysis taken in this study. First, the term “discourse” is defined followed by the critical approach taken to discourse analysis of public health policy and news media texts.

The term “discourse” concerns both language usage and social relations. As Parker (1992, p. 4) outlines, discourse is concerned with the “system of statements” that formally creates, describes, and categorises an object, such as hepatitis C and hepatitis C-positive persons, at a particular moment, or period, in time. Discourse is “realised in texts” (p. 6). Saunders (1993) offers the following straightforward and useful definition of discourse:

A discourse is the ‘language’ of an institution [or an institutional practice such as medicine] not only with regard to what is said, but what kinds of things are (normally) sayable, and with regard to the way the ‘sayable’, and the knowledge and power that attaches to it, is unevenly distributed among the speaking positions [or subject positions] that constitute it. (p. 26)

Importantly, discourses support institutions, producing, (and often reproducing), power relations (Parker, 1992, p. 17). However, discourses are not absolute, and competing discourses may effect change (Saunders, 1993, p. 31).

According to Fairclough (1995b), the first way in which “discourse” is commonly used is associated with language studies, which sees discourse as social action and interaction between people in social situations. The second common usage of the term, which refers to “a social construction of reality, a form of knowledge” (p. 18), is associated with post-structuralist social theory. Fairclough incorporates both aspects in his usage of the term:

The first sense is most closely associated with the interpersonal function of language, and with the concept of genre...The second sense is most closely associated with the ideational function of language, and with discourses—notice that in addition to being used as an abstract noun for this general view of language in social use, discourse is used as a count noun (*a discourse, several discourses*) as a category (alongside ‘genre’) within the intertextual analysis of texts. (Fairclough, 1995b, pp. 18–19)

“Discourse” is used as a count noun when analysing representations in a text, that is, the “discourses” used therein: “A discourse as a type of language associated with a particular representation, from a specific point of view, of some social practice” (p. 41).

In keeping with critical social theory, Fairclough’s (1995b, p. 55) schema is based on the premise that language use is “socially shaped and socially constitutive”. Language use is constitutive when it either contributes to maintenance of the status quo or when it transforms social identities, social relations, and systems of knowledge and belief (p. 55). Accordingly, the public health policy and news texts analysed in this study, are considered as partly constituting: “social identities” such as people affected by hepatitis C; “social relations” between those in the partnership specified in the *Strategy*; and systems of knowledge and beliefs about aspects of the natural and social world, such as the hepatitis C virus, the hepatitis C epidemic and those directly affected by hepatitis C, as evidenced in representations in the respective texts.

In his framework for critical discourse analysis, Fairclough (1995b, p. 54) also follows the tradition of critical social theory in seeking to elicit the connections between language usage and the exercise of power, including forms of social control that lessen or transform opposition (Kellner, n.d.). Accordingly, common-sense assumptions about “rights, relationships, knowledge and identities” (Fairclough, 1995b, p. 54) come into play in communication events such as a consultation between a doctor and a patient, or a news media interview of a person living with hepatitis C, or that with a hepatitis C medical specialist. Power relations underlie, and are sustained by, the way in which such practices are organised and conducted:

Power is conceptualised both in terms of asymmetries between participants in discourse events, and in terms of unequal capacity to control how texts are produced, distributed and consumed (and hence the shapes of texts) in particular sociocultural contexts. (Fairclough, 1995a, pp. 1–2)

Relations of power in society are evident in the producer(s) construction of identity and social relations in texts (Fairclough, 1995b, p. 127). To this end, analysis of the linguistic features of media texts takes in modality and “interactional control features” such as “turn-taking”, the sequencing of interviews, and the control of topics (p. 128).

Fairclough’s framework is suited to analysis of media texts (press, radio, television, and online) and governmental policy documents (and related texts such as speeches and media releases) that considers the relationship between the text, the producer and the audience or consumer of texts. As Fairclough (2003, p. 124) notes

discourses constitute part of the resources which people deploy in relating to one another—keeping separate from one another, cooperating, competing, dominating—and in seeking to change the ways in which they relate to one another.

The detailed linguistic analysis of single texts, or a small number of texts, provides substantial data for those who are asked, as I was as senior project officer at the HCWA, to contribute to submissions and to comment on draft government policies in the consultation phase of policy development.

Halliday’s (1978) view (cited in Fairclough, 1995a, p. 6; 2003, pp. 26–28) that texts function ideationally, interpersonally and textually is incorporated into Fairclough’s framework for critical discourse analysis (1989; 1995b; 2001; 2003). As such analysis in this framework attends to both the linguistic and the discoursal features

of a text. In so doing, issues of genre, intertextuality, and identity are considered (Fairclough, 1995b, p. 2). It is assumed that a text contains traces of the producer's experiential, relational and expressive values, as it represents the natural and social world, constructs social identities (such as those set up for hepatitis C specialist Dr Stuart Roberts and hepatitis C "sufferer" Mr Alan Morgan in "Hepatitis C Increasing to Epidemic Proportions" televised on the ABC's *7.30 Report* (Tynan, 2000) analysed in Chapter Eight), and sets up relations between participants thereby giving rise to questions of power (Fairclough, 1989, pp. 110–139; 1995a, p. 6; 1995b, pp. 5 & 17).

Analysis of a communicative event takes in three features of that event: the text; discourse practice (that is, processes of text production, distribution, and consumption); and sociocultural practice (that is, the sociocultural context within which the communicative event takes place, and of which it is a part) (Fairclough, 1995a, p. 2; 1995b, pp. 16 & 57). Discourse analysis shows the "systematic links between texts, discourse practices, and sociocultural practices" (Fairclough, 1995b, p. 17). The discourse practices of social institutions such as departments of public health, which use language in conventional ways, comprise a set of discourse types or "orders of discourse": "The order of discourse of a social institution or social domain is constituted by all the discursive types which are used there" (p. 55). Analysis of hepatitis C-related public health policy discourse and news media discourse encompasses both the communicative event, such as the *Strategy* and specific news texts, and the order of discourse (and the discursive types therein) (pp. 55 & 56).

In its publication *The Australian Media Guide to Hepatitis C*, the AHC (2001) demonstrates critical awareness of the importance of language, particularly lexical choices, in media coverage of hepatitis C-related issues. There is scope for NGOs representing the hepatitis C-affected community to undertake more in-depth textual analysis—including analysis of ways of representing hepatitis C and people living with hepatitis C and genres and the mixing of genres—in an attempt to further shift the discursive practices of the media and other institutions to effect social change. For as Fairclough shows, texts are deliberately constructed:

Formal choices constitute choices of meaning potential—how to represent a particular event or state of affairs, how to relate to whoever the text is directed at, what identities to project. And these choices are in turn linked to choices at a different level: what genres to draw upon in producing (or interpreting) a text, what discourses to use...Such a view of text encourages analysts to be sensitive to absences from the text—the choices that were not made but might have been—as well as the

presences in it, as well as to weigh presences against possible alternatives. (Fairclough, 1995b, p. 18)

In *Language and Power*, Fairclough (1989, p. 26) differentiates three dimensions or stages of critical discourse analysis, namely, description, interpretation, and explanation. These three dimensions of analysis are not clear-cut. For example, the act of “selecting” by the researcher, when analysing the linguistic features of a text, is itself interpretative. Description, interpretation, and explanation may not be undertaken in a strict sequential order, rather there is interplay between the dimensions that is driven by the research questions and theorising as the research progresses. Notwithstanding this, the critical discourse framework includes within its scope:

- Analysis of discourse practice;
- Intertextual analysis of texts;
- Linguistic analysis of three processes evident in texts:
 - Representation:
 - Ideational function;
 - Textual function;
 - Construction of relations, and
 - Construction of identities. (Fairclough, 1995a, pp. 6–7)

The analysis of texts in this framework incorporates close linguistic analysis that acknowledges the inherent relationship between meaning and form, rather than focusing solely on the content of the text (Fairclough, 1995a, p. 4; 2003, pp. 12–13). Just as representation is partly achieved through the vocabulary of a text, including metaphor, and through the grammar of the text, so discourses are realised in both the vocabulary and the grammar of texts. Therefore, analysis includes consideration of:

- Vocabulary and semantics (that is, the meaning attached to words or symbols);
- Grammar, and
- Textual organisation such as the “cohesion” of, or logical connection within, sentences, turn-taking in interviews, and the whole-of-text structure. (Fairclough, 1995a, p. 188; 1995b, pp. 57 & 101)

At the same time, interpretative analysis seeks to elucidate the ideational (that is, knowledge and beliefs), interpersonal (that is, social relations and social identities) and textual functions of the text (Fairclough, 1995b, p. 58). Analysis encompasses that which is explicit and that which is implicit, often presupposed or “taken as given” (Fairclough, 1995a, pp. 5-6). What is absent or excluded from a text is as important a consideration as what is apparent or included in that text (Fairclough, 1995a, pp. 5 & 210; 2003, pp. 135–137).

The analysis of discourse practice evident in the communicative event is concerned with text production, text distribution, and text consumption (Fairclough, 1995a, p. 9; 1995b, p. 58). The “institutional routines” or “institutional processes” in the production, distribution, and consumption of media texts are considered by Fairclough (1995b, p. 59) in *Media Discourse*, as are the “transformations which texts undergo in production and consumption” (that is, interpretative processes). The institutional processes and transformations in the production, distribution, and consumption of hepatitis C-related health policy texts can and will be considered in a similar fashion. Discourse practice—institutional and interpretative processes—connects sociocultural practice to the text (pp. 59–60). A communicative event draws upon an order of discourse, “help[ing] reproduce its boundaries and relationships, or help[ing] restructure them” (p. 60). It follows that textual heterogeneity (in terms of forms and meanings) is often indicative of sociocultural change (p. 60). Drawing upon the work of Bakhtin (1986), in particular, Fairclough (1995a, p. 188; 1995b, p. 61) directs the analysis and interpretation of a text towards illuminating the traces of genres, discourses, and narratives—“conventionalised practices”—evident in its production. Therefore, texts like the *Strategy* may constitute a “discourse type” within the order of the discourse of public health policy, with “relatively stabilised configurations of genres and discourses within the order of discourse” (1995b, pp. 66–67). For those representing the hepatitis C-affected community, it is important to consider if, and in what way, the voices of those living with hepatitis C are represented in and by texts. In this regard, Fairclough’s (p. 81) critique of news texts is relevant to public health policy texts with regards to the prominence afforded some voices over others, the use of particular voices to frame others, the transformation of certain voices into more palatable discourses, and the ordering and “hierarchisation of voices” within a text. Moreover, it is important to search for the “absences and silences” (Carabine, 2001, p. 285) in a text, that is, what is *not* spoken about that might be expected to be spoken about.

In the critical discourse analysis framework, intertextual analysis of texts demonstrates “how links between one text and other texts and text types are inscribed in the surface of the text” during the production and consumption of texts (Fairclough, 1995a, pp. 4–5). In this study, intertextual analysis of a text includes consideration of how the producer(s) of that text blend genres and discourses, from which the audience is to draw upon when interpreting the text. Evidence of the transformation of texts and the embedding of texts, and the representation of various voices (and exclusion of other voices), is also an important consideration (Fairclough, 1995b, pp. 75–77; 2003, p. 47). Discussing the complexity of the context of hepatitis C public health policy in their report of the findings of a survey around the issue of hepatitis C education for young people, researchers from the National Centre in HIV Social Research and the Australian Research Centre in Sex, Health and Society note the intertextual nature of such policy:

Governmental response to hepatitis C are included in policy specific to hepatitis C as well as policy concerned with HIV/AIDS, communicable diseases and illicit drug use...An understanding of the policy context...entails interrogating policy which has been developed through a variety of processes and which comes out of multiple Government departments and agencies. (Van De Ven, Youdell, Smith, Mistler & Pan, 2001, p. 9)

As well as the immediate context of a communicative event and its institutional context, the critical discourse framework used in this study encompasses the wider social and cultural contexts of discourse practices: “[The] wider contextual matrix must be attended to because it shapes discourse practices in important ways and is itself cumulatively shaped by them” (Fairclough, 1995b, p. 50). Analysis of texts such as the *Strategy*, therefore, includes consideration of the relations of power and control involved in its development and the form that it takes, the likely constraints that such relations place upon the genres and discourses drawn upon and represented in the evolution of subsequent strategies, and the opportunities for change (p. 78).

While my professional and personal experiences, and knowledge of the literature, sensitised me to what was “going on” in the data, these resources (Fairclough, 1989, p. 11) could also act as “blindness” (Strauss & Corbin, 1990, p. 75). I kept in mind Carabine’s (2001, p. 307) caution about the need to “step outside” the data when dealing with policy documents that impacted on my work as project officer at the HCWA. Posing analytic categories or concepts in the form of questions, as Fairclough (1989, pp. 110–111; 2003, pp. 191–194) recommends, helped reduce bias in the interpretation of

data and opened up the range of my understanding. Asking questions (Who? What? Where? How? Why?), and making comparisons by considering other choices that could be taken by the producers of texts, when applying Fairclough's framework, aided the analysis and enhanced the interpretation.

Narrative Analysis of Interviews

Personal narratives were collected by unstructured interviews of informants. QSR N6 (Nud*ist) software was used to store the raw data and generate line numbering of transcripts of audiotapes for initial analysis. Labov's (1972, 1982) framework for narrative analysis outlined by Riessman (1993) was used to structure my analysis. Labov's structural framework has the following six common elements:

- Abstract (summary of the substance of the narrative);
- Orientation (orient the listener to time, place, situation, participants);
- Complicating action (sequence of events);
- Evaluation (significance and meaning of the action, the attitude of the narrator—how he/she has chosen to interpret the action);
- Resolution (what finally happened), and
- Coda (returns the perspective to the present). (Riessman, 1993, p. 18)

I initially transcribed interviews verbatim, including my guiding questions and probes. I tried to capture the rhythm of talk and features of speech (such as pitch and emphasis) in the transcription. Considering how informants told their stories, I identified discrete narrative segments. I identified stretches of talk that formed a narrative: "A discourse organised around time and consequential events in a 'world' recreated by the narrator" (Riessman, 1990, p. 1195). I looked for bracketing devices that signalled the start and ending of narrative segments, "entrance" and "exit" talk (Riessman, 1993, p. 17). I re-listened to the tape recordings attending to the function of phrases or passages, keeping in mind Labov's elements. I focused on the way in which informants ordered their experiences, and the narrative types used: story lines adapted by informants (organising myth or myths); themes; imagery; core/organising metaphors or rhetorical devices.

Narrative segments that are structurally and thematically coherent were identifiable in Leanne's (name changed) interview, for instance. For the most part, these segments were tightly sequenced. As we talked in the small sitting room that opened into her kitchen, Leanne told me several stories about her life with hepatitis C. She directed my interpretation by the way in which she organised her narratives in the interview. Leanne tied together a particular event, or events, connected by a theme, or a message that she wished to express. Leanne told me about her life philosophy and hepatitis C, about situations in which contamination could occur, the importance to her of belonging to a strong community, of not being hyper-focused on sensations, and of dealing with her sense of the unknown. Leanne indicated where a narrative started and ended. During the course of talking about "indicator species", for example, Leanne signalled that she was about to move on to talk about "contaminatory situations" when she said, "Of course, on the darker side of it there's all [the] contaminatory metaphors which are much harder to deal with" (Leanne, Interview, April 2, 2003, Lines 53–54).

As Riessman (1993, p. 59) notes, not all narratives fit into Labov's framework. This was apparent when I was coding for "complicating action", a sequence of events in Leanne's interview. The complicating action or sequence of events did not always refer to specific events. Instead Leanne described the circumstances in which something was likely to happen. She says that the hepatitis C "might rear its head if I'm feeling particularly low" (Leanne, Interview, April 2, 2003, Lines 209–210). When she feels low she becomes particularly aware of the impact of the virus.

I grouped lines around a topic within a clause coinciding with the rhythm of Leanne's speech. My questions and comments were excluded from the core narrative along with her false starts and other utterances that broke the rhythm of the passage. I was cognisant of Riessman's (1993, p. 65) criteria for validating narrative work so that readers can determine the trustworthiness of my interpretations. Regarding persuasiveness and plausibility, I support my interpretation with evidence from Leanne's account. Readers will thereby be able to judge whether my interpretation is reasonable and convincing.

Due to time constraints, the narrative analysis of the remaining interviews was set aside. However, my concern to include these narratives remained. As Treichler (1987, p. 287) says in relation to HIV/AIDS, but it applies equally to hepatitis C, many voices "should contribute to the construction of official definitions". I re-listened to, and re-read my transcripts of, these interviews to become familiar with narrative segments.

These narratives alerted me to the mediation of the voices of people living with hepatitis C in public health policy and news texts. I chose, therefore, to include excerpts from these interviews to frame chapters and/or sections, providing a counterpoint to the discourses evident in the public health policy and news texts, (including the testimony of lay people included in news texts).

Study Limitations

A number of limitations stem from the scope of, and the research methods employed in, this study. Due to time constraints and the scope of the initial plan of this study, the lived experiences of persons living with hepatitis C have been, for the most part, set aside. I found, as Saukko (2003, p.15) argues in her overview of the history of cultural studies in North America and Western Europe, that

The new ethnographic quest to be truthful to the lived realities of other people runs into a contradiction with the poststructuralist aim to critically analyse discourses that form the very stuff out of which our experiences are made.

Biomedical, public health and news media discourses of hepatitis C partly structure or construct the individual's experiences of living with hepatitis C (Hepworth & Krug, 1999; Krug, 1995). However, recovering the individual's experiences of living with hepatitis C—at a given point in time and within a particular social context—while critically analysing institutional discourses, is problematic. As Saukko (1998) indicated in her earlier work, it is not an easy task to combine methodological perspectives, as orientations of voice, commonsense discourses, and space, encompassing global connections, compete with each other:

One cannot without friction recuperate the experiences or voices of people and critically assess the discourses that form the very stuff out of which our experiences are made. Neither is it easy to map chains of events that give shape to vast, discursive and other formations and to be attentive to the nuance of people's experiences within these formations. (p. 76)

This study encompasses aspects of the institutional routines or processes for producing and distributing texts. The consultation process in the production of hepatitis C-related public health policy, for instance, is examined as part of this study. However, the reception, by various audiences of the texts analysed in this study is not formally investigated by face-to-face methods. While text-processing research to determine lay

readers' comprehension of texts was not undertaken, the analysis of the linguistic and information structuring in texts offers insight into possible interpretations available to the reader. I count myself as a member of the audience of the *Strategy* and media texts both in my role as senior project officer of the HCWA and as a member of the public, and thereby offer my interpretative analysis of the texts. With regards the *Strategy*, documents such as the AHC's report summary of the 2002 review by Levy, Baum and Thomas, the AHC's own evaluative submission to the Commonwealth Department of Health and Ageing (AHC, 2002), and the Australian Injecting & Illicit Drug Users League's (AIVL) (2002) submission to the review of the first national hepatitis C strategy are written indicators of the consumption and reception, and interpretation of this policy document by representatives of the hepatitis C-affected community.

I have indicated instances wherein the research process falls short in providing data for exploration of issues or problems that arose during the course of this study, or where issues are tangential to the research question. An example is the possibility that the funding arrangements for the provision of services by NGOs stifles advocacy and the debate of public policy by NGOs (Maddison, Dennis & Hamilton, 2004), discussed in Chapter Five. This issue provides scope for "critical ethnographic" research (Fairclough, 1995a, p. 10) to be undertaken into the impact of texts on community-based organisations representing the hepatitis C-affected community.

Conclusion

In this chapter I provided an account of the research process used to examine the construction of representations of hepatitis C and people living with hepatitis C in Australian public health and news media discourse. The first national hepatitis C strategy, the *National Hepatitis C Strategy 1999–2000 to 2003–2004* produced by the Commonwealth Department Health and Aged Care (2000b) was selected as the primary text upon which to base this critique of public health discourse about hepatitis C, while news texts were sourced from the ABC news services, *The Australian* newspaper and the *Herald Sun* newspaper between 1996 and 2003. These primary sources of data were supplemented by interviews of four people living with chronic hepatitis C, which offer other perspectives not represented in the official discourse and media discourse.

Representing the hepatitis C-affected community, staff working in hepatitis C NGOs serve on advisory committees, consultation groups, make submissions to reviews

of hepatitis C public health policy, and advise persons working in the media about reporting on hepatitis C related issues. Fairclough's framework for critical discourse analysis makes plain the constructed nature of public health policy texts and news media texts such as the choices made regarding genres and narratives (Fairclough, 1995a, p. 210). A powerful analytic method, it provides an alternative way of thinking about texts. NGOs can advocate for the Government and its departments to choose different genres, different discourses and/or different narratives in developing public policy—so too media producers when constructing news programs—that legitimate, and comprehensively represent, the experiences of persons living with hepatitis C.

CHAPTER THREE

PUBLIC HEALTH POLICY DISCOURSE ON HEPATITIS C: THE MINISTER SPEAKS

“I think, too, hep C is this horrible disease that is associated with drug addicts or injecting drug users. So there’s a stigma. A lot of people who’ve got it don’t like to say anything...And statistics say that 90 percent of people have got it through injecting. So it’s got this horrible stigma to it...People don’t have a clue. If people understand a bit more then probably they’ll be a bit more sympathetic and maybe, you know, more money might get spent on it. ‘Cause it seems to me it’s just a sort of push it down and hide it away sort of disease. They spend a lot more money on other diseases. The number of people with this...if there were 16,000 people diagnosed a year with TB the medical profession would be in an uproar, they’d be spending all sorts of money, and having all sorts of campaigns. Nobody seems to bother too much about hep C.”

– Carol, Interview, April 2003

Introduction

In Australia, the Commonwealth Department of Health and Aged Care (the Department) (today known as the Commonwealth Department of Health and Ageing) can be described in Foucault’s (1973, p. 28) terms as the official organ of “collective consciousness of pathological phenomena”, including hepatitis C. The Department operates at “both the level of experience and the level of knowledge, in the international as well as the national space” (p. 28). The *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b) was selected for study as it is the first of Australia’s population health strategies addressing hepatitis C as a national public health issue in its own right, rather than as a disease that bears some relationship to HIV/AIDS. The *Strategy* follows other health policies and the establishment of organisational structures, a number of which incorporate hepatitis

C within the infrastructure of the National HIV/AIDS Strategy (see Table 1). This study of the *Strategy* comprises two parts, reflecting the two distinct genres evident in the text: the first is the *Foreword* (Wooldridge, 2000a) by the then Minister for Health and Aged Care (the Minister), Dr Michael Wooldridge, and the second is the *Strategy* produced by the Department.

Table 1

National Hepatitis C-Related Health Policies and Organisational Structures in Australia, 1993 to 2000

Year	Policies and Committees
May 1993	Joint task force Australian Ministers Advisory Council (AHMAC) and National Health and Medical Research Council (NHMRC)
October 1994	National Hepatitis C Action Plan released by AHMAC
November 1995	Nationally Coordinated Education and Prevention Approach released by AHMAC
December 1996	National HIV/AIDS Strategy 1996–97 to 1998–99: third national strategy integrating National Hepatitis C Action Plan
August 1997	Australian National Council on AIDS and Related Diseases (ANCARD) Hepatitis C Sub-committee
1998	Hepatitis C Virus Projections Working Group reporting to ANCARD Hepatitis C Sub-committee ANCARD Education Sub-committee Intergovernmental Committee on HIV/AIDS and Related Diseases (IGCARD) Education Managers Forum IGCARD Hepatitis C Education and Prevention Working Party
November 1999	Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD), ministerial advisory body on HIV/AIDS and hepatitis C, established (dissolved September 2003), includes dedicated Hepatitis C Committee Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases (IGCAHRD) responsible for implementing National Hepatitis C Strategy (at national, state and territory levels)
June 2000	National Hepatitis C Strategy 1999–2000 to 2003–2004 launched

Sources: Australian Govt Dept Health & Ageing, 2001; ANCAHRD, 2004; ANCARD, Hepatitis C Sub-Committee, (2002); Commonwealth Dept Health & Aged Care, 2000b, pp. 8-9; Lowe & Cotton, 1999, p. 9

The two parts to this study of public health policy discourse on hepatitis C are concerned with the way in which meanings around hepatitis C are constructed by the public health institution in Australia. In seeking meaning, the analysis is, therefore, not

neutral in the sense that Dreyfus and Rabinow (1982, p. 49) ascribe to Foucault's (1972) method in *The Archaeology of Knowledge*. This chapter provides an in-depth analysis of the textual features (including linguistic features and organisation, generic conventions and discourse types) of the *Foreword* (see Appendix E), which are not explicated in Hepworth and Krug's (1997) work on hepatitis C public health policy.

The linguistic-discursive textual structures of the *Foreword* construct hepatitis C and people living with hepatitis C in a particular fashion. It was found that through its mechanisms of representation and the notion of "partnership" the text maintains the dominance of the scientific and biomedical forms of knowledge identified by Hepworth and Krug, disempowering hepatitis C positive people under the guise of empowering them. In particular, people with hepatitis C are constituted as objects and bearers of the virus to be targeted by biomedical discourse and procedures.

In the *Foreword* (Wooldridge, 2000a) the Minister has the authority to speak on behalf of the Australian Federal Coalition Government about the hepatitis C epidemic. The Minister establishes, for the reading audience, the approach taken by his department to develop the national strategy. He emphasises that a community of experts validated the correct identification of the problem, and the course of action settled upon. While injecting drug use had been considered a problem in Australia before the publication of the *Strategy*, the *Foreword* places those who inject illicit drugs at the centre of public health discourse about hepatitis C. In their examination of political and public health discussions about hepatitis C, Hepworth and Krug (1997, p. 5) note that the public health response to hepatitis C in Australia is based on medical and scientific models of disease, and influenced by managerial and bureaucratic practices. I argue that there is little contestation of this state of affairs in the *Foreword* and the *Strategy* despite, or rather because of, the partnership approach taken in the development of the *Strategy*. The partnership approach, which indicates openness, works to moderate any opposition that Foucault (1982, p. 212) informs us might otherwise be expected to arise in "struggles against the privileges of knowledge".

As a separate entity from the *Strategy*, the *Foreword* has a communicative purpose directed at its intended readers or "discourse community" (Verstergaad, 2000, pp. 98-99). It has communicative features in common with political speeches, and shares communicative purposes with this genre of text (Trosborg, 2000, pp. 122-144). The *Foreword* attempts to persuade the audience to support the Government's hepatitis C strategy. Analysis of the micro and macro discursive features of the *Foreword*,

together with the Minister's message to the reader, reveals that the Minister entrusts the protection of the Australian community from the hepatitis C epidemic to the scientific and medical communities, which are to work closely with the hepatitis C-affected community.

The Minister's commentary is distinct from the policy document, the *Strategy*. The *Foreword* bears Dr Michael Wooldridge's name as its author, and his title as the then Minister for Health and Aged Care. The *Strategy*, by comparison, does not have a single author but has a collective-named author, the Commonwealth Department of Health and Aged Care. This produces a different modality in each of the texts, such as the first person mode of address found in the *Foreword* versus the third person in the *Strategy*. The *Foreword*, however, as with political speeches and media releases in general, is likely to have involved more persons than Wooldridge in its writing. The text works to construct Wooldridge's identity as the Minister for Health. Wooldridge speaks in the plural for the Federal Coalition Government, and on behalf of the Australian people.

The *Strategy* was launched by Dr Michael Wooldridge in a pre-recorded video address to the 2nd National Hepatitis C Educator's Workshop in Brisbane 29 June 2000. According to the director of the HIV/AIDS and STIs Section of the Commonwealth Department of Health and Ageing, "the *Foreword* and *Strategy* were completed before the speech was written" (D. Dumbrell, personal communication, June 15, 2004). The *Strategy's* launch was also accompanied by a Ministerial media release entitled: "National Strategy to Map the Way for Treatment and Prevention of Hepatitis C" (Wooldridge, 2000b) and another by the Australian National Council on AIDS, Hepatitis and Related Diseases (ANCAHRD) entitled: "ANCAHRD Welcomes New National Plan to Combat Hepatitis C" (ANCAHRD, 2000). According to the then Chief Executive Officer of the Australian Hepatitis Council (AHC), the *Strategy* was not tabled in the federal parliament (J. Wallace, personal communication, April 20, 2004). Like the inaugural presidential address described by Trosborg (2000, p. 137), the *Foreword*, and the *Strategy* itself, are a call to action. In this case, the texts call to action members of Government, the Opposition, professional managers in the public health sector, professionals in the scientific and health care sectors, and workers in the community sector in Australia.

Wooldridge addresses a number of audiences in the *Foreword*, which can be categorised as lay and professional readerships. For example, in the fourth paragraph of

the *Foreword*, he establishes contact with the opposition parties when he refers to establishing “non-partisan” relationships with governments throughout Australia. Wooldridge addresses the entire Australian population and, in particular, the scientific and medical communities in the opening paragraph of the *Foreword*: “Australia is leading the international community...Australia is recognised as a world leader” (Wooldridge, 2000a, p. iii). Although the mode of address in the *Foreword* is professional, it is inclusive of its constituencies in terms of “community consultation” for “setting priority areas for action” and the inclusion of “people affected by hepatitis C”—those served by the professional constituency—in partnerships for action. The micro features and macro-structural and macro-generic features of the *Foreword* as it relates to the lay readers and professional readers are discussed in turn.

Persuading Lay Readers: Injecting Drug Use Core of Hepatitis C Epidemic

In terms of the lay reader and the communicative purpose, the *Foreword* contains features, or “moves”, of the persuasive text described by Verstergaard (2000, pp. 100–101; 106): problem; solution; argumentation; and appeal. The problem, described by Wooldridge (2000a, p. iii), is two-fold: firstly, hepatitis C infections in Australia are at epidemic proportions as “more than 200,000 Australians are already infected”. Experts, including public health professionals, have forecast the health problem and identified interventions to stop the epidemic. Secondly, injecting drug use in Australia is identified as the core component of the problem: “with over 90 per cent of all new hepatitis C infections occurring among people who inject drugs” (p. iv).

The representative function of the *Foreword* concerns the presentation of facts about the world; objective statements that can be verified true or false (Fairclough, 1989; Trosborg, 2000, pp. 122–123). Just as the news media commonly use statistics as a discursive strategy (Lupton, 1992, p. 31), Wooldridge presents facts as evidence—objective statistics that can be verified—in the aforementioned declarative sentences to stress the magnitude of the problem (Fairclough, 1989, pp. 125–126; Jakobson, 1981, p. 23; Verstergaard, 2000, p. 103). In so doing, Wooldridge conforms to an empiricist tradition that favours propositional thought, presenting a reasoned argument associated with the discourse pattern of science (Halliday & Martin, 1993, p. 7; Lyons, 1995, pp. 336–337). Wooldridge (2000a) clearly makes the association of hepatitis C with injecting drug use, a causal relationship between the increasing incidence of injection of

illicit drugs and hepatitis C infections. In his assessment, recognition of this association is paramount as he predicts that: “The increasing use and injection of illicit drugs in Australia will have a powerful influence on the course of the hepatitis C epidemic here” (p. iv).

Wooldridge (2000a, p. iii) proposes a solution to the hepatitis C epidemic (the problem): the speedy implementation of the *Strategy* by governments, medical, scientific and health care professionals, and people affected by the virus. He describes the *Strategy* as a “comprehensive framework”, and attributes the determination of priority areas for action and the development and content of the *Strategy* to the Commonwealth Department of Health and Aged Care, lay people and experts in the field:

The priority areas for action identified in this Strategy have been developed in response to a national population health review process followed by extensive community consultation during 1999; they are also supported by advice from the nation’s foremost experts on hepatitis C. (p. iii)

The *Foreword* relies on readers reading the *Strategy* to learn more about the priority areas for action. The introduction of the *Strategy* outlines the action required (the solution). Government, community organisations, medical, health care, scientific and research communities and affected people are to take action to: reduce hepatitis C transmission; treat those who are infected; provide health care and support to those affected; prevent discrimination; and alleviate stigma and isolation (Commonwealth Dept Health & Aged Care, 2000b, pp. 1 & 2). The *Strategy*, then, is a framework indicating the resources, services, environments, responsibilities, and standards that have to be in place to ensure “population health”. In the *Foreword*, too, Wooldridge projects onto the lay audience his assumptions, beliefs and values about the benefits of science and medicine (predominantly orchestrated and implemented by professionals), in effecting a solution.

The *Foreword* does not specify details of the solution. However, it is not unusual for each of the moves of a genre to be incompletely covered in a text (Verstergaard, 2000, p. 107). It is therefore significant that Wooldridge specifies at least one intervention—that of needle and syringe programs—in the proposed solution to reduce hepatitis C transmission. Paragraph six of the *Foreword* contains the reason for this aspect of the solution: “the increasing use and injection of illicit drugs in Australia” (Wooldridge, 2000a, p. iv). In this same paragraph, a number of interpretations are

possible with regards to the “appeal” to lay readers. Wooldridge’s ambiguous acknowledgment of the “increased visibility of this serious population health problem” can be interpreted as a reference to both injecting drug use and hepatitis C as population health problems. The problem of the use and injection of illicit drug is thereby declared common knowledge, a “visible” problem and an aspect of Australian society, though not condoned (see later discussion). On the basis of this common knowledge of the state of things Wooldridge appeals to readers to accept harm-reduction initiatives like needle and syringe programs (NSPs).

Although the Minister addresses lay readers in the *Foreword*, he primarily addresses professionals, and the hepatitis C epidemic is depicted as a “challenge” to these professionals. The following section describes the communicative features of the *Foreword* directed towards its professional audience. In this the Minister establishes his social relationship with his primary audience, asserts his authority and draws readers’ attention to the paradigm of partnership that underpins the *Strategy*.

Directing Professional Readers: The Government Takes Command

The *Foreword*’s primary readership is professional, comprising scientific and health care professionals, members of the Government and the professional managers in the public health sector, the Opposition, and community sector workers. Its communicative purpose differs from its lay readership as Wooldridge tries to persuade his readers to a point of view and instigate action on their part. With regards to this professional readership, the *Foreword* contains features or moves of the hortatory text described by Verstergaard (2000, pp. 101 & 106): establishing authority; presenting the problem; issuing commands; and creating motivation. The *Foreword* addresses an audience that may be divided in its attitude to the problem including some members of the Government, the Opposition, community-based workers, and health care workers. It nonetheless calls for the aforementioned readers to take a specific course of action in relation to hepatitis C, and to adopt a particular point of view particularly in relation to the maintenance of services concerned with the use and injection of illicit drugs. Analysis of the macro-structural features of the *Foreword* shows that Wooldridge presents the problem of the hepatitis C epidemic, establishes his authority and the authority of the Australian scientific and medical communities to deal with the problem, issues commands to partners, and tries to create motivation. In so doing, he creates a

distinction between the nation state and the Australian community, which will be discussed later.

Hepatitis C a “Serious Population Health Problem” for Professionals

The problem presented to professional readers is the same as for lay readers: the hepatitis C epidemic and its prevalence amongst people who inject illicit drugs. In addition, Wooldridge (2000a, p. iii) predicts that the epidemic poses a liability and a drain on resources, a “burden of [a] disease”. He relates the disease and the response to the disease to economics, a relationship that is flagged in the introduction of the *Strategy*. According to Filc (2004, p. 1278), evidence-based medicine “articulates the need to control costs...with the need to maintain an acceptable level of health-care services”. Wooldridge estimates that the hepatitis C epidemic poses a burden to those infected and to the community generally. It is the Australian community that is impacted by hepatitis C: all Australians; Australians in danger of getting hepatitis C; and those Australians infected with the virus. This verdictive act—concerned with evaluation and judgment about how *serious* the situation is (Trosborg, 2000, p. 124)—extends beyond Wooldridge and his Department and is attributed in the text to other sources, including Australia’s “foremost experts”, who contributed to the development of the *Strategy*.

Wooldridge’s evaluation of the state of affairs revolves around the mechanics of dealing with the problem, and he does not attempt a portrayal of individuals affected by hepatitis C. The reader is not given a sense of what it is like, for example, to be stigmatised, to fear discrimination from health professionals, or to be unable to work because of hepatitis C infection. In his pre-recorded speech launching the *Strategy*, screened at the 2nd National Hepatitis C Educator’s Workshop, Wooldridge (2000c) states:

I would especially like to acknowledge and thank those who attended the public forums or drafted submissions for consideration in the development of the Strategy. Many profound—and at times provoking—personal stories were honestly and generously relayed to us during these consultations. These stories expressed the negative—and positive—experiences of people affected by hepatitis C in Australia and the experiences of their families and supporters.

In the above text, Wooldridge employs the technique of “synthetic personalisation” (Fairclough, 1989, pp. 62; 195) to give the impression that he is relating to each

individual and thanking each of those who attended public forums or wrote submissions. The mention of people's stories is a useful public speaking technique to engage or gain the attention of the audience. Synthetic personalisation, as Fairclough explains, is the means by which the Minister (the professional) "handles" hepatitis C educators and the lay public (his clients) at the workshop. However, stories of people living with hepatitis C do not fit in with, and are marginal to, Government discourse about the disease. People with hepatitis C are the *entrée* into the *Strategy* yet their stories are not valued in their own right. Instead, hepatitis C positive people are positioned as bearers of the virus and the disease.

Wooldridge's acknowledgement of the importance of the stories of people living with hepatitis C masks inequalities in the espoused partnership. Hence, "solidarity" such as that expressed by the Minister could be interpreted as a "strategy of containment" (Fairclough, 1989, p. 195). As previously noted, Krug and Hepworth (1999, p. 106)—exploring communication ethics in public health—similarly found that the participation by representatives of an injecting drug use (IDU) support group at an international medical and public health conference reflects the group's appropriation into mainstream practices "re-creating themselves to fit more closely within the dominant paradigms of medicine, epidemiology, and health". Krug and Hepworth argue that such groups are appropriated and constrained by the very public health and medical communities that afford them recognition and "empowerment" (pp. 114–115).

Compared to Wooldridge's launch speech, the *Foreword* to the published *Strategy*—a policy document and one-way public discourse—is business-like, stripped of emotion and of consequences for the individual. In the *Foreword* Wooldridge does not identify the personal costs of the disease for individuals infected with hepatitis C; nor does he identify the benefits accruing to the individual from the *Strategy*. The label "serious population health problem" used by the Minister (Wooldridge, 2000a, p. iv) lacks reference to the realities of injecting drug use for many in Australia. (A similar omission in Tynan's (2000) story "Hepatitis C Increasing to Epidemic Proportions", televised on the ABC's *7.30 Report* program, is discussed in Chapter Nine in relation to the subject position of the audience). The poverty and the living conditions of illicit injecting drug users addressed in studies such as *Sydney Case Study: Kings Cross* (Southgate & Weatherall, 2003), for instance, are not mentioned in the *Foreword*. The absence of the ordinary, the personal, and the social is characteristic of the discourse of science and biomedicine (Filc, 2004; Halliday & Martin, 1993, p. 3). The solution to the

problem, as it is outlined to lay readers, is action by a range of professionals as previously discussed.

Professionals to Work in “Partnership” with Affected Community

A large part of the text is taken up with the issue of commands to professional readers, albeit indirect. The directive function of the text focuses on the receiver (Trosborg, 2000, p. 124; Verstergaard, 2000, p. 104). The sender of a message may try to change the receiver’s mind about something or commit the receiver to doing something in directives or commands (Cooren, 2004, pp. 383–385; Searle, 1982, p. 154; Trosborg, 2000, p. 125). The Minister’s *Foreword* is “performative”; he is giving commands (see Austin, 1976, pp. 4–7; Searle, 1969, pp. 16–19; 138). Analysis of this directive function includes consideration of the social relations coded in the *Foreword* as in other texts characterised as speech acts (Fairclough, 1989, pp. 156–157).

Wooldridge proposes that service providers at all levels commit serious effort to “combating” hepatitis C, as the current state of affairs—200,000 Australians infected—is unacceptable. Australians have let Australia down. Hence, the *Foreword* contains modal verbs in phrases such as: “we must act now”; “we cannot defer”; “need to work in a collaborative, non-partisan manner”; “must be maintained” (Wooldridge, 2000a, pp. iii & iv) to show how necessary action is. Being the Minister for Health and Aged Care, Wooldridge is in a clear position of power that allows him to express his requests or commands in an indirect fashion (Fairclough, 1989, p. 156; Searle, 1982, p. 154). Nonetheless, by using the imperative form, linking “must” to reasons why service providers must act, the Minister imposes obligations upon those he lists as partners: “people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals” (Wooldridge, 2000a, p. iii). Modality in the text indicates Wooldridge’s attitude and relation to his message and communicates his social relationship with his audience, that is, his authority in relation to others (Fairclough, 1989, pp. 126–127; Halliday, 1976, p. 100). The Minister issues two major commands: one concerning the adoption of the paradigm of “partnership” by those implementing the *Strategy* and the other concerning the injection of illicit drugs by people in Australia, the latter requiring readers to have experience of contemporaneous and older texts.

The origins of community development as a guiding concept in state public health in Australia arose with the Whitlam Labor government reforms of the 1970s (Dowsett, 1998; Maddison, Dennis & Hamilton, 2004, p. 10; Petersen, 1994, pp. 214–215). This concept is expressed by rhetorical terms like “partnership”. Community participation in public health policy development through partnerships between “the practitioners and organisations of public health, practitioners and organisations of health care, stakeholders, and policy-makers in the ‘other sectors’ of social practice, and citizens” is now part of the *modus operandi* of governments of both the right and the left in Australia (Webster, 2002, p. 133). According to Petersen (1994, pp. 213 & 215), however, evaluative accounts of the Community Health Program of 1973 conclude that community involvement in activities, such as defining objectives and decision-making processes, “remained enmeshed within dominant power structures...[with] continuing professional dominance and a strong adherence to the biomedical model”. This is in accord with Grace’s (1991) finding that the professional perspective is privileged over that of the individual consumer in health promotion discourse, thereby creating a situation of “pseudo-participation”. (Grace’s study is discussed in more detail in Chapter Nine in relation to the institutional and societal processes and ideological meanings in the *7.30 Report* program “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000).)

In the *Foreword*, the Minister situates the *Strategy* within a communicable diseases framework (Wooldridge, 2000a, p. iv). While the *Foreword* draws predominantly on medical and scientific discourse to establish authority (discussed in the next section of this chapter), the Minister also builds in a social perspective by instructing his professional audience to involve affected communities. In his review entitled “Social Inclusion and the Public Health: The Case for Partnerships”, Webster (2002) cites the national HIV-AIDS and hepatitis C strategies as examples of national public health initiatives in Australia with the theme of community partnerships. As discussed in Chapter Nine, the development and support of partnerships with non-government organisations (NGOs) representing people living with hepatitis C also underpins the marketing strategy of public relations companies for the biopharmaceutical industry in Australia. The choice of wording in the *Foreword* seeks to establish specific social relations between partners (Fairclough, 1989, p. 116). Examining the governance and ethics of health promotion in Australia, Britain and America, Coveney (1998, p. 464) notes the similarities between the “individualistic

transactions” of the medical model and the notion of “social contract” associated with the social model. The social model of “new” public health requires that the individual “actively participates in the community in order to identify problems and reflect on the consequences for themselves and for others” (p. 464). In this regard, the social model requires a “competent community” that is a collective subject (p. 465). Both the medical model and the social model require individuals to be “self-reflective” and “self-regulating” choosing subjects in accord with protocols set by experts. Both models, argues Coveney, “practice a form of power which is aimed at directing the conduct of others” (p. 466). The social model of health promotion is expected to reduce the need for “policing” of the individual by state bureaucracies. Nonetheless, individuals are governed at a distance “bound into the language of expertise” (p. 466). While Coveney does not explore how socially excluded individuals become self-reflective and self-regulating, and collectively form competent communities, the inclusion of NGOs, particularly peer-based injecting drug user (IDU) organisations in the development and implementation of the *Strategy*, is expected to fulfil this requirement.

Rhetorical features are limited in the *Foreword*, as in the *Strategy*. However, repetition of the word “partnership” serves a rhetorical function (Trosborg, 2000, p. 127). The concept of partnership is a dominant cohesive feature of the *Foreword* that is repeated in various ways throughout the *Strategy* itself, extending to a prescription of modes of being, that is, the manner or way in which the partners are to behave. “Overwording” (Fairclough, 1989, p. 115) indicates preoccupation with partnership as a strategy for implementing public health policies, which draws upon vocabulary associated with the ideological framework of the Australian Labor Party of the 1970s (discussed previously). The concept of groups of Australians working together to achieve a common goal is introduced in the first paragraph of the *Foreword*: “renewal of our efforts to deal with the serious impact of hepatitis C” (Wooldridge, 2000a, p. iii). A number of words in the text are to do with working together and shared activity to achieve the primary aims of the *Strategy*: “consultation”; “collaborative”; “non-partisan”; “joint efforts”; “cooperation”; “coordinated”; and “involving” (pp. iii & iv). These words are also reinforced by Wooldridge’s repeated use of the first person plural pronouns “we” and “our”—pertaining or belonging to us—in the *Foreword*: “Our community”; “Our response”; “Our knowledge”; “We cannot defer”; and “We must act now” (p. iii). In paragraph two of the *Foreword*, for example, Wooldridge calls upon all levels of government and scientific and health care professionals to commit

themselves—in a “coordinated” way—to the next “phase” of the fight against hepatitis C: “We cannot defer further action...we must act now” (p. iii). The concept of partnership, then, flows through the *Strategy* via cohesive chains of words that convey the Minister’s message of working in teams to combat the hepatitis C epidemic. However, the vocabulary of the text also permits ideologically different interpretations of the social relationships between participants in the partnership dealing with the hepatitis C epidemic.

The concept of partnership emphasised by the Minister in the *Foreword* is a central concept in the forerunners of the *Strategy*. For instance, in *Proving Partnership: Review of the Third National HIV/AIDS Strategy* the authors cite Feachem’s (1995) evaluation of the second national HIV/AIDS strategy: “The concept of partnership involves a commitment from all parties to work together as equals to solve the problems created by HIV/AIDS” (ANCARD, 1999, p. 131). *Proving Partnership* admonishes excessive concern by some partners with representation in decision-making and policy-formation processes at the expense of appreciating the expression of “goodwill” and “good faith” by all partners (p. 136). Commissioned by the Minister for Health and Ageing to review the *National Hepatitis C Strategy 1999–2000 to 2003–2004*, Levy, Baum and Thomas (2002, pp. 97 & 112) conclude that “partnerships have been developed and affected communities have been engaged to some extent...that the non-government and community sector has been engaged to some extent under the auspices of the Strategy”. Their call for more “equitable partnerships”, though, is principally concerned with the distribution of resources amongst existing key stakeholders in the partnership. Levy, Baum and Thomas do not evaluate the composition of key stakeholder groups representing people living with hepatitis C, nor do they evaluate the level(s) of participation by people living with hepatitis C. Analysis of the discourse of the *Foreword* indicates from the outset that the partners are not equal in the partnership between affected communities and government, medical, health care, research and scientific communities. The dominance of the expert and managerial voices on bureaucratic bodies advising the Minister is discussed later. At the level of discourse it is assumed that key stakeholder groups are representative. Representativeness, however, is not straightforward in relation to the “affected community”.

Representatives of those living with hepatitis C—predominantly from NGOs—have been co-opted into the process of expert management of the health of the Australian population. Considering who is authorised to speak for a community,

Pettman (1992) is quoted by Petersen (1994, p. 216) as cautioning: “those who claim to speak for a category or community frequently claim representativeness by virtue of being a member of that category or community”. Peterson himself notes that those who represent community groups on bureaucratic committees or boards “are under pressure to speak for everyone from their presumed community” (p. 216). In a set of three qualitative case studies of public participation at the regional level in Quebec’s healthcare system, Contandriopoulos (2004) examines the construction and appropriation of legitimacy by lay individuals, small organisations, and regional boards claiming to be representative. Contandriopoulos considers Pitkin’s (1967) three dimensions of representation: formal representation, that is, how people come to be designated as representatives; descriptive representation, that is, “the degree to which representatives are similar to the ‘average’ represented”; and symbolic representation, that is, “subjective perceptions from the participant’s viewpoint at the origins of consent and legitimacy” (p. 322).

Analysis of representation of ANCAHRD, and its successor, the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH), using Pitkin’s (1967) framework outlined by Contandriopolous (2004, p. 322), indicates that the descriptive representation of these bodies is limited as the majority of members are appointed from the upper echelon of the medical, scientific and managerial communities and are not appointed on the basis of their similarity to the “average” person living with hepatitis C. In the *Foreword* the Minister states that ANCAHRD—his primary advisory body at the federal level—will report directly to him on the *Strategy*’s implementation (Wooldridge, 2000a, p. iv). ANCAHRD, and now MACASHH, are directly under the authority of the Minister who, in turn, appoints members (Commonwealth Dept Health & Aged Care, 2000b, p. 57). The AHC—the national peak organisation for state/territory based Hepatitis C Councils funded by the Commonwealth—notes in its submission on the review of the *Strategy* that the “membership of ANCAHRD and its committees [is] expertise based rather than representational” (AHC, 2002). Commenting on ANCAHRD, the AHC criticises the “absence of members with specific hepatitis C expertise...and the lack of real ownership of hepatitis C related issues by the broader committees”. The formal, descriptive, and symbolic representation of governance and advisory structures intended to respond to hepatitis C in Australia forms a discrete area requiring further study.

In the *Foreword*, the Minister states that the process of identifying priority areas for action involved “extensive community consultation” (Wooldridge, 2000a, p. iii). This implies a broader focus on “non-scientifically produced information and knowledge” in support of the *Strategy* (Dobrow, Goel & Upshur, 2004, p. 212). However, the Minister reassures readers that the “affected community’s” opinion and/or interests, obtained through the process of public consultation, were ratified by “the nation’s foremost experts” (Wooldridge, 2000a, p. iii). The Minister differentiates between the knowledge of experts and that of affected people. In the context of formal public health policy, “experts” occupy a more eminent subject position in the discourse just as in the *7.30 Report* case study discussed later. In terms of Fairclough’s (1989) classification scheme, experts constrain the affected community’s contribution to the content (that is, the activities, topics and institutional purposes) of the *Strategy*. As Contandriopoulos (2004, p. 325) argues, the process of top-down formal public consultation “usually describes a situation in which the public can voice its opinion without any direct possibility of decision in the end”. The AHC has flagged this problem as being of concern. It stated in its submission on the review of the *Strategy*:

We had the opportunity to comment on the workplan of the national social research centres. However, it was unclear how these comments would be used, particularly given that the national centres’ Scientific Advisory Committees had already provided advice on the workplans, and there was little guidance from CTARC [Clinical Trials and Research Committee] as to their expectations. (AHC, 2002)

As Dobrow, Goel, and Upshur (2004, pp. 213–215) argue, stakeholder representation can affect the sort of evidence introduced into the decision-making process, the interpretation of evidence, and the application of evidence to support or justify decisions. So too, the small number of lay citizens who participate in public consultation forums intended to inform policy-making about hepatitis C is problematic, as it may not constitute statistical representation. Additionally, the extent to which organised groups—despite what Contandriopoulos (2004, p. 325) terms their “well argued and documented positions”—represent the hepatitis C affected community’s opinion or interests is unknown.

As the analysis of the *7.30 Report* story, “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) in Chapter Nine shows, the biomedical perspective may dominate news or current affairs reporting despite the inclusion of a hepatitis C “sufferer” and a representative of a community-based hepatitis C group amongst the

categories of news actors. Community representatives may not effectively contest the medical perspective, and may be used by media producers to endorse the testimony of medical experts in a way that mirrors the marketing strategies of public relations companies for the biopharmaceutical industry. It also shows that the patient (or consumer) with firsthand experience of hepatitis C is not on equal footing with the medical and/or research expert.

As Petersen (1994, pp. 215–216) demonstrates, the concept of “community” in public health policy “is often used to mean a ‘target group’, identified for government management of difference and provision of services”. The Commonwealth and state/territory governments in Australia target specific communities when purchasing services from the non-government and community sectors. This is evident in the statement, by the then Senior Policy and Planning Officer for the Sexual Health and Blood-Borne Virus Program with the Department of Health, WA, outlining the public health response to hepatitis C in WA:

WA was the second state in Australia to fund a community-based hepatitis C council...The Department of Health WA contracts the Hepatitis Council of WA to provide “core” services related to hepatitis C education, prevention and support services. Additional projects have been initiated through funding such as the Commonwealth Hepatitis C Education and Prevention funding. (Bevan, 2003, p. 2)

While the Commonwealth Department of Health and Aged Care (2000b, pp. 16; 22 & 42) specifies in the *Strategy* that community-based organisations such as state/territory hepatitis C councils and peer-based drug user groups—funded by state and territory governments—are to be involved in activities such as setting the research agenda in relation to hepatitis C, health promotion activities and service provision through formal participation structures, the representativeness of such non-government organisations themselves is problematic. The Hepatitis Council of WA (the HCWA), for instance, initially founded as a bottom-up, grass-roots support group (Marsh, 2001, p. 1), had 135 financial members in December 2003 (V. Brown, personal communication, December 12, 2003), while the Hepatitis C Council of NSW had 799 financial members in June 2003 (Hepatitis C Council of NSW, 2003, p. 10). These memberships are less than one percent of the estimated 19,000 people living with hepatitis C in WA in 2001, and 1.4% of the 55,000 residents of New South Wales notified as infected with hepatitis C by 1999 (Delpech, Habib & McAnulty, 2001) respectively. Hence, these memberships reflect but a small percentage of the infected populations that each of

these Councils “stand for”, “speak for”, and “act for” (ANCAHRD, Hepatitis C Sub-Committee, 2002, p. 24). Moreover, given the means of contracting and transmitting the virus through blood-to-blood contact—most commonly during injecting drug use with shared injecting equipment—those living with hepatitis C in Australia constitute a heterogeneous group of people rather than a community (Campora, 1999, p. 147; Krug & Hepworth, 1999, p. 104; MacDonald, Sullivan, Locke, Wodak & Kaldor, 1998). Besides trying to attract and maintain lay memberships, hepatitis C councils work to increase their contact with the affected community in other ways. The Hepatitis C Council of NSW, for instance, operates the Hep C Australasia Internet forum with 172 members registered on April 19, 2005, not all of whom live in New South Wales (Hepatitis C Council of NSW, 2005). The ways in which NGOs such as hepatitis C councils undertake symbolic and political work to objectify their status as legitimate representatives of all people living with hepatitis C in Australia is outside the scope of this study, but require further investigation (see Contandriopoulos, 2004, pp. 327–328).

Phrases in the *Strategy* like “people affected by hepatitis C and their community organisations” (Commonwealth Dept Health & Aged Care, 2000b, p. 60) imply that hepatitis C councils and their counterparts are representative. However, the nature of the community coupled with low membership of “community-based” organisations, and the way in which services and projects are determined and funded, indicates that representativeness cannot be presumed. In their assessment of governance and partnership in the *Strategy*, Levy, Baum and Thomas (2002) do not consider the composition and representativeness of those peak bodies in the non-government and community sector for which they seek additional and more equitable representation. The extent to which the hepatitis C-affected community can be regarded as a collective subject and a “competent community” (Coveney, 1998) are outside the scope of this study. However, community involvement or participation in hepatitis C-related public health programs and the decision-making process, including exploration of the nature of the hepatitis C-affected community and of those non-government and community groups representing this community in governance structures and partnerships, warrants further investigation.

The second major command issued by the Minister relates to the problem of the injection of illicit drugs by people in Australia. He directs the professionals in the partnership to provide needle and syringe programs designed to prevent the transmission of the hepatitis C virus amongst people who inject illicit drugs, which are

defined in the glossary of the *Strategy* as “a drug whose production, sale or possession is prohibited”, that is, illegal (Commonwealth Dept Health & Aged Care, 2000b, p. 70). The social phenomenon of injecting drug use is couched in terms of the statistical data about the transmission of the infective agent, the hepatitis C virus. The use of epidemiological data and biostatistics is characteristic of evidence-based medicine. The term “evidence-based” reflects the dominant approach to medicine, prominent from the early 1990s, which has been extended to policy-making in various areas including the health sector (Black, 2001, p. 275; Dobrow, Goel & Upshur, 2004, pp. 207–208; Filc, 2004, p. 1277; Hanney, Gonzalez-Black, Buxton & Kogan, 2003, pp. 2 & 5). The term reflects the view that “scientific research should drive policy” and practice (Black, 2001, p. 275). While considering the available scientific evidence and drawing heavily on expert evidentiary sources, Wooldridge’s remarks also reflect a “practical-operational orientation” in the decision-making and the development of hepatitis C-related health policy (Dobrow, Goel & Upshur, 2004, p. 209).

In a practical-operational orientation, contextual political factors, including ideological and economic, influence decision-making and policy at the population level. Referring to needle and syringe programs in the *Foreword*, Wooldridge (2000a, p. iv) tells professional readers that: “these essential prevention measures must be maintained and, more importantly, enhanced”. There is a sense that the Minister expects to encounter some opposition to this proposal. “Must” and “must be...enhanced” indicate that service providers are bound by the *Strategy* to provide such services and extend, rather than stall, the provision of needle and syringe programs. The Minister (and the Commonwealth Government) holds the authority and the power to ensure that state and territory governments comply. At the same time, the statement “preventing high risk behaviours such as injecting drug use” (p. iv) reflects the common-sense assumption of members of Government and the medical, scientific and health care professionals involved in the partnership that injecting drug use is not desirable and poses a risk to health. Moreover, it is a statement as to how individuals should behave, and about the norms to which they should conform. The individual who does inject illicit drugs—a “high risk behaviour”—is expected to manage his/her behaviour to reduce the risk of acquiring and/or transmitting the hepatitis C virus (as will be discussed in relation to the *Strategy*).

The injection of illicit drugs is considered in the *Foreword* from medical and public health perspectives. However, the professional audience is also directed to make operational links with the *National Drug Strategic Framework 1998–99 to 2002–03*. The Minister presupposes that readers have knowledge of, and are familiar with, the national drug strategy, which forms part of the intertextual context of the *Foreword* (Fairclough, 1989, pp. 141, 145 & 152). The text thereby constructs the “ideal reader”, the professional, for whom specific policy documents are common knowledge. Implicit in the Minister’s directive is adherence to the stance stated in the glossary to the *Strategy* that “governments do not condone illegal risk behaviours such as injecting drug use” (Commonwealth Dept Health & Aged Care, 2000b, p. 70). This stance persists, and was reiterated in a joint communiqué by the Ministerial Council on Drug Strategy which comprises the Commonwealth and state/territory Ministers for Health, Law Enforcement, Justice and Police and Education: “while Ministers endorsed harm minimisation as the Australian approach, they also stressed that harm minimisation does not condone drug use” (Ministerial Council on Drug Strategy, 2004). In this way population health policy such as the *Strategy* is consistent with the ideological focus of the Coalition Government. Further study of the interrelationship between the discourse of health and public health policy and the discourse of national policy for illicit drugs is indicated.

In commanding professional readers to work in partnership with the hepatitis C-affected community, and to provide needle and syringe programs, the Minister appeals to their capacity for logical thought, that is, reasoning and inference, rational thought and argument. He also appeals to national pride: “Australia is recognised as a world leader in developing and implementing effective population health responses to other blood-borne viruses” (Wooldridge, 2000a, p. iii). In so doing, the nation appropriates the professional. The *Foreword* is devoid of poetic elements that might appeal to the reader’s emotions. At the syntactic level, however, some sentences offer contrast and carefully balanced construction to attract the readers’ attention:

Our knowledge of the factors affecting transmission and progression to advanced illness is evolving, but we cannot defer further action until all the pieces of the puzzle are in place: we must act now, using the best available evidence while still pursuing an improved knowledge base. (p. iii)

The frequent use of the words “we” and “our” emphasises that the task of halting the spread of hepatitis C lies with the collective Commonwealth government, state/territory and local governments and medical, scientific and health care professionals who are gathering knowledge about HCV and HCV-positive people. The general relationship between the different professionals of the state/territory and local governments, medical, scientific and health care communities appears symmetrical (see Brown & Gilman, 1982, pp. 257–259). The Minister clearly places the Commonwealth Government at the head of the governance structure, as the leader (Wooldridge, 2000a, p. iv) at the same time as he addresses the aforementioned professionals as “solidary”, facing a common task (Brown & Gilman, 1982, p. 261). The notion of partnership, and the specification of representatives of the hepatitis C-affected community as partners (as previously discussed), reflects a bid to acknowledge the status of lay people and include them in the discourse of public health policy. However, the partnership is limited. People affected by hepatitis C are not enabled. The “pronouns of solidarity” (Brown & Gilman, 1982) in the above quote are not inclusive of the affected community; the affected community is not constituted as *equally* responsible for collective action dealing with the hepatitis C epidemic. Moreover, the representativeness of organisations speaking for, or acting on behalf of, the affected community in federal, state/territory institutional arrangements and participation processes requires further investigation.

The social relations between the hepatitis C-affected community and the professional community are not portrayed as problematic in the *Foreword*. There remains a clear gap between the professional subject and the lay subject. Individuals infected with the hepatitis C virus are not portrayed as having the knowledge or qualifications commensurate with that of the professional partners addressed by the Minister, hence they do not attain the status of “expert” in public health policy about the hepatitis C epidemic in Australia. In the next section, the way in which the Minister establishes his authority over those to whom he speaks and those about whom he speaks is discussed. The institutional sites of medical discourse that exercise controlling authority over the Government’s response to the hepatitis C epidemic and those affected by the virus are also detailed.

Establishing Authority of Scientific and Biomedical Discourse

Wooldridge (2000a) acknowledges that the Government is liable to be called to account for the hepatitis C epidemic, and that it has responsibility for the health of the Australian population and so must curtail the epidemic. The Commonwealth Minister for Health's authority and acceptance of responsibility is reflected in cohesive chains of words in the text concerned with hierarchy and obligation: "we aspire"; "a renewal of our efforts"; "our response"; "we cannot defer further action"; "we must act now"; "our response"; "the Commonwealth will continue its strong leadership role" (pp. iii & iv). This is then taken up in Section Seven of the *Strategy* in which the roles and responsibilities of the partners are specified (Commonwealth Dept Health & Aged Care, 2000b, pp. 55–61).

The Commonwealth Government is committed in the *Foreword* to action. The commissive function of a speech focuses on what the speaker says he/she will do or commit to doing in the future (Austin, 1976, pp. 156–163; Trosborg, 2000, p. 124; Verstergaard, 2000, p. 104). The Minister's commitment or promise to his audience is found in the performative verbs he uses such as: "we aspire to" and "launch a renewal of our efforts"; and modals expressing commitment or the necessity to take action such as: "we cannot defer further action" and "will continue". The *Foreword* constitutes a promise—to the Australian community—by the Minister on behalf of the Government to "deal with" the hepatitis C epidemic.

The metaphor of the puzzle—"we cannot defer further action until all the pieces of the puzzle are in place" (Wooldridge, 2000a, p. iii)—suggests that the medical and scientific communities will be able to apply rational thought to put the pieces together and solve the problem. In Wooldridge's assessment, sufficient pieces are in place for action: "We must act now, using the best available evidence while still pursuing an improved knowledge base" (p. iii). As discussed in the preceding section, this reflects a practical-operational orientation that accommodates evidence as "emergent", reflecting "the state of knowledge at a particular time and place" (Dobrow, Goel & Upshur, 2004, p. 209). The "puzzle" metaphor also suggests that the Minister and the Commonwealth Department of Health have the overall picture whereas the respective partners may only have knowledge of the parts. The notion of the "bigger picture" is reinforced in paragraph seven: "To ensure that the overall health outcomes achieved are greater than the sum of the individual parts" (Wooldridge, 2000a, p. iv). Hence, there is a sense of

power or authority evidenced in organisational structures such as reporting hierarchies and role relationships:

The Australian National Council on AIDS, Hepatitis C and Related Diseases will report to me on the Strategy's implementation... The Strategy provides State and Territory governments with the flexibility to respond to the particular demands of the epidemic in their jurisdictions, while at the same time providing a framework for ensuring that consistent national standards are maintained. The Commonwealth will continue its strong leadership role. (Wooldridge, 2000a, p. iv)

There is a named social identity in the *Foreword*, as in the genre of the political speech, who speaks and constitutes others, and speaks about them to others. In this case, the social identity is Dr Michael Wooldridge, then Minister for Health and Aged Care. As the individual who publicly launched the *Strategy*—and issued a media release from his Department to signal its launch—Wooldridge occupies a privileged position. Wooldridge operates from within a particular discourse and is subjected to this discourse (Foucault, 1969/2002; Hall, 1997, p. 55). Moreover, the text reflects specific knowledge and meanings familiar to those to whom Wooldridge speaks, creating particular subject-positions (Fairclough, 1989, pp. 39; 102; Hall, 1997, p. 56). In *The Archaeology of Knowledge* Foucault (1969/2002, pp. 55–61) poses three questions about “the formation of enunciative modalities”: Who is speaking? What are the institutional sites from which the speaker makes his/her discourse? What is the position of the subject? Each of these questions can be asked in relation to the *Foreword*, a discussion of which follows.

Regarding “Who is speaking?” Wooldridge has been given the right to “speak” in the *Foreword* to the *National Hepatitis C Strategy 1999–2000 to 2003–2004*. He is qualified to do so on this occasion because he holds the position of Minister for Health and Aged Care. His portfolio responsibilities include “overarching policy responsibility for all issues pertaining to health” in Australia, along with administrative responsibilities. A list of similar portfolio responsibilities for the current Minister published on the Department's website includes population health (Australian Govt Dept Health & Ageing, 2004a). The Minister responsible for the health portfolio is accountable to Cabinet (and the Prime Minister) and to the Australian people for issues within his/her jurisdiction. The Minister has the power and authority to take decisions independently, and is expected to be trustworthy and diligent in performing his/her task.

In addition, Wooldridge's status as a medical practitioner and all that that professional position entails lends weight to his qualifications to speak as the Minister for Health, that is, his: specific competencies and knowledge; relations with others; roles in society; financial remuneration; and the right to make medical statements (see Fairclough, 1989, p. 64; Foucault, 1969/2002, pp. 55–56). Wooldridge's professional qualifications and experience—he is listed in *Who's Who in Australia* (De Micheli, 2004) as having been resident medical staff at the Alfred Hospital 1982 to 1985 and a tutor of anatomy at the University of Melbourne from 1985 to 1986—give him the status of the expert. It is the prestige inspired by Wooldridge's medical qualifications that satirical commentators on current affairs John Clarke and Bryan Dawe (Clarke & Dawe, 2001) attack in their regular spot broadcast on the Australian Broadcasting Corporation's (ABC) *7.30 Report* (shown in Figure 1).

Reporter: Bryan Dawe

JOHN CLARKE IS STANDING IN FOR DR WOOLDRIDGE, BRIAN DAWE IS INTERVIEWING HIM.

Bryan Dawe: Mr Wooldridge thanks for your time again.

John Clarke: Doctor, it's Dr Wooldridge.

Bryan Dawe: Oh, I'm sorry.

John Clarke: I'm sorry, it's Dr Wooldridge.

Bryan Dawe: Dr Wooldridge, of course, yeah.

Look, I wonder if I could ask you about the Government's health policy for the upcoming election.

John Clarke: Yes, indeed, yes indeed, you may.

Bryan Dawe: Yeah, so Mr Wooldridge - -

John Clarke: Dr Wooldridge, it's Dr Wooldridge.

Bryan Dawe: Yes, I'm sorry. Dr Wooldridge.

John Clarke: I'm a doctor.

Bryan Dawe: Dr Wooldridge, some time ago, you resigned from Parliament so why are you now - -

John Clarke: I did but, nevertheless, even though I have resigned, I am still the current Federal Health Minister in this country.

Figure 1. Excerpt from "Clarke and Dawe"

Source: *7.30 Report*, ABC television, November 1, 2001.

Medical practitioners have particular relationships with others within Australian society. As Foucault (1969/2002, p. 56) notes, medical practitioners have a form of contract with individual patients who they diagnose and/or treat and the community in which they practice medicine. In Australia, medical practitioners are governed by state statutory legislation—the Medical Act—in relation to their professional capacity, which is administered by the respective state medical boards (Medical Board of WA, n.d.). Under common law, medical practitioners have a contractual relationship with patients whom they examine, diagnose, and/or treat for hepatitis C (Staunton, 1985, pp. 6–7 & 73–74). Professional organisations such as the Australian Medical Association (AMA) also publish codes of ethics to “guide doctors’ conduct in their relationships with patients, colleagues and society” (AMA, 2004, p. 1). Medical practitioners have a contractual relationship with the Australian community, for example, to reduce hepatitis C transmission within the community and to contribute to the surveillance of hepatitis C via notification protocols (discussed later). In so doing, they fulfil the roles attributed to doctors in society including that of “guardian, and guarantor of the health of a population, a group, a family, an individual” (Foucault, 1969/2002, p. 56). In the *Foreword*, the Minister formally creates and establishes such roles for medical, scientific and health care professionals, in statements such as: “responding to the challenges identified in this Strategy will help us to prevent the burden of disease increasing for those directly affected by hepatitis C as well as for the broader community” (Wooldridge, 2000a, p. iii).

The institutional site(s) from which the discourse of the *Foreword* derives include a number of those sites identified by Foucault (1969/2002, pp. 56–57) in his consideration of nineteenth-century medical discourse. The “laboratory”, the “hospital” (predominantly tertiary treatment centres) and public health agencies feature as important sites for the production of discourse on hepatitis C. These sites supply information to medical and health care professionals, governments and affected communities about, for example, the epidemiology (including the natural history of the virus), the transmission of the hepatitis C virus and treatment for hepatitis C (including treatment protocols and monitoring the virological response to treatment as discussed in Chapter Nine in relation to the subject position of news actors). Federal public health bodies—for which the Minister for Health has administrative responsibility—collect and monitor statistical information, composing the “documentary field” identified by Foucault (p. 57). The Minister cites the prevalence of the disease in Australia and its

incidence amongst people who inject drugs. He refers to the systematic, large-scale “national population health review process” from which the *Strategy* derives (Wooldridge, 2000a, p. iii). The experiences of individuals infected with the virus were absorbed into this review process on the basis of their shared features. The extent to which “community consultation” modified the institutional sites of medical discourse cannot be determined from analysis of the *Foreword* alone. Community consultation, however, is described as a step in the process of identifying areas for action by the professional community: “A national population health review process *followed* [my emphasis] by extensive community consultation in 1999” (p. iii). The Minister reassures the reader, though, that the priority areas for action “are also supported by advice from the nation’s foremost experts on hepatitis C” (p. iii). The resultant national population health “framework”—which reflects an averaging process (Foucault, 1969/2002, p. 57)—therefore sets out a series of ideas and principles to deal with hepatitis C in Australia that are legitimated by experts as being valid or conforming to standards and fact. Institutional sites of medical discourse exercise controlling authority over the Government’s response to the hepatitis C epidemic and those affected by the virus.

In the *Foreword* the Minister is constituted as a subject of power who can speak about others and hepatitis C as “objects”, and direct others. The Minister occupies a particular position in relation to these discursive objects (Foucault, 1969/2002, pp. 57–58). The primary objects about which he speaks comprise the hepatitis C virus, the hepatitis C epidemic and people who are infected with the virus. The way in which the Minister speaks to the professional audience about the hepatitis C epidemic and people infected with the virus—the objects—depends on discourse conventions of medicine, science (including epidemiology, that is, the science of epidemics), government and also warfare. Persons living with hepatitis C are the collective objects and the virus is the object upon which the Minister’s attention as subject is focused, and towards which action is directed.

The hepatitis C virus is a natural object of study, and the laboratory is the site for interrogating the virus. The hepatitis C virus was known to cause post-transfusion hepatitis before it was itself identified: “researchers gave it a name that reflected what it was not: they called it non-A, non-B hepatitis” (Deutsches Hepatitis C Forum, 2001). Identification of the virus in 1989 solved a medical riddle, and was a “discursive event” (Danaher, Schirato & Webb, 2000, p. 34). Writing for the HCWA’s newsletter, microbiologist Dr Jaksic (2001b, p. 5) describes the discovery in epic terms: “a long and

challenging search for an agent of non-A, non-B hepatitis finally resulted in identification and characterisation of hepatitis C virus”. Professor Cossart (1990, p. 39) takes a similar tone in her review of diagnostic testing for the hepatitis C virus written for the New South Wales public health bulletin: “Hepatitis C diagnosis and control have taken *a great step forward* [italics added] with recent cloning of this *elusive* [italics added] non-A non-B (NANB) hepatitis virus.”

The development of molecular biology techniques such as polymerase chain reaction (PCR)—which amplifies genetic material (DNA or RNA)—enable the hepatitis C virus to be studied as an object, to obtain more accurate knowledge of it. The virus has been classified and its similarities and differences described: “HCV is a single-stranded, enveloped RNA virus belonging to the Flavivirus family” (Sasadeusz, Locarnini & Kidd, 2001, p. 10). Hepatitis C viral genotypes are classified numerically and their prevalence by geographical region mapped (Jaksic, 2001a, p. 2). Scientists and medical practitioners continue to explore how the virus enters the liver cells of the infected person, replicates and mutates to produce quasispecies that elude the host’s immune system, affect the efficacy of antiviral therapies and thwart the development of vaccines (Jaksic, 2001a, p. 2; Sasadeusz, Locarnini & Kidd, 2001, p. 10). Virologists, infectious diseases physicians, gastroenterologists, hepatologists, general practitioners, and others also explore other aspects of the object such as: the natural history or pathogenesis of hepatitis C infection; clinical features (signs and symptoms) of infection; prognosis and epidemiology and transmission.

Krug (1997, p. 94) accurately notes that hepatitis C “only exists in lab tests, electron microscopes and in its effects on real people...[that] there is no sign of HCV; there are only signifying processes.” It is not surprising, then, that it is the practices of science and medicine and the scientific/medical knowledge about hepatitis C described above that Wooldridge (2000a, p. iii) alludes to when he writes: “Our knowledge of factors affecting transmission and progression to advanced illness is evolving”. Imagery in the *Foreword* positions the hepatitis C virus as an enemy in the same way that Jaksic (2001a) does in the title of her article: “The Hepatitis C virus: A Formidable Adversary”, and other medical writings do when listing hepatitis C virus as one of the viruses that *attacks* the liver or *targets* the liver (see Chapter Seven for further discussion of the metaphorical representations of hepatitis C). The imperative in the *Foreword* draws heavily upon classification schemes of, and common metaphorical

representations found in, scientific and the biomedical discourse (see Fairclough, 1989, p. 110–111; 114–115; 119–120).

PCR technique, which enables the detection of hepatitis C viral RNA, is a tool in the medical diagnosis of hepatitis C infection and a gauge of clearance of the virus either spontaneous or with treatment. The technique allows the identification of the hepatitis C virus itself in the blood and tissues ahead of antibody production by the infected person's immune system (antibodies being markers that the virus is present or has been present). This molecular technique has been employed in the screening of donated blood in Australia since 2000, superseding serological tests.

Techniques such as PCR also serve another purpose, that of disease surveillance by public health authorities: “the continuing scrutiny of all aspects of the occurrence and spread of a disease” (Commonwealth Dept Health & Aged Care, 2000b, p. 72). People with hepatitis C are collective objects of study in epidemiological studies of hepatitis C in specific populations, particularly those at greatest risk of contracting a disease (Atthowe, Thompson & Giele, 2002, p. 1). PCR is an extremely sensitive tool for identifying infected individuals. It assists in the identification and documentation of social activities such as injecting illicit drugs, whereby the individual can be scrutinised and recognised as an IDU. Testing for the virus assists in uncovering the patient's “true” identity—what may otherwise be hidden—as he or she is ultimately categorised according to known risk factors for the transmission of the virus. The virus, an object found in the blood, functions as an identifying mark, linked both to the disease and to social behaviour (Sturken & Cartwright, 2001, p. 298 & 301). Moreover, the hepatitis C virus has become a signifier for injecting drug use.

As noted, the Minister is the subject who has the authority to speak about the hepatitis C virus, the hepatitis C epidemic and persons who are hepatitis C positive in the *Foreword*, conceiving and speaking of the objects of the discourse. In *The Archaeology of Knowledge*, Foucault (1969/2002) does not consider people objects, while the subjects of discourse are subjects of power such as the Minister in the *Foreword*. However, the objects of public health discourse about hepatitis C are not just the infectious disease but also those living with the virus, spoken for and about in the *Foreword*. This is not to say that Foucault was not concerned about people. In a paper on “The Subject and Power”, Foucault discusses the “objectivising” of human beings, of the subject (Faubion, 1994, pp. 326–327). His concerns include the way in which “the subject is either divided inside himself (*sic*) or from others” (p. 326) and “the way a

human being turns him- or herself into a subject” (p. 327), in both instances subjugating him/herself. As objects of the discourse in the *Foreword*, hepatitis C positive-persons are given “subject positions” to take up (Fairclough, 1989, p. 39; Hall, 1997, p. 45; Sturken & Cartwright, 2001, p. 368). The discourse implies particular things about its object. Hepatitis C positive people are expected, for example, to take up particular roles and exhibit characteristic behaviour(s) according to the discourse of public health policy at the population level. However, following Foucault’s argument (Faubion, 1994, pp. 331–332), people living with hepatitis C do not have to submit to the forms of subjection evident in the *Foreword* and the *Strategy*.

Hepatitis C-positive persons are positioned as recipients of care and the objects of public health surveillance to “prevent the burden of disease increasing for those directly affected by hepatitis C as well as for the broader community” (Wooldridge, 2000a, p. iii). The hepatitis C virus exists as a natural pathogenic object, and people infected with the virus are constructed in the *Foreword* in terms of the risk behaviours by which the virus is transmitted. The discourse implies the following specific subject positions: people requiring health care services; bearers of the virus who pose a risk to others in the community; and people who engage in high risk behaviours, particularly the injection of illicit drugs. The latter two of these subject positions, upon which the discourse is primarily focused, are discussed in more detail.

Each hepatitis C-positive person is positioned as a host to the disease-producing hepatitis C virus or a reservoir: “The hepatitis C epidemic is already well established in our community—more than 200,000 Australians are already infected” (Wooldridge, 2000a, p. iii). The host bears the object, the hepatitis C virus. Hepatitis C-positive persons are thus spoken about as a source from which the virus can be transmitted to others in the community. The virus endangers the health of the infected individual in the future, and poses a risk to others in the community. The Minister draws on epidemiological knowledge of risk when foregrounding injecting drug users as a undifferentiated subgroup of the total population infected with hepatitis C: “With over 90 per cent of all new hepatitis C infections occurring among people who inject drugs” (p. iv). Diagnosis of the status of host of the virus is associated with expectations that individuals will “police” their day-to-day behaviour thereby reducing risk to themselves and to others (Foucault, 1988, p. 18; Hutton, 1988, p. 132). Faye’s (2000, p. 102) research bears this out. She notes that after diagnosis her informants (both IDU and non-IDU) were “*condemned* to constant vigilance and action to avoid *contaminating* others

with HCV” circulating in their blood. Krug (1995, p. 315; 1997, p. 101) also recognised the push for individuals, rather than institutions, to police the spread of hepatitis C as a focus of public health. In the *Foreword*, the Minister similarly places the imperative for preventing the transmission of the virus onto the infected individual, with state-funded infrastructure enabling them to act appropriately.

The increased demand on needle exchange programs, noted by the Minister, re-packages IDUs as individuals who will undertake self-surveillance. Persons who use or inject drugs illicitly are represented as retaining control over their actions, including aspects of the context in which they inject drugs. In this identity IDUs are cast as individuals who will regulate their injecting behaviours (by using sterile injecting equipment), to prevent transmission of the virus to others, and to prevent them acquiring other strains of the virus. This relies on people believing that they should behave responsibly towards others and not deliberately cause harm to others. Government-funded needle and syringe programs (including the provision of fixed-site and mobile needle and syringe exchanges and needle and syringe disposal containers) are intended to shape the way in which IDUs undertake injecting activities including the safe disposal of used needles and syringes. The discourse of the *Foreword* implies that what IDUs understand about themselves depends on choosing to “do the right thing” as a general guiding principle. Interviews with current and past-IDUs conducted by Pugh (1998) illustrates that IDUs may, at some point in their history of injecting, interact according to such a set of “rules”:

It is my responsibility to ensure that other people don’t get it [hepatitis C] from me. (Cathy [not her real name], 41, hepatitis C positive.)

You have to be responsible. If you’re going to use you need to be responsible. I mean when you decide to use you should really take that on board. (Linda [not her real name], 23, hepatitis C positive.)

In the last couple of years I, I do, I do think more about the, my responsibility to not share hep C with somebody else. And I don’t share needles, syringes or filters or anything with anybody else. And in the past I used to do that because I didn’t want to catch anything, but now it’s changed a bit to be that I don’t share now because I don’t want to give anybody hep C. (Rick [not his real name], 46, hepatitis C positive.)

The *Foreword* incorporates a social identity for the responsible IDU that is evident today in other examples of public health discourse. Lowe and Cotton (1999, p. 16) stress the need to reduce the prevalence of unsafe injecting. The Town of Vincent (n.d.)—a metropolitan municipality located close to the centre of Perth in Western

Australia—lists safe needle and syringe disposal as one of its services. Disposal units are provided at specific spots in the Town of Vincent for the safe disposal of needles and syringes by people who use drugs. Binary opposites such as “safe injecting” and “unsafe injecting” and “safe needle and syringe disposal” and “unsafe needle and syringe disposal” serve to classify the injecting behaviours of IDUs. As Coveney (1998, p. 460) notes, individuals are “required to construct themselves as subjects with a ‘correct’ concern for the ‘proper’ way of behaving”. Fraser (2004, p. 203) notes similarly, in her critique of health promotion materials on hepatitis C prevention and safe injecting, that IDUs are to demonstrate responsibility to themselves and to others. Further, some health promotion materials “recruit” IDUs to “actively campaign among others for safer injecting practices”(p. 204). The “responsible IDU” is, therefore, represented as an ethical individual who behaves according to standards of moral conduct held by public health authorities and the average person. The Minister indicates in the *Foreword* that the Government, and the Australian community, are prepared to acknowledge that injecting drug use occurs but not to tolerate IDUs who behave irresponsibly with regards to their injecting practices.

The subject position of the IDU produced in the discourse is not clear-cut though. While constructing IDUs in the mode of the responsible IDU, the *Foreword* also reflects the Government’s acknowledgement of the fear of the “other”, of the “marginalised” that many in the community hold. Lawrence (2004) believes that fear of the other distorts the development of public policy in a range of areas in established democracies like Australia: “fear can be manipulated and attached to objects and circumstances which do not pose an objective threat.”

In the *Strategy* itself the chance of an IDU transmitting the hepatitis C virus to a non-IDU is described as extremely small:

Hepatitis C is not passed on through social contact such as hugging, kissing, sneezing or coughing. Sharing food, drinks, plates, eating utensils, laundry or toilet facilities are not considered risk factors for transmission...The risk of transmission of hepatitis C through medical procedures in Australia is also considered minimal because of the introduction of Standard Precautions for infection control. (Commonwealth Dept Health & Aged Care, 2000b, p. 5)

The discourse of public health policy, nonetheless, plays up to the moral panic around injecting drug use in the Australian community such as typifies news media reporting in Australia. (See analysis of the *Herald Sun* newspaper story “Bad Blood Blamed for

Deaths”, in Chapter Eight, in which blame for the contamination of the national blood supply with the hepatitis C virus and subsequent hepatitis C-related deaths is attributed to persons who inject illicit drugs.) It is the role of the State to protect the community from harm from others. Population health policies are developed by the Population Health Division to “protect and promote the health of all Australians” through activities such as “the control of disease, including through notification of communicable disease” (Australian Govt Dept Health & Ageing, 2003b). Krug (1997, p. 97) describes media statements about hepatitis C eluding experts because the most likely “carriers” of the disease, injecting drug users, are “positioned outside of the social order”. This is not the sense given in the *Foreword* though. The primary audience who are professionals, whom the Minister speaks to and of, comprise those who have the ability to understand, who have ready access to bodies of medical and scientific knowledge, and have the ability to act (Foucault, 1969/2002, p. 74). The subject position for such professionals is that of “authoritative figures of knowledge” (Sturken & Cartwright, 2001, p. 368). In the Minister’s address to this audience there is a sense that the experts can contain hepatitis C if they engage community members, including IDUs, to restrict the spread of the virus by behaving in certain ways, provide specific services, and vigorously pursue excellence in their scientific and biomedical areas.

A variety of words used in the *Foreword*, and as defined in the *Chambers English Dictionary* (Landau & Ramson, 1988), denote the Government’s response to the hepatitis C epidemic as that of a military operation. The word “strategy” is a deployment, defined as “the art of conducting a campaign and manoeuvring an army” (p. 1452). “Platform to launch” is a missile metaphor with “platform” defined as “a position prepared for mounting a gun” (p. 1116). “Action” calls up images of a battle, combat, and warfare (p. 13). Similarly, the word “operational”, defined as “ready for action” (p. 1006) is also associated with the military and so pertains to warfare. The hepatitis C virus and the disease that the pathogen produces is thereby positioned as hostile, the enemy in war harmful to the host and potentially harmful to others in the community. However, the hepatitis C virus, the object, is an adversary that cannot be seen outside the blood as it is studied in the laboratory, nor without tools that amplify its genetic material. However, those who harbour the virus in their blood are visible. Agency for escalating the hepatitis C epidemic is attributed to the people in Australia who inject illicit drugs. Injecting drug use is referred to as a serious population health problem. Although other risk factors for transmitting the hepatitis C virus are listed in

the *Strategy*, those who inject drugs are identified as causing the problem in the majority of cases in both the *Foreword* and the *Strategy*. As Krug (1995, p. 310) hypothesized, hepatitis C has become a signifier for disease or contagion. The signified, though, is much more clearly defined as injecting drug users in the *Foreword* than in Krug's paper. The Government can launch a "war"—a precision campaign—against groups of people whose high risk behaviour threatens to contaminate the nation's blood supply and endanger the health of the community, for example, by the unsafe disposal of used needles and syringes. The *Foreword* does not signal any substantial changes in the approach taken by the Government to the use of illicit drugs by people. It is, however, a plan that the Minister believes is capable of destroying the enemy (the hepatitis C virus) within host bodies and/or capable of destroying the virus's usual route of transmission.

People infected with hepatitis C are also subjects in the sense of being citizens. In the *Foreword* the Minister speaks about people with hepatitis C and their representatives as subjects who can speak and affect the discourse around hepatitis C, who can act and be acted upon. Hepatitis C councils in Australia, for example, undertake activities such as supporting and informing people affected by hepatitis C, publishing materials, and exchanging stories. People affected by hepatitis C and representative NGOs (including groups representing injecting drug users) occupy a subject position as one of the partners in the discourse of Government public health policy, albeit with limited authority. The *Strategy*, bearing as it does the name of the disease "Hepatitis C", serves to bring not only the virus but also people who inject drugs to the notice of professionals. As previously discussed, people who inject drugs can occupy the subject position of the responsible IDU created by the discourse. (See for example, the Town of Vincent's (n.d.) description of its services in which it details its work with the Western Australian Substance Users Association (the WASUA) to operate safe needle and syringe disposal services in the local area.) IDUs who do not identify with, or operate according to, this subject position are not given a voice. Moreover, even though representatives of hepatitis C positive people from NGOs can and do construct a range of texts and do participate in a range of activities, the professional "reality" is privileged in the *Foreword*. The technique of engaging community representatives as partners in the development of public health policy, as discussed previously, enables representatives of institutions such as government (including public health) and science (including medicine) to limit or restrict the

expression and actions of people living with hepatitis C and their representative organisations.

The Minister occupies particular positions in an information network concerned with these objects (Foucault, 1969/2002, p. 58). Foucault indicates the increasing importance of written documents in nineteenth-century medicine and this is ever more apparent in Australia today with both state/territory and federal governments publicly releasing successive public health policy documents concerned with the control of diseases in the Australian community. Within a system of both oral and written communications the Minister “emits” information, for example, producing the *Foreword* to the *Strategy* and sending out a media release for the launch of the *Strategy* (see Wooldridge, 2000b) that is also circulated on his Department’s website. As previously noted, the Minister launched the *Strategy* via a video address to the 2nd National Hepatitis C Educators Workshop in Brisbane in June 2000. The Minister “receives” information from a number of sources. He receives, for instance, statistical data about the hepatitis C epidemic from divisions in his portfolio for which he has administrative responsibility such as the Surveillance and Epidemiology Section of the Department of Health and Ageing, the coordinating body for national surveillance of notifiable diseases. As the Minister is positioned at the apex of a reporting hierarchy, ANCAHRD is to report to him on the implementation of the *Strategy* as well as “how best to respond to the challenges that have already been identified as well as those that emerge over time” (Wooldridge, 2000a, p. iv). The Minister for Health is also positioned in relations with other government departments and institutions. In particular, the Minister states: “Links and opportunities for joint efforts will be explored with the *National Drug Strategic Framework 1998–99 to 2002–03*, to ensure that health-promotion messages are well coordinated” (p. iv).

The Minister fulfils the role of the “listening subject” identified by Foucault (1969/2002, p. 58), considering information given to him by ANCAHRD, the Government’s peak advisory body at the time. ANCAHRD’s membership and that of its Hepatitis C Committee reflect a mix of medical, scientific and health professionals, general consumer representatives, representatives of hepatitis C NGOs and representatives of peer-based organisations for people who use, or have used, illicit drugs. Similarly, the current peak Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis and its subcommittees comprise a mix of representatives. However, the expert and managerial voice dominates both the MACASHH and its

Hepatitis C Subcommittee membership with members drawn predominantly from medicine, science, academia, and management (see Appendix F). The extent to which ANCAHRD and its successor MACASHH are representative of people living with hepatitis C warrants further exploration as noted in the previous section of this chapter.

The Minister also fulfils the role of the “observing subject” identified by Foucault (1969/2002, p. 58). As previously discussed, the Minister receives information from “intermediaries” that coordinate the national surveillance of notifiable diseases. In 2001, for example, the Commonwealth Department of Health and Aged Care funded the National Centre in HIV Epidemiology and Clinical Research—overseen by ANCAHRD—to review surveillance data on the occurrence of HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia (National Centre in HIV Epidemiology, 2001, p. 1). The National Centre is affiliated with the Faculty of Medicine at the University of New South Wales. It reports general patterns of hepatitis C diagnoses in Australia such as the number of newly acquired hepatitis C infections by year and state/territory, and by age group, year and sex; the hepatitis C prevalence in blood donors and entrants to the Australian defence forces; and the number of liver transplants by year and primary cause of liver disease. Surveillance data for sentinel populations move perceptually to the cellular level of the body. Although imperceptible to the layperson, technologies such as recombinant DNA technologies, electron microscopy and molecular virology have given doctors and scientists the means to look beyond the surfaces and depths of the patient’s body to the cellular level. It is at this level that the “object”, the hepatitis C virus, is constructed. It is at this cellular level, too, that it is established whether a person is infected with the hepatitis C virus, or not. The National Centre, for example, reports the number of injecting drug users with the hepatitis C antibody in their blood detected by hepatitis C antibody testing of a “finger prick blood spot” (National Centre in HIV Epidemiology, 2001, p. 89). The Minister demonstrates his understanding of information acquired with such technologies. His justification for funding nucleic acid testing of blood, for example, is based on the observations that result from such technology—a technology that extends human perception. Responding to a request in parliament in May 2000 to outline health initiatives in the budget the Minister states:

There is money for nucleic acid testing of our blood. Our blood is already very safe but it can be even safer. Nucleic acid testing started some months ago and it is now formalised in this budget. I should inform honourable members that earlier this week I received the first advice that

a unit of blood that was contaminated with hepatitis C and that had tested normal on the ordinary tests for donated blood had in fact been picked up with nucleic acid testing as being hepatitis C positive. (House of Representatives, 2000, p. 16182)

As a conduit emitting information, the Minister depends on the perceptual fields and information systems associated with institutional sites such as the hospital, the laboratory, university faculties of medicine, and departments of population health.

Authors have examined the way that public health activities such as health promotion produces self-regulating subjects. Coveney (1998, p. 461) too draws upon Foucault's (1988; 1989) concept of the technologies of power to show how health promotion in the area of nutrition operates "through processes like surveillance and normalisation" thereby making individuals objects of control. The paradigm of partnership that frames public health policy on hepatitis C is sympathetic to the Liberal Party of Australia's (the major party of the Coalition Government) beliefs about the importance of: individual initiative, responsibility and enterprise; the role of voluntary effort and voluntary organisations putting the onus back on to the community; minimum Government intervention and the role of the private sector; and the decentralisation of power (Crosby, n.d.; Liberal Party, n.d.). While the Commonwealth Government retains power through bureaucratic control, the *Foreword* contains examples in which local empowerment is the espoused guiding principle:

The contributions by all participants in the process, especially State and Territory governments, are acknowledged and much appreciated...the Strategy provides State and Territory governments with the flexibility to respond to the particular demands of the epidemic in their jurisdictions. (Wooldridge, 2000a, pp. iii & iv)

There is a tension with the rhetoric of partnership and community noted previously. Paradoxically, the *Strategy* is accompanied by increased regulation and surveillance. The paradigm of partnership implies that there will be a shift of decision-making back to the local level. However, as outlined in Chapter Nine in relation to the subject position of news actors in the 7.30 *Report* "Hepatitis C Increasing to Epidemic Proportions" (Tynan, 2000), a hierarchy of institutionalised power exists in Australia governing standardised treatment protocols, national surveillance and regulating the provision of products such as medicines, blood and diagnostic tests for hepatitis C. Consequently, the patient undergoing treatment for hepatitis C, and the virus that the patient harbours, are positioned as objects of medical intervention. At the same time,

institutional bodies in Australia direct the conduct of the prescribing medical practitioner. Wooldridge (2000a, p. iv) states in the *Foreword* that the *Strategy* prescribes standards, and that partners implementing the *Strategy* are themselves subject to control to achieve prescribed ends: “The Australian National Council on AIDS, Hepatitis C and Related Diseases will report to me on the *Strategy*’s implementation...The *Strategy* [ensures] that consistent national standards are maintained.” In effect, Wooldridge outlines government by the state in relation to hepatitis C via a range of practices including: policies (such as the *Strategy* that sets the framework of resources, services, environments, responsibilities and standards to ensure population health in response to the hepatitis C epidemic); programs (such as needle and syringe programs); and communication techniques (such as health-promotion messages). This reflects the construction of the nation state providing paternalistic intervention (including the policing of ordinary citizens, groups of citizens and organisations by the state) as the community has let the state down. The way in which the vocabulary and the syntax of the text achieve a separation of Australia the nation state from the community is discussed in the next section.

Hepatitis C a “Challenge” to Modern Science and Medicine

The text creates motivation for the professional reader to follow the instructions or commands of the Minister by a number of rhetorical devices such as the phatic functions of the text, figurative language, the expressive function of the text, and the way in which Wooldridge constructs Australia, the nation-state.

In the *Foreword*, the Minister compares recent Australian history to the present. In the opening paragraph he first describes what happened before and then applies this to the present problem and situation:

Australia is leading the international community in responding to the hepatitis C epidemic, and this pioneering strategic document establishes a comprehensive framework to guide future action. Australia is recognised as a world leader in developing and implementing effective population health responses to other blood-borne viruses—and now we aspire to mirror these achievements for hepatitis C. These earlier lessons and experiences provide us with a platform to launch a renewal of our efforts to deal with the serious impacts of hepatitis C within the Australian community. (Wooldridge, 2000a, p. iii)

This opening serves to attract and maintain the attention of the audience by exploiting phatic communication functions (Jakobson, 1981, p. 24). In this respect the *Foreword* is

similar to political speeches that also exploit phatic functions to capture the attention of the audience and make and keep contact with them (Trosborg, 2000, p. 122). In his leadership role as Minister for Health and Aged Care, Wooldridge appeals to the patriotic pride of health care service providers in the results of past population health programs for dealing with communicable blood-borne viruses on a national scale. Australia's history and status as a world leader in this area is emphasised through repetition in this opening paragraph. The opening sentence is jingoistic: "Australia is leading the international community...this pioneering document" (Wooldridge, 2000a, p. iii). He tries to convince readers that they can approach hepatitis C in a similar professional manner. This sentence is repeated with a single word change in Chapter One of the *Strategy*: "Australia is leading the world in responding to the hepatitis C epidemic" (Commonwealth Dept Health & Aged Care, 2000b, p. 7). The same tenor is found in Wooldridge's media release accompanying the launch of the *Strategy*: "this Strategy, which is believed to be the world's first national strategy on hepatitis C" (Wooldridge, 2000b). In his closing statement Wooldridge (2000a, p. v) employs political rhetoric to convey his deference for his professional readership: "I commend to you the National Hepatitis C Strategy 1999–2000 to 2003–2004". The *Foreword* is Wooldridge's eulogy to the myth of Australia's pioneering background that makes Australians great inventors, competitive and desirous of being at the cutting-edge of scientific research and practice. The Minister is, himself, linked to the achievements of the recent past, and continuity is established as he acknowledges the evolution of knowledge and practice in the field.

Recent past efforts, though, have fallen short in relation to hepatitis C. The prevalence of the disease in the Australian population as a whole is the impetus for action: "the hepatitis C epidemic is already well established in our community—more than 200,000 Australians are already infected" (Wooldridge, 2000a, p. iii). Wooldridge's use of statistics, the noun "burden" and the adjectives "serious" and "advanced illness" in the second paragraph of the *Foreword* emphasise the drain on the Australian community posed by hepatitis C. Rather than being a millstone, though, the hepatitis C epidemic is framed as a challenge (a test), and a puzzle for modern science and medicine, the professional audience. Professionals working in the area invoke such a representation. For example, Dr Cheryl Brunton (1999, p. iii), from the Department of Public Health and General Practice at the Christchurch School of Medicine in New Zealand, writes in the foreword to the conference proceedings of the second

Australasian conference on hepatitis C: “the global hepatitis C epidemic poses a major personal and public health challenge...there is still much we still do not know and there are many challenges still to be met”. The *Foreword* is almost entirely lacking in figurative language. However, one of the few metaphors used repeatedly by Wooldridge is that of the challenge, evoking the notion of a “test” that makes demands on the skills or abilities and the intellect of the Australian scientific and medical communities. The hepatitis C epidemic is given form as a challenger in phrases such as “future challenges the epidemic may present” (p. v). The epidemic is portrayed as a stimulating test of abilities, and the Minister is confident of success. He implies that Australia will be judged by other nations in relation to its ability to deal with the hepatitis C epidemic. Cohesive chains of words concerning forward movement are evident: “renewal”; “a sense of urgency and momentum”; “next phase of our response”; “lessons” and “experiences” (p. iii). The Minister expresses his faith that the Australian scientific and health care communities will succeed in dealing with hepatitis C just as they succeeded in dealing with other blood-borne viruses. The professional community will respond with military precision—mounting manoeuvres—as previously discussed.

The expressive function of the *Foreword* to the *Strategy* concerns Wooldridge’s attitude, his personal opinion or evaluation and values. In this regard, the expressive function of the *Foreword* is subjective (Fairclough, 1989, p. 119; Jakobson, 1981, p. 22; Trosborg, 2000, p. 123). Wooldridge’s opinion is evident in his choice of lexis, that is, the stock of words, and the connotative meaning(s) suggested by words or phrases in the *Foreword* (Fairclough, 1989, pp. 118–119; Trosborg, 2000, p. 123). Wooldridge appeals to values associated with the scientific medical process. The previous discussion of the representative function of the *Foreword* shows Wooldridge using statistics as “transparent” evidence to persuade audiences. As Filc (2004, p. 1277) argues, the practice of evidence-based medicine deals with statistics and epidemiology uncritically as providing fact. The dominant ideology evident in the *Foreword* values science as improving life for those Australians infected with the hepatitis C virus and the Australian community generally. Ideology can be described as “a set of social values, ideas, beliefs, feelings, representations, and institutions by which people collectively make sense of the world they live in” (O’Shaughnessy & Stadler, 2002, p. 191). However, Fairclough’s (2003, p. 9) critical approach goes beyond this representative function to consider ideologies as “representations which can be shown to contribute to social relations of power and domination”. Thus meanings, assumptions and

presuppositions evident in texts should not be “taken as given” (Fairclough, 1989, pp. 2–5; 2003, p. 58) (this will be discussed further in subsequent chapters on the *Strategy* and news media discourse).

Wooldridge (2000a, p. iii) emphasises the progressive scientific advances in relation to hepatitis C: “our knowledge of the factors affecting transmission and progression to advanced illness is evolving...we must act now using the best available evidence while still pursuing an improved knowledge base”. In this he alludes to technological advances that are specified in the *Strategy* such as the development of: blood testing for antibodies to the virus; nucleic acid testing that permits direct detection of the virus in the blood; genotype testing; and antiviral drugs. He also alludes to fields of study such as virology, concerned with the scientific study of the hepatitis C virus and of hepatitis C (the disease the virus causes), molecular biology, epidemiology concerned amongst other things with the natural history of the virus, and clinical medicine. He assumes that his audience values science similarly. This echoes the dominant narrative in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) analysed in Chapter Nine. Wooldridge assures readers that they can look to and trust science (including medicine) to solve the problem of the hepatitis C epidemic. This is the myth of science as problem solver, socially neutral with its benefits equally distributed (Fiske, 1990, p. 170).

The Minister refers to Australia as a single entity, separated from the people (Australians) who live in Australia. He opens the *Foreword*: “Australia is leading the international community” and continues: “Australia is recognised as a world leader” (Wooldridge, 2000a, p. iii). Australia is identified as a nation by reference to particular attributes (O’Sullivan, Hartley, Saunders, Montgomery & Fiske, 1994, p. 321). Australia is constructed in relationship to other countries as a nation recognised for leading the way in population-wide health programs dealing with blood borne viruses. It is portrayed as a “world leader” in science and medicine. Australia (the abstraction) becomes a reified object. Australia (the island continent) is transformed into Australia (the being) at the syntactic level, that is, through the grammatical structure of the sentence. As noted, the text expresses Wooldridge’s “liberal” beliefs, attitudes and feelings about the role of technological advances in science and medicine, and of government, in relation to the hepatitis C epidemic. The text reflects a willingness to take an empirical approach—a practical-operational orientation as previously

discussed—to the hepatitis C epidemic; medicine and government based on practical experience rather than solely on theory and scientific proof:

Our knowledge of the factors affecting transmission and progression to advanced illness is evolving, but we cannot defer action until all the pieces of the puzzle are in place: we must act now, using the best available evidence while still pursuing an improved knowledge base. (Wooldridge, 2000a, p. iii)

The hepatitis C epidemic is discussed as a problem requiring consideration, of relevance to population health policy. Australians infected with hepatitis C are portrayed as affecting Australia (the state) in a negative way and hence pertinent to government and institutions such as medicine. In particular, those who inject illicit drugs are presented by the Minister as having some bearing on the current and future state of Australian society:

With over 90 per cent of all new hepatitis C infections occurring among people who inject drugs, the increasing use and injection of illicit drugs in Australia will have a powerful influence on the course of the hepatitis C epidemic here. (Wooldridge, 2000a, p. iv)

The need to guard the collective health of the Australian population is a spur to professionals, that is, motivating them to make a greater effort. Injecting drug users are to be encouraged by professionals, such as public health and health care professionals, to utilise needle and syringe programs, thereby normalising particular types of injecting practices yet not condoning illicit drug use (see previous discussion of subject positions constructed in the discourse). This requires identification of injecting drug use. The diagnosis of hepatitis C infection is accompanied by medical examination that scrutinises the patient's actions, past and present, to determine the route of transmission of the hepatitis C virus. Injecting drug users are to alter and reduce risky injecting practices, thereby policing themselves to prevent contracting and/or transmitting the hepatitis C virus to others in the community. With diagnosis comes the obligation for all patients to undertake self-surveillance (no matter how they contracted the virus).

Conclusion

In this chapter I have discussed the *Foreword* to the first *National Hepatitis C Strategy: 1999–2000 to 2003–2004*. The *Foreword* reflects a high degree of Commonwealth Government decision-making in which the expert and/or professional voice dominates. This chapter provides an in-depth textual analysis of a seminal public health policy document on hepatitis C and a critique of the discourse. It raises questions in relation to assumptions about community participation in the partnerships espoused by the *Strategy*, and documents the way in which the *Foreword* draws mainly on scientific and medical discourses to represent hepatitis C in public health policy.

The communicative function of the *Foreword* is both directive and commissive. The Minister appeals to his primary audience—state/territory and local governments, medical, scientific, and health care service providers—to acknowledge their responsibility to the “broader” Australian community, to prevent the transmission of hepatitis C within the Australian community, and to do their part in improving the health of affected persons.

The Minister emphasises that the *Strategy*—as a population health policy—has a strong scientific, evidentiary base. His reference to experts tells of the strong links between the medical and scientific research communities and the health policy decision-making community in Australia. In the *Foreword* it is implied that people living with hepatitis C are involved in the construction of knowledge around the virus. Still the “medical formation lays claim over the personal domain” as Krug (1995, p. 317) found. Scientific and medical knowledge of the hepatitis C virus has greatly increased since Krug reviewed the medical formation of hepatitis C. It is such scientific discovery and technological advances that Wooldridge (2000a) places value on, and says will protect the Australian community against the hepatitis C epidemic. In the *Foreword* scientific and medical discourses construct the hepatitis C virus as an object and those living with the virus as patients. The *Foreword* also clearly constructs hepatitis C positive people as IDUs, identifying the disease with the major risk behaviour for transmission of the virus.

The Minister’s reference to the affected community suggests strong support for the policy from that direction. In order to obtain the position of a partner and participate in the development on public health policy on hepatitis C, though, hepatitis C positive

people (and organisations representing them) have had to narrow their differences on hepatitis C. The hepatitis C-positive person and their representative organisations are subject to the ways of representing the epidemic by the professions. Even though the Government consulted the hepatitis C-affected community when developing the *Strategy*, experts carry the most weight. The text privileges professional, expert knowledge about hepatitis C over that of hepatitis C positive persons. It naturalises the perspective of professional communities (such as the medical and scientific communities). The partnership approach is an important method or technique in engaging those infected with the virus, and diluting any resistance.

The professional reading audience—charged with implementing the *Strategy*—is asked to put aside their philosophical beliefs and assumptions about injecting drug use and consider the evidence. The hepatitis C epidemic is framed as predominantly amenable to scientific, biomedical and managerial interventions (including risk management). However, such framing obscures, for example, the socio-cultural phenomena implicit in the Minister’s instruction to state and territory governments to provide needle and syringe programs. Despite the rhetoric of the *Foreword*, and the inclusion of hepatitis C positive people and IDUs on bureaucratic committees involved in the development of public health policy around hepatitis C, people who inject illicit drugs in a manner that does not conform to acceptable standards remain excluded. The text constructs the subject position of IDUs as self-governing individuals. Importantly, though, IDUs who do not conform to the notion of the responsible IDU constructed in this text are marginal to the discourse.

Critical discourse analysis provides useful information about the population-level health policy decision-making process around hepatitis C. Representations of the disease and of hepatitis C positive people in the *Strategy*—a document that directs professionals to take a particular course of action and adopt a particular perspective—are discussed in subsequent chapters.

CHAPTER FOUR

THE STRATEGY: PROFESSIONALS SPEAK FOR AND ABOUT HEPATITIS C-POSITIVE PEOPLE

When HIV first threatened the Australian community, governments responded quickly and effectively...The public health response to hepatitis C has been nowhere near as decisive...In responding to hepatitis C we are taking on an epidemic that is well-established and primarily affects a group of people [IDUs] who are extremely marginalised within society. In addition, by and large hepatitis C is not perceived as a major threat to the broader community.

– Annie Madden, Australian Injecting &
Illicit Drug Users League (AIVL), 2004

Introduction

In the preceding chapter I described the persuasive and hortatory communicative purposes of the foreword (the *Foreword*) to the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b), which draws heavily upon the discourse patterns of the institutions of science and medicine. In the *Foreword*, the then Minister for Health and Aged Care (the Minister), Dr Michael Wooldridge (2000a), is the named social identity speaking about the hepatitis C epidemic in Australia. He is legitimated to speak about people affected by hepatitis C and to speak about them to others. In presenting the problem to be addressed by the *Strategy* and how the problem is to be dealt with, the Minister delineates concepts, specifies objects, gives arguments and justifications (Lemke, 2001, p. 191), and nominates “partnership” as the core strategy for implementing public health policy. The *Foreword* and the *Strategy* illustrate aspects of Foucault’s (1979) concept of “governmentality” outlined by Lemke (2001), in particular, the rationalisation of the control and management of the “hepatitis C epidemic” by the state, which co-opts non-

government organisations (NGOs) as agents for the expert management of the health of populations, and the construction of the hepatitis C-positive individual as morally responsible for his/her behaviour. The Minister employs the politics of separating the nation state from the community, constructing the nation as requiring paternalistic state intervention because members of the community have let the state down. People living with hepatitis C are involved in the development of the *Strategy* as clients of the then Commonwealth Department of Health and Aged Care (the Department) despite the rhetoric of partnership. It is argued that the 1970s Whitlamesque rhetoric of bottom-up community engagement, although standard in health policy discourse, is gutted, driven by the small “I” liberal, small state ideology of the Australian Federal Coalition Government (the Government) that abhors large-scale government intervention and privileges normative individuals and the nuclear family as the pivots of the nation-state.

The vocabulary of the *Strategy* points to the way in which the Department, on behalf of the Government, represents the natural and the social world. Producers of the *Strategy* draw upon styles or genres (including classification schemes) from specific types of professional discourse, thereby restricting who has ready access to the discourse (Fairclough, 1989, pp. 62–65; Van Dijk, 1993, pp. 255–256). The Government’s ideological perspective of the world is coded in the vocabulary of the text, that is, the experiential value of words (Fairclough, 1989, pp. 112–114). The *Strategy* is an expository text that publicly explains what is the case, what ought to be done, and the Government’s plan for dealing with the hepatitis C epidemic. Despite the rhetoric of partnership with affected communities, it is a prescriptive text in which people with hepatitis C are spoken for and about, rather than permitted to speak for themselves. The vocabulary reflects the dominant health paradigm, and expresses concern for control and containment of the hepatitis C virus and those infected with the virus, in particular injecting drug users (IDUs).

The focus of the analysis in this, and following chapters, is those aspects of the text that maintain the dominance of the professional community over the hepatitis C-affected community. To this end, the language, and the ideological and dominant assumptions embedded therein, is examined. It is important to consider this public health policy discourse, as it is part of the context for the experiences of persons affected by hepatitis C in Australia from 1999 onwards. The *Strategy* is the inaugural population health policy addressing the hepatitis C epidemic in Australia, and serves as a template for subsequent strategies. It formalises the language for talking about

hepatitis C and people affected by hepatitis C, and it sets the forms for interactions between governments, medical, scientific and health care professionals, and between these professional communities and the lay community affected by hepatitis C. As Cooren (2004) argues texts, such as policy documents, span both space and time, contributing a stabilising effect on organisational activities. As a text, the *Strategy* is controlling; it tells members of the partnership what it is they are to do, and what it is they are accountable for (see Cooren, 2004, pp. 384–385).

The Language of Government: A Strategically-Oriented Approach

The introductory pages of Chapter One of the *Strategy* permit a study of the language of government. In this section I argue that the vocabulary of the text constructs the Government as being effective and accountable in its response to the hepatitis C epidemic, its policy underwritten, as it were, by experts. As the Government's response to the hepatitis C epidemic, which is portrayed as a threat to the health of the Australian population, the text addresses professionals first and foremost through its formality, conventions of design and whole-text language organisation. Moreover, the strategically-oriented approach adopted by the Government has the potential to impact negatively on advocacy by hepatitis C NGOs.

A Blueprint for Professionals

The formality of the text constrains access to the discourse as it places demands on participants in social relationships (Fairclough, 1989, p. 65). The complex sentences and restricted language set favoured in the *Strategy* indicates the status and position of the intended audience of this text. Terminology intended for managers, for example, includes words and phrases such as: “partnerships”; “linked”; “optimal implementation”; “coordination”; “surveillance”; “monitoring”; “evaluation”; “performance indicators”; “nationally consistent standards”; “clarification of roles and responsibilities”; and “work plans”. The restricted accessibility of the vocabulary of the text is reinforced by the whole-text language organisation of the text, that is, the large-scale structures of the text (see Fairclough, 1989, pp. 137–138).

The *Strategy* lists limited education or a low standard of literacy, which adversely impacts health maintenance, as a characteristic of an undisclosed number of people living with hepatitis C (Commonwealth Dept Health & Aged Care, 2000b, pp.

1–2). The *Strategy* is not aimed at these people (or they are unable to read it). In terms of the standard of literacy required to read the *Strategy*, the text best suits those readers with a professional background. The readability scoring tools of the Microsoft® Word 2000 word processing program were used to calculate the reading level of the *Strategy* (Microsoft Corp, 1999). The Flesch Reading Ease score is “normally used to assess adult materials”, whereas the Flesch-Kincaid Grade Level rates the text according to elementary and secondary grade school levels in the United States (Micro Power & Light Co, n.d.; Microsoft Corp, 1999). The *Foreword* and Chapters One, Two, and Three of the *Strategy* were sampled. These pages contain aspects of the format that is repeated throughout the *Strategy*, specifically, an introductory paragraph and bulleted lists of objectives, guiding principles, challenges, and opportunities. The readability scores of this sample of text were as follows:

Averages

Sentences per paragraph	3.0
Words per sentence	27.0

Readability

Passive sentences	3.0
Flesch Reading Ease	12.7
Flesch-Kincaid Grade Level	12.0

The Flesch Reading Ease score of 12.7, of this sample of text from the *Strategy*, indicates that the text is difficult to understand (standard documents score between 60 to 70 on the 100-point scale). The Flesch-Kincaid Grade Level score of this same selection of the text is 12 (standard documents score between 7 to 8). By comparison, Chapter Nine of this thesis, “News Actors and the Dominant Discourses in Media Coverage of Hepatitis C: A Case Study”, has a Flesch-Kincaid Grade Level score of 12, and a Flesch Reading Ease score of 33, indicating that it is easier to understand than the *Strategy*. In a study of selected articles published in the *British Medical Journal* and *JAMA* in 2001, Weeks and Wallace (2002, p. 1451) consider scores less than 30 on the Flesch ease of readability index as extremely difficult reading for the public. It is inferred that the *Strategy* is more difficult to read than the text of this thesis, and best suits a reading

audience with an above average standard of literacy, specifically the professionals listed in the partnership.

Although addressing an audience of above average literacy, the whole-text organisation of the document reflects an attempt to provide for clarity through design features. The conventions used present elements in a particular order linking parts together, and includes pedagogical devices intended to create a reader-friendly document (Fairclough, 1989, p. 137; 2001, p. 257). In so doing, though, the *Strategy* addresses an audience that is familiar with the closely related genres of technical writing, including professional scientific and research articles or reports and business reports, all of which have a consistent format (Trosborg, 2000, p. ix). This audience will, therefore, have certain expectations about the content and the format of the *Strategy*, that is, the way in which the publication is presented, organised and arranged (Fairclough, 1989, p. 138).

The producers of the *Strategy* have used a consistent format throughout to organise information in the 83-page document. The text contains many of the major components found in technical and scientific communication: front and back covers; title page; edition notice; table of contents; foreword (in place of a preface); introduction; body chapters; glossary; abbreviations; and references (McMurrey, n.d; Perelman, Paradis & Barrett, 1998). This national strategy is linked to the *National HIV/AIDS Strategy 1999–2000 to 2003–2004: Changes and Challenges* and the *National Drug Strategic Framework 1998–99 to 2002–03: Building Partnerships: A Strategy to Reduce the Harm Caused by Drugs in Our Community* by elements of cover design such as: the position of the title; simple typeface; the border on the top and right-hand side; the location of the logos of the Australian Government and the Commonwealth Department of Health and Aged Care at the top and right-hand borders respectively; and the absence of images other than the logo (see Figure 2). Visually, the three documents form a set, differentiated one from the other by cover colours: the hepatitis C strategy in dark maroon; the HIV/AIDS strategy in dark blue; and the drug strategic framework in aquamarine. It is assumed that the colour-coding and consistent design are for the benefit of professionals, for example, managers in the public health sector, who are most likely to use all three documents. At a glance, the cover design of the *Strategy* is not consumer-friendly and inviting; it projects expertise and speaks to a specialised audience:

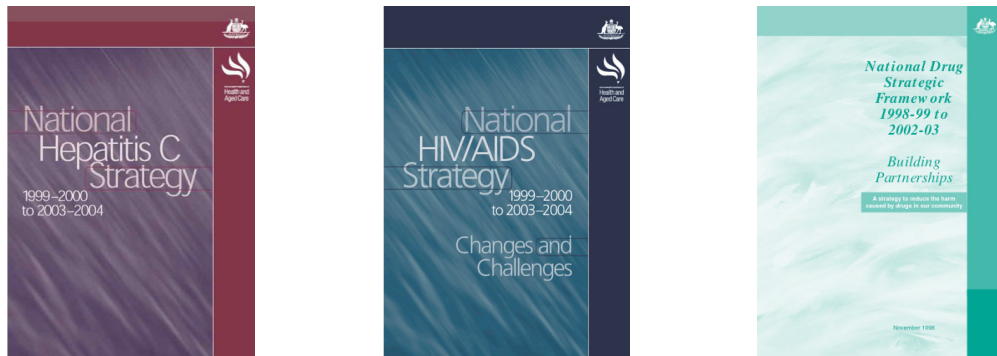


Figure 2. Covers (left to right) *National Hepatitis C Strategy 1999–2000 to 2003–2004*; *National HIV/AIDS Strategy 1999–2000 to 2003–2004: Changes and Challenges*; *National Drug Strategic Framework 1998–99 to 2002–03: Building Partnerships: A strategy to reduce the harm caused by drugs in our community*.

Source: Commonwealth Dept Health & Aged Care, 2000b & 2000c; Ministerial Council on Drug Strategy, 1998.

The title page of the *Strategy* duplicates the cover minus the artwork and organisational logos, while acknowledging the Commonwealth Department of Health and Aged Care as both the author and the producer of the text (Fairclough, 2003, p. 12). Department staff, which wrote or produced the document, are not acknowledged, thereby attributing the work of individual people to the Department and “reaffirming the identity and existence of the organisation” (Cooren, 2004, pp. 379–380). The edition notice on the verso of the title page gives: the date of publication; copyright symbol and copyright statement regarding permission to copy the text; the publications approval number; and details of the in-house production unit. Apart from the cover, colour is not used in the *Strategy*. This and the modest page design give a certain impression of the Government and its *Strategy*. It suggests that the Government is not one that wastes public money, but is modest in its expenditure. It suggests that the Government is concerned with efficiency. It suggests, too, that the *Strategy* is, foremost, a communication tool of the Government, with practical application.

Reference to the author(s) of the *Strategy* is not given so the Commonwealth Department of Health and Aged Care is taken as the author, speaking on behalf of the Government. As in a preface, the *Foreword* (Wooldridge, 2000a) by the Minister, preceding the table of contents, is a commentary on the Government’s intentions in producing the *Strategy*, thereby introducing its proposed action. Emphasis is placed on

summarising for the reader “the problem” that the *Strategy* addresses. Contextual detail is also given to establish why the problem is important, along with the Government’s plan to solve the problem. Such problem-solution framing is a feature of texts written for a managerial audience (Perelman, Paradis & Barrett, 1998, p. 19) as it implies a solution and an expert with that solution.

The whole-text language organisation of the *Strategy* indicates that the text targets a mixed audience of experts and managers with a specific level of technical expertise and specific uses (see Perelman, Paradis & Barrett, 1998, p. 13). The text is suitable for general and specific experts who have extensive knowledge in the field of hepatitis C. Managers, such as those responsible for state/territory public health hepatitis C services, are likely to be general experts in the field of hepatitis C. A glossary lists specialist terms and their definitions that may be unfamiliar to general experts and managers. Only two instances of in-text definitions were found, those for the terms “prevalence” and “incidence” in the introductory chapter. For the most part, glossary definitions conform to usual technical writing practices in that they are incomplete sentences, give information about the class the term belongs to, explain its distinguishing characteristics, and, in the case of complex terms, give supplementary definitions and more detailed discussion (McMurrey, n.d.). Acronyms and other abbreviations that may be familiar to specific experts but not general experts are listed on the abbreviations page following the glossary. Background information is supplied in Chapter One and at the start of subsequent chapters, and concepts are presented in detail appropriate to the general expert and the manager (Perelman, Paradis & Barrett, 1998, pp. 13 & 14). Hence, the explanation of the concept of “harm reduction” in Chapter Two incorporates its place within the Government’s *National Drug Strategic Framework*, and the actions directed towards reducing drug-related harm (the processes).

The implementation of the *Strategy* by managers in the health care sector at the State level is linked to performance indicators in funding agreements as will be discussed later on. The brevity of the *Strategy* and the segmentation of information make the document especially suited to such managers (see Perelman, Paradis & Barrett, 1998, p. 14). It is also suited to managers who are responsible for making decisions on behalf of consumers, though not necessarily suitable reading for the layperson (nor is it, with its utilitarian cover design, likely to be attractive to the layperson). The table of contents contains three levels of detail that are outline

numbered and provide descriptive headings for each section to help the reader locate information within the text (see Appendix G). The organisation of sections within the nine chapters is standardised for the four priority areas of action listed on page two of the *Strategy*, with the following headings repeated in each: “Objectives”; “Guiding Principles”; “Contexts”; “Challenges”; and “Opportunities”. Additional headings are included to further help readers locate specific information. For example, the contents for “Contexts” in Chapter Four, “Treatment of Hepatitis C Infection”, contains five additional headings: “The Potential Demand for Treatment”; “Barriers to Clinical Treatment”; “Testing”; “Access to Treatment”; and “Complementary and Alternative Therapies”.

As its title implies, the *Strategy* promotes the Government’s policy direction in relation to hepatitis C. It presents the problem and its solutions. Each chapter introduces data and arguments in support of the Government’s list of objective. A list of guiding principles outlines the Government’s platform, the basis of its proposed action. Obstacles to achieving its objectives are discussed under “Risk” and “Context”, and form the largest component of Chapters Three to Six. Visually this draws the reader’s attention to the enormity of the task confronting the Government and health care service providers. However, readers who are pressed for time may skim these sections and focus on those sections foregrounded by bulleted lists. The section entitled “Challenges” lists solutions to the problem, what needs to be done. The section “Opportunities” primarily shows the links that service providers operating under the banner of the *Strategy* are to pursue with other parts of public infrastructure such as mental health services. The implementation of solutions listed under “Opportunities” is covered again in the Chapter Seven “Roles and Responsibilities” and Chapter Eight “Implementation”. Of particular relevance to a managerial audience is the complex array of activities embedded in communication arrangements such as: national committees; funding arrangements; work plans; and mechanisms to track performance and measure how well objectives have been achieved. The final chapter of the *Strategy*, “Monitoring and Evaluation”, lists internal and external monitoring and evaluation activities. The evaluation section has secondary status in the overall *Strategy*.

The producer uses pedagogical devices or conventions common to the genre to try to make the *Strategy* easier to read and understand, and to orientate the reader (McMurrey, n.d.). For example, the footer for the left-hand, even-numbered page includes the title of the text with the page number, and the right-hand, odd-numbered

page includes the title of the chapter. The three levels of descriptive headings (differentiated by bolding and diminishing font size the lower the heading level) demarcate sections and subsections of the *Strategy*. As in the table of contents, headings use a numerical outlining system that would be familiar to a particular reading audience. Bulleted lists, standard dot, emphasise important points and increase the amount of white space. In technical writing bulleted lists are indicated for items that do not require an order (McMurrey, n.d.). Authors of the *Strategy* go further and state, for example, that the essential components of Australia's response to hepatitis C listed "are complementary and non-hierarchical" (Commonwealth Dept of Health and Aged Care, 2000b, p. 11). The improved rapid scanning and emphasis that comes with the use of bulleted lists, however, is undercut by the use of headings as lead-ins to lists in many sections, and the over-use of lists with greater than seven items (and in some instances, greater than ten items).

The text lacks examples and analogies to illustrate concepts for the lay reader. A level of knowledge is assumed as the following excerpt from Chapter Three of the *Strategy*, "Reducing Hepatitis C Transmission in the Community" shows:

Both sharing and re-using injecting equipment are risk behaviours associated with particular cultural and social determinants. The meanings and rules of sharing and re-using—including the items shared and the social circles where the sharing takes place—will vary across communities and social contexts. (Commonwealth Dept of Health and Aged Care, 2000b, p. 23)

This excerpt, from the subsection "Risk Factors and Contexts", assumes that the reader has background knowledge about the way in which people in groups behave and interact. Concepts such as "risk behaviours" and "social determinants" are, therefore, not explained or illustrated and so function as jargon. In addressing professionals, particularly managers in the public health sector, the *Strategy* links the work of the public sector, in safeguarding the Australian community from hepatitis C, to performance indicators in funding agreements.

Safeguarding the Australian Community from the Hepatitis C Epidemic

The *Strategy* reflects a strategically-oriented model for performance measurement for the public sector as described by Atkinson and McCrindell (1997) in the business magazine of the Society of Management Accountants of Canada (CMA

Canada). This approach has been widely adopted by the Australian Government, which has published a range of national strategies including: the *National Palliative Care Strategy*; the *National Drug Strategic Framework 1998–99 to 2002–03: Building Partnerships*; the *National Mental Health Plan 2003–2008*; the *National Action on Illicit Drugs 2001 to 2002–3*; *Changes and Challenges: National HIV/AIDS Strategy 1999–2000 to 2003–2004*; the *National Heroin Overdose Strategy*; and the *National Alcohol Strategy: A Plan for Action 2001 to 2003–4*.

The *Strategy* is an extensive, public five-year project. The document, itself, “remains active” (Cooren, 2004, p. 385) over this period of time, and until superseded. In accordance with the strategically-oriented model, the *Strategy* links the Government’s goals and priorities to the performance of the public sector (and its agents) by identifying and communicating its objectives to public sector managers and other stakeholders in the partnership, that is, state/territory and local governments, community organisations, people affected by hepatitis C, and the medical, healthcare, scientific and research communities. This model is similar to that of the national governments in Britain, New Zealand, the United States, and Canada from the early 1990s (see Atkinson & McCrindell, 1997).

The vocabulary represents the Government as accountable to, and protecting, the Australian population as a whole. In the *Foreword* the Minister acknowledges the Government’s responsibility for the health of the Australian population, with the vocabulary of the text reflecting his sense of obligation. The vocabulary of the *Strategy* emphasises the Government’s leadership and ability to deal with the epidemic, to safeguard the community and consider the interests of all stakeholders as evident in the following statements:

- Strong and inclusive response from all levels of government, community organisations, the medical, health care and scientific and research communities, and people affected by hepatitis C;
- People affected by hepatitis C are central to the success of this *Strategy*;
- Promote and support the health, safety and wellbeing of all Australians in relation to hepatitis C;
- Most effective way to reduce the harms to individuals and the community;
- Regardless of how hepatitis C infection is acquired, the social, medical and economic impacts for the individual and the broader community are profound;
- Health outcomes for all will be improved by preventing discrimination and alleviating the stigma and isolation;

- Responding to the challenges and building on the opportunities the *Strategy* links with government policies.
- Build[ing] on achievements;
- Two primary aims;
- Four priority areas for action, [and]
- Essential components. (Commonwealth Dept Health & Aged Care, 2000b, pp. 1–2)

The Department, on behalf of the Government, is concerned with producing a favourable impression on its professional reading audience, those affected by hepatitis C, and the general community. To that end, the vocabulary is about being effective, that is, getting the intended result. A key component of the strategically-oriented approach, therefore, is that the Department will assess whether or not those organisations (both public and private) that deliver Government hepatitis C-related services achieve the Government's aims, and progress the four priority areas for action.

According to a web-based survey of the perceptions of staff of Australian NGOs that engage in “advocacy”, “lobbying”, or “activism” about the barriers that limit their participation in public debate, conducted by The Australia Institute (TAI), the strategically-oriented approach has proven problematic for some NGOs in Australia (Maddison, Dennis & Hamilton, 2004). The authors report that Government funding agreements and the perceived threat of “defunding” constrain NGOs’ ability or willingness to speak about Government policy at both the local level and the national level, resulting in “self-censorship” and conformity to the Government’s line (p. x).

This study of the *Strategy* does not delve into the effects that acceptance by hepatitis C-NGOs of Government contracts to deliver services has on their advocacy on behalf of the hepatitis C-affected community. However, in response to a letter about these issues written by executive director of TAI (Hamilton, 2004, p. 5), the editor of the Hepatitis C Council of NSW’s newsletter replies that the relationship between governments and the News South Wales (NSW) Council has not significantly limited public debate by the Council in NSW. The experience of workers of the Hepatitis C Council of NSW may be in keeping with that of many of the NGOs in the TAI survey, which report that state governments are less likely to seek to silence public debate than the Federal Coalition Government (Maddison, Dennis & Hamilton, 2004, p. 38). Moreover, the workers of the Hepatitis C Council of NSW operate within the context of a state public health system that since the mid-1990s committed to developing a network of partnerships between service providers, managers, government, and the

affected community, engaging community participation, and developing “capacity building” at a community level to assist communities to determine public health issues and problems and their solutions (Hawe, 2000, p. 22; Webster, 2002, p. 134; Zonta & Wilson, 2000, pp. 26–27). Nevertheless, the Hepatitis C Council of NSW relies on its “Deductible Gift Recipient” status to attract private donations to undertake activities, such as advocacy, that are not funded by its “statutory grant providers” (Hepatitis C Council of NSW, 2003, p. 3). Instances of advocacy by the hepatitis C-NGOs can be found. The story “Call for Health Minister to Act on Hepatitis C Report” (Yaxley, 2003), broadcast on the Australian Broadcasting Corporation’s (ABC) AM radio program, is one such example. In this news report the president of the Commonwealth-funded Australian Hepatitis Council (AHC), the peak organisation of state/territory hepatitis C councils, is openly critical of the Government’s actions:

Louise Yaxley [journalist]: The review of the hepatitis C strategy, which has been in place since 1999, says there’s been inadequate research and surveillance and a lack of resources to fight the disease. The President of the Australian Hepatitis Council, Stuart Loveday, says the Health Minister, Kay Patterson, should not keep sitting on the report because the epidemic is growing so rapidly.

Stuart Loveday: Now we recently received information that the estimated new infections has gone up by 45 per cent, from an estimated 11,000 new infections in 1997, to an estimated 16,000 new infections in 2001. Now that represents an increase to a level of one new hepatitis C infection every 30 minutes.

Louise Yaxley: Stuart Loveday backs the review’s findings that not enough is being done.

Stuart Loveday: It’s as if the Federal Government has hit the pause button. Nothing is happening. Nothing seems to be happening at a national level and there are services on the ground which are being threatened. In one case in New South Wales, we understand that social workers and hepatitis C clinical nurse consultants have had to be let go.

While the TAI survey includes NGOs from the field of “disability and mental health”, the relevance of its findings to hepatitis C-related NGOs (including peer-based IDU groups)—which the federal government funds to deliver services—warrants further study.

As well as assessing the performance of organisations contracted to deliver hepatitis C-related services, the *Strategy* specifies that state and territory governments are to submit program performance reports to the Department. In the final chapter of the *Strategy* it is stated that the Department will collect and publish “State and Territory governments’ performance information against agreed indicators in their respective

Public Health Outcome Funding Agreements” (Commonwealth Dept Health & Aged Care, 2000b, p. 66). Disease surveillance reports, individual project reports, and research reports from various national centres will also be considered. On receipt of this information, the Minister, who is at the apex of the reporting hierarchy of a complex and sophisticated information network (described in the preceding chapter), will be able to judge whether the following have occurred: a reduction in hepatitis C transmission; a move forward in treatment programs; improvements in health maintenance, care and support for people affected by hepatitis C; less discrimination; and reduced stigma and isolation. Thus the Minister will be able to inform the Cabinet, and the Australian people, about the effectiveness of the activities of Government and its agents (see Atkinson & McCrindell, 1997, pp. 20–21).

The Department, as the “principal Commonwealth agency”, has the responsibility for providing “public information on action being taken to prevent hepatitis C transmission” (Commonwealth Dept Health & Aged Care, 2000b, p. 55). A feature of the Government’s mode of operation is the communication of information to the public via the Department’s website. The *Strategy*, for example, is available free to the public on the Internet. A wide array of other hepatitis C-related documents can be downloaded including the following: media releases by the Minister for Health and Aged Care and those by the National Health and Medical Research Council; statistical estimates of the hepatitis C epidemic, such as the *Hepatitis C Virus Projections Working Group: Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2002* (ANCAHRD, Hepatitis C Sub-Committee, 2002); statements about Commonwealth action on hepatitis C; information for consumers; information for health professionals; indexes of hepatitis C research (categorised as virological and immunological, epidemiological and clinical, and social); and summaries of completed hepatitis C research. The Department also publishes information about decision-making bodies. A list of the members of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH), established in 2003, for example, is available from the Department’s website.

Making information freely available contributes to the construction of Government activity in relation to the hepatitis C epidemic as transparent. Although some publications are also available in printed format, the increasing use of the Internet to distribute information assumes that the public readily uses this technology. However, the Electronic Information Access Project, commissioned by the Department in 2000,

identifies constraints to access to electronic information by workers and volunteers in HIV/AIDS councils, hepatitis C councils, drug user groups, needle and syringe programs and by people who have HIV/AIDS, hepatitis C or who inject drugs (Queensland Alcohol & Drug Research & Education Centre, 2001, p. 1). The constraints listed in the key findings of this report include: low income (below \$40,000); low educational attainment; lack of knowledge about available information; lack of skills; and lack of infrastructure and resources (particularly at home). The timing of the publication of information may also affect whether or not the Government is perceived as “transparent” in its activities. The Government chooses the moment to release information to, or withhold information from, the public thereby affecting perceptions of its transparency. In one instance, *The Australian’s* “Secret Report Hid Hep C ‘Epidemic’” (Schubert, 2003) and the aforementioned “Call for Health Minister to Act on Hepatitis C Report” (Yaxley, 2003) broadcast on ABC Radio’s AM program, report that the Federal Health Minister, Senator Kay Patterson, failed to promptly release the independent review of the *Strategy*, which she held for over six months, because reviewers were particularly critical of the impact of the Government’s “zero tolerance” drug policies on hepatitis C transmission rates and of the lack of resources to implement the *Strategy*.

In Chapter Two of the *Strategy*, the Department forewarns readers that the federal government’s ability to achieve the results it seeks hinges as much on the states and territories as on national initiatives. The “success” of the *Strategy* “depends on” the states and territories taking the “approach” embedded in the “Six Essential Components”:

- Developing partnerships and involving affected communities;
- [Improving] access and equity;
- [Developing] harm reduction [interventions];
- [Undertaking] health promotion;
- [Undertaking] research and surveillance, [and]
- Link[ing] strategies and infrastructures. (Commonwealth Dept Health & Aged Care, 2000b, p. 11)

“Depends on” is an ambiguous phrase. It may signal that the Federal Coalition Government has confidence in the state and territory governments’ ability to develop, or move forward with, activities outlined under the essential components over the five-year period. In an alternative interpretation, the Federal Coalition Government’s success in dealing with the hepatitis C epidemic will be decided by the implementation

of the *Strategy* by the state and territory governments (and their agencies). Ironically, implementation of the *Strategy* by state and territory governments and contracted service providers (including NGOs) depends on Commonwealth funding, which is surrounded by uncertainty as will be discussed.

Despite the importance of the state and territory governments' implementation of the *Strategy*, and the lack of detail of funding agreements, the federal Government is constructed as taking the hepatitis C epidemic seriously and responding appropriately. To this end, the final sentence of the introductory chapter reads: "The importance of hepatitis C as a significant population health issue is also demonstrated in its reflection in the title of the ministerial advisory committee [Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD)]" (Commonwealth Dept Health & Aged Care, 2000b, p. 9). ANCAHRD, the named body with the right to "speak" about hepatitis C, and to speak about people with hepatitis C to others, draws mainly on the institutional sites of medicine, science, academia, and public health management. The specification of "Hepatitis C" in the title of this national advisory body is represented as affording the disease and those living with hepatitis C status and prominence in the public health sphere. It suggests, too, that the Minister is doing something about hepatitis C. In Chapter Two of the text readers are reassured that the Government is on the right path, and that the *Strategy* is the culmination of dialogue with and between interested groups:

Lessons learnt from other population health strategies, as well as the 1998 review of Australia's response to hepatitis C, informed the process of identifying these components. The components were also strongly supported in the public forums convened and the written submissions received as part of the national consultations associated with the *Strategy's* development. (Commonwealth Dept Health & Aged Care, 2000b, p. 11)

The Government is represented as: responsive; proactive (for example, convening formal public forums); consultative (for example, considering submissions); and reflective, with "lessons learnt" from past strategies and commissioned reviews.

The concluding paragraph of Chapter One of the *Strategy* informs readers that the Minister will receive "independent" and "expert" advice regarding progress from the ANCAHRD. While the Minister's authority in relation to others (modality) is stipulated, it is the choice of the words "independent" and "expert" advice that is significant. As discussed in the preceding analysis of the *Foreword*, expert groups such as ANCAHRD

and its successor, and related subcommittees, have limited descriptive representation (Contandriopoulos, 2004, p. 322) as members are appointed by the Minister predominantly from the upper ranks of the Australian medical, scientific and managerial communities, rather than being “similar to the ‘average’ [person] represented”. Institutional sites of medical discourse, such as the laboratory, tertiary treatment centres and public health agencies such as the Surveillance and Epidemiology Section of the Commonwealth Department of Health and Ageing, inform the Government’s response to the hepatitis C epidemic. “Expert”, then, relates to persons who possess the type of knowledge produced and re-produced within and through the practices of these institutional sites. Experts are knowledgeable in their particular field, hence able to provide specialised information to the Minister. Experts are likely to employ the problem-solving and reasoning processes associated with their field. Experts may strive to be free from the control of, or the influence from, interested parties. However, they are unlikely to be independent of the knowledge and practices of the institutions of medicine, science, epidemiology, and other professional sites heavily represented in the partnership. The producers of the *Strategy* acknowledge the authoritative sources of information—by in-text citations of the author and date of publication in parentheses—used to explain what is being said or to support the Government’s position. This convention, commonly associated with academic writing, helps to establish the Government’s intellectual integrity, credibility and its ability to take good care of the Australian community in relation to the hepatitis C epidemic.

Conclusion

The *Strategy* establishes a frame for future hepatitis C-related health policy-making. In this chapter, I have shown that the standard language of the *Strategy* is not the language of lay people with hepatitis C, and constructs a barrier to community participation. The text is a blueprint for professionals dealing with the affected community and the hepatitis C epidemic. In the next chapter, the dominance of experts in the development and implementation of hepatitis C public health policy that espouses the involvement of the hepatitis C-affected community amongst stakeholders is considered.

CHAPTER FIVE

THE STRATEGY: CONTROLLING PARTICIPATION OF HEPATITIS C-POSITIVE PEOPLE

As a guiding principle of the National Hepatitis C Strategy, involving affected communities in the response to hepatitis C is critical to the Strategy's success...One of the ongoing tenets of our response to hepatitis C is the principle that health services and policy should reflect the needs of people with hepatitis C—rather than those of service providers and policy-makers.

– Australian Hepatitis Council,
Position Statement, September 2004

Introduction

In the preceding chapter I argued that the language of the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b), which frames future hepatitis C-related public health policy-making in Australia, forms a barrier to community participation. The text is a blueprint for professionals dealing with the affected community and the “hepatitis C epidemic”. It is a prescriptive text in which the hepatitis C virus is spoken about, and people with hepatitis C are spoken for and about. Advocacy by hepatitis C non-government organisations (NGOs) may be limited by the Federal Coalition Government’s (the Government) strategically-oriented approach, which links funding to performance.

In this chapter, I argue that the rhetoric of partnership in the *Strategy* reflects a particular notion of public participation that is controlling and constraining. Although representatives of hepatitis C NGOs and peer-based injecting drug users (IDU) groups participated in the development of the *Strategy*, their role was subsidiary to that of the professional members of the partnership. The development of the *Strategy* followed a

rational, problem-solving model of policy-making controlled by public sector professionals, and dominated by professionals from biomedical sciences, public or population health, and academia. Community representatives remain on the periphery of networks (including social networks) that influence hepatitis C public health policy-making such that any consensus reached can be regarded as “selective”. In this model of policy development and implementation NGOs are required to conform to professional practices. Moreover, the complex that constitutes the partnership has adopted the professional voice with which to express itself, pushing the lay voice further to the margin.

Consumer Participation in the Formulation of the Strategy

The *Strategy* espouses the establishment of partnerships between people affected by hepatitis C, all levels of government and the medical, scientific and health care communities (Commonwealth Dept of Health & Aged Care, 2000b, pp. iii & 12). Incorporating public participation in health care decision-making has been a concern of governments in Australia and overseas countries including Britain, Canada and the United States for over two decades, and the establishment of partnerships between interest groups is not a new practice of government (Charles & DeMaio, 1993; Fairclough, 2001, pp. 245–266; Singer, 1995; Stewart, 1999, pp. 309–331; Webster, 2002). The evolution of Australia’s national HIV/AIDS policy, which integrated hepatitis C policy and action plans from the mid 1990s until the development of the *Strategy*, was characterised by consultation with, and participation by, the gay community (Dowsett, 1998, p. 178). The national hepatitis C policy follows on with the principles of the 1986 Ottawa Charter specified as providing the “basis” of the *Strategy* (Commonwealth Dept of Health & Aged Care, 2000b, p. 15). However, as shown in a later chapter, the Government’s model of communication in the *Strategy*—which state and territory governments and health care service providers are directed to take up—also resembles that of the public relations company Edelman in relation to its inclusion of affected communities (Edelman, 2000, 2001, n.d.).

The language of the *Strategy* is carefully worded to be inclusive of people infected with hepatitis C, reinforcing the representation of the Government as fair and equitable towards all Australian citizens. It is an assumption of the text that its readers value partnership positively (an expressive value of this text). With the priority areas set, the *Strategy* is not a discussion document, but the Government’s plan of action, one

that attempts to effect certain social relations. In directives the text commits members of the partnership to: implementing the *Strategy*; regarding other partners as important and useful; talking to other partners; and engaging them in activities. The Commonwealth Department of Health and Aged Care (the Department) stipulates that people affected by hepatitis C should be involved in the planning, delivery and evaluation of policy and services. The preoccupation with partnership as a public health strategy, and participation by people affected by hepatitis C and the hepatitis C-affected community, is expressed in words such as: “share”; “value”; “foster”; “dialogue”; “collaborate”; “consult”; “support”; “inclusive”; and “joint decision-making”. Such “overwording” (Fairclough, 1989, p. 115) is echoed in the *Foreword* (Wooldridge, 2000a) as previously discussed. Whereas the Minister employs the inclusive first person plural pronouns “we” and “our”, the use of the modal verb “will” in the *Strategy* effectively orders members of the partnership to take an “inclusive approach”:

- [Will] share a commitment to the aims of the National Hepatitis C Strategy;
- [Will] value the diversity of views and expertise within the partnership;
- [Will] foster continuing dialogue between partners;
- [Will] draw on expertise from various disciplines;
- [Will] collaborate, consult and coordinate across diverse sectors, [and]
- [Will] support partnership members in fulfilling their roles and responsibilities. (Commonwealth Dept Health & Aged Care, 2000b, p. 12)

Details of public participation in the development of the *Strategy* itself are available in Lowe and Cotton’s (1999) report *Hepatitis C: A Review of Australia’s Response*, (a discussion of which follows).

The *Strategy* offers a particular view of Australian society through its portrayal of the social relationships between, and the status and power of, members of the partnership: the Government; professional managers in the public health sector; professionals in the scientific and health care sectors; and workers in the community sector. In its position statement entitled “Beyond Tokenism—Increasing Consumer Participation in Our Response to Hepatitis C”, the Australian Hepatitis Council (AHC) (2004b, p. 1) advocates the inclusion of people with hepatitis C in policy planning. NGOs have a central role to play in ensuring that marginalised and stigmatised groups have a voice in Government policy development, implementation, monitoring, and evaluation (Maddison, Dennis & Hamilton, 2004, pp. vii–viii). The discourse of the *Strategy*, however, belongs to specific institutional and societal processes, and reflects the dominance of particular perspectives and the continued inequality of power relations

between professional experts and consumers or the hepatitis C-affected community (the lay community). Further, the influence of professional experts is largely maintained through the formal social networks involved in the *Strategy's* development, implementation, monitoring, and evaluation.

The production of information associated with the development of the *Strategy*, produced by the Department, is consistent with rational or problem-solving models of policy-making outlined by Feldman (1989, p. 80). The Department commissioned a review, which was coordinated by Department staff, to inform the development of the *Strategy*. The review, conducted by management and health services consultants David Lowe and Ruth Cotton, focuses on a specified problem, namely, the population health response to the hepatitis C epidemic before 1998. The report, entitled *Hepatitis C: A Review of Australia's Response* (Lowe & Cotton, 1999), was intended to inform policy-making, that is, the development of a strategic document outlining the plan for Australia's future response to the epidemic. The review, commenced in 1998 and published in January 1999, is bounded by, and draws upon, existing policies, in particular, the *National HIV/AIDS Strategy 1996–97 to 1998–99* (which integrated the *National Hepatitis C Action Plan*). Lowe and Cotton's report was directed towards shaping the Department's decision process, and the *Strategy* reflects the Department's close use of this document.

The specialised expertise of the consultants in the public sector areas of education, community services and health (Mandala Consulting, n.d.) framed Lowe and Cotton's (1999) review and report writing process, which in turn informed the Department's policy-making. Lowe and Cotton collected information by the following direct and indirect means: submissions from the general public sought by a national media advertisement; submissions sought by invitation to specific individuals and organisations; a survey of the implementation of the recommendations of the 1994 *National Hepatitis C Action plan* and the 1995 *Nationally Coordinated Hepatitis C Education and Prevention Approach*; interviews with state/territory health care services providers (including nursing, medical, counselling, public and environmental health), researchers from national drug and alcohol research centres, community groups (including hepatitis C, HIV/AIDS, haemophilia and injecting drug user groups) and correctional services about the management of hepatitis C; and mid-review workshops with professional services providers to discuss the information collected and models (pp. 179–188).

Parts of Lowe and Cotton's (1999) report were written by individuals or small groups of people from the following organisations: the Department's Evaluation and Research Unit in the Population Health Division; the National Centre in HIV Epidemiology and Clinical Research within the Faculty of Medicine at the University of New South Wales; the Department of Public Health at the University of Sydney; the Victorian Infectious Diseases Reference Laboratory; the AHC; and community groups, namely, the Hepatitis C Council of Victoria and the Australian Intravenous League (AIVL). These departments and organisations are major players in the development of the *Strategy*. The network of departments, organisations and committees (the governance structures) for dealing with the issue of the hepatitis C epidemic mentioned in Lowe and Cotton's report are also found in the *Strategy*. The institutional sites from which information was sourced, and from which the processes for commenting originated, reflect particular ways of thinking about issues and concerns, and of determining what is relevant, what is a problem or potential problem, and who should be involved in solving it. This can be seen in the emergence, over a number of years, of interpretations of the issues and concerns around hepatitis C in Australia which reflect a shared understanding of the need for a hepatitis C strategy in its own right rather than under the umbrella of HIV/AIDS.

The mid-review workshops run by Lowe and Cotton (1999), that produced information for the production of the *Strategy*, indicate what Feldman (1989, pp. 100–101) terms “concurrence”, that is, a commenting process for reaching agreement between representatives of organisations or groups. Participants had the opportunity to define or re-define issues and concerns, and influence the facts represented in the report according to the interests of the organisation or group that they acted for. The perspectives from which the consultants, Lowe and Cotton (1999), and staff from the Department see the hepatitis C epidemic influenced which organisations were included in the consultation process. Who is consulted is an important decision, which subsequently affects the content of reports that inform policy-making, as Feldman's (1989) work the United States' experience shows. The role of the project officers and the program advisers in, and consultants hired to produce reports for, state/territory and Commonwealth departments of health in Australia has parallels with “bureaucratic analysts” in the United States, having “analytic skills and responsibilities” and requiring “hierarchical approval” within the public sector (see Feldman, 1989, p. 4). In her

observations of the process of information production and policy-making in the US Department of Energy, Feldman notes:

Determining which organisations are relevant to a given issue or request for information is not only a question of history, politics, and knowledge, but also of interpretation or perspective. The perspective from which one sees an issue influences which organisations appears to be related to the issue. (p. 100)

The consultation process in the development of the *Strategy* is no exception. Those participating in the mid-review workshops of the review of Australia's response to hepatitis C reflect expertise in the following areas: public health and population health at both state/territory and federal levels; specialist medical practice; general medical practice; research, particularly epidemiological and clinical; alcohol and drug services; correctional services; community-based support groups; peer-based injecting drug users services; and academic and public sector management. Individuals are listed in the review's appendix by name, organisation and their position. For this study, workshop participants listed by Lowe and Cotton (1999, pp. 185–188) were grouped into categories and frequencies calculated (shown in Table 2).

Despite their inclusion in the consultation process, NGOs may not counterbalance the influence of other members of the partnership over government decision-making as is one of the important functions of NGOs identified in the discussion paper *Silencing Dissent: Non-Government Organisations and Australian Democracy* published by The Australia Institute (TAI) (Maddison, Dennis & Hamilton, 2004, pp. vii–viii). According to Newcombe (2004), from the Department of Consumer and Employment Protection in Western Australia, certain voices are “lost” in evaluations of public policy: “Affected parties do not get equal input to the review process...Consultation processes still favour the urban, educated, articulate and empowered”.

Table 2

Categories of Workshop Participants for Hepatitis C: A Review of Australia's Response, Conducted by Lowe and Cotton 23 July 1998

Ranking	Category	<i>n</i>
1	State/territory public / population health	10
2	Academic &/or medical research/ & public health	8
3	Federal public / population health	7
4	Specialist medical	7
5	Advisory body (HIV/AIDS & related diseases; clinical trials & treatment; & alcohol & drug related)	3
5	General medical practice	3
5	Corrective services	3
5	Injecting drug use organisation	3
5	Peak body (Hepatitis C &/or HIV/AIDS)	3
6	Drug & alcohol clinical services	2
6	Consumer / support group (hepatitis C & haemophilia)	2
	Other	2

The majority (66%) of participants in the mid-review workshop run by Lowe and Cotton (1999) were drawn from the categories of “State/Territory Public/Population Health” (mainly, departments or units for diseases control and population health planning including evaluation and research), “Medical and Academic and/or Medical Research”, and “Federal Public/Population Health” (see Appendix H for listing of participants by organisation and position). State/territory and federal public/population health and advisory body representatives make up 37.7% of the mid-review workshop participants (and were likely, to have taken a position, much like the bureaucratic analysts in Feldman’s (1989, p. 73) study, that reflects a balance between their own expertise and the position of their department on the hepatitis C epidemic and related issues). Those participants from the categories of “Consumer or Support Groups”, “Injecting Drug User Organisations” and “Peak Bodies (Hepatitis C and/or HIV/AIDS)” comprise 15% of the total number of mid-review workshop participants. Groups representing recipients of hepatitis C-contaminated blood products exclusively—groups that differentiate members as “tainted blood victims” (Tainted Blood Product Action

Group, n.d.)—are absent. It is assumed that the Haemophilia Foundation of Australia represents haemophiliacs infected with hepatitis C through blood products used in their treatment (Haemophilia Foundation Australia, 2005), and the Hepatitis C Council of New South Wales, and representatives of peak bodies such as the AHC and the Australian Federation of AIDS Organisations represent all people affected by hepatitis C. Overall, there is a gross imbalance of medical and bureaucratic representatives compared to lay representatives, the latter of which are fractured into small groups.

Both the process of reviewing Australia's response to hepatitis C and the written document, *Hepatitis C: A Review of Australia's Response* (Lowe & Cotton, 1999), incorporate the advice of an advisory committee, that of the chairperson of the Australian National Council on AIDS and Related Diseases (ANCARD), and that of staff of the Evaluation and Research Unit of the National Population Health Planning Branch. Sections were written by a number of contributors and Evaluation and Research Unit staff coordinated the project (see Appendix I). Even though half of the advisory committee members were drawn from the categories of consumer or support groups, injecting drug user organisations and peak bodies, these categories (representing the lay person affected by hepatitis C) comprise just below one-third of the total number of named persons who provided advice on the review process and the written document. Like the mid-review workshop, the majority of advisors to the review were drawn from the categories of public or population health, medical, scientific, and academic and/or research. Lowe and Cotton's report reflects the framing of the problem by this group of influential contributors, experts whose advice subsequently influenced the development of the *Strategy*. As with the *Strategy*, the institutional sites from which the discourse of Lowe and Cotton's review derives are predominantly those of the biomedical sciences (including epidemiology and public health), academia and public or population health. The selection of advisors and contributors frames the review process and the content of the report from the perspective of the "expert", in particular, professionals from the medical, scientific, and the public sector (public and population health) communities. The content of Lowe and Cotton's report reflects the concerns of those involved in the processes of consultation (from whom they acquired information), concurrence, and writing, including chapters or sections of the report. This arrangement forms the context of the process of policy development in Australia in relation to hepatitis C. Subsequently, much of the content and the concerns of the review are found in the

Strategy, particularly in relation to the emphasis on epidemiology, research and the push to increase the number of people undertaking antiviral treatment for hepatitis C.

Community Representatives on the Periphery of Networks Influencing Policy-Making

Illicit Drug Users Support Call for Community Representation on Top Federal Government Advisory Committee on HIV & Hepatitis C...Ms Jackie Du Dayle, AIVL President said “some of the appointments to the newly formed Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH) seem to fly in the face of 20 years of experience and proven effectiveness.”...AIVL believes there is an urgent need for a review of the membership of the MACASHH to ensure that appropriate community representatives are included. AIVL is also very concerned about the appointment to the MACASHH of individuals with no clear expertise on HIV/AIDS, hepatitis C or sexual health matters.

– Ms Jackie Du Dayle, President, Australian Injecting & Illicit Drug Users League (AIVL), Media Release, 2004

Despite adhering to the principles of economic rationalism and a minimalist government role in all aspects of the economy, the Government utilises state bureaucracy extensively, including public-funded NGOs, for its policy-making and the implementation of the *Strategy*. The Government is informed and influenced by a network of inter-connected, long-standing:

- Expert committees (such as the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) and its hepatitis C subcommittee;
- Organisations (including national research centres);
- Departments (such as the Evaluation and Research Unit of the National Population Health Planning Branch of the Department’s Population Health Division); and
- Other bodies (such as the National Health and Medical Research Council (NHMRC), which coordinates and funds hepatitis C research and is a member of the National Public Health Partnership).

These expert committees, organisations, departments, and other bodies, link researchers and policy-makers, thereby “feeding into the priority setting, and ensuring key policy-makers are aware of relevant research” (Hanney et al., 2003, p. 16). Networks are represented as a key means of canvassing and engaging participation, signalled by overwording (Fairclough, 1989, p. 115) such as: “cross-membership”; “forums”;

“intergovernmental committee”; “intersectoral cooperation”; and “liaison groups” (Commonwealth Dept of Health & Aged Care, 2000b).

However, a relatively small number of experts in Australia belong to the social networks that influence policy-making processes and the way in which hepatitis C and hepatitis C-positive people are spoken about. This occurs through mechanisms such as: membership of bureaucratic committees like the Australian Government Department of Health and Ageing’s Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH), which replaced ANCAHRD in September 2003; professional roles; research publications; and participation at professional meetings such as research conferences.

An example of an expert who belongs to the social networks that influence hepatitis C policy-making processes in Australia is physician Professor Robert Batey. He is a member of the advisory committee for Lowe and Cotton’s (1999) review, is Chairperson of MACASHH (and was formerly Chairperson of ANCAHRD) and holds the position of Clinical Chair in the Division of Medicine at John Hunter Hospital in Newcastle, New South Wales (Australian Govt Dept Health & Ageing, 2004b). Batey publishes clinical research findings in journals such as the *Medical Journal of Australia* (*MJA*), the journal of the Australian Medical Association. Batey authored or co-authored nine research articles between 1994 and 2003 published in the *MJA*. In the same period Batey is cited by authors of four other clinical research articles published in the *MJA*, and receives thanks for his role as a reviewer in five issues.

In his editorial “Hepatitis C: Where are We At and Where are We Going?” Batey (2002) summarises the progress in Australia’s handling of the hepatitis C epidemic, and in a subsequent editorial, he discusses the findings of a Commonwealth Government report on needle/syringe programs in Australia (Law & Batey, 2003). Not only do expert networks function to generate knowledge (including evaluative information), but their members may put pressure on the Government and other bodies in relation to hepatitis C in accordance with their personal perspective. For example, Batey (2002, p. 362) informs readers of the *MJA* that the following needs to be done better in relation to hepatitis C:

Needle/syringe programs, while unpopular with many people in our society, have the potential to reduce the risk and must be supported by those who are in a position to influence policy...The HCV research effort requires further support from major funding bodies.

Batey also calls for debate within the community about, and evaluation of, alternative strategies including: “medically supervised injecting centres, drug law reform, a trial of medically supervised prescription of illicit drugs for treating refractory drug users, [and] introduction of harm-minimisation strategies in prisons” (Law & Batey, 2003, p. 198).

Experts like Batey, who have formal roles in public health policy networks and strong ties in professional networks, are important figures in the diffusion of ideas. Batey’s status is recognised by community-based groups like the Hepatitis C Council of NSW, which lists him as one of the medical and research advisors for its newsletter the *Hep C Review*. However, further study is required to determine whether Batey, and others like him, should be regarded as “central” or as “marginal” figures when it comes to urging their peers, the Government and the Australian community to adopt politically-controversial public health innovations such as medically supervised injecting centres (see Granovetter, 1973, pp. 1366–1367).

Those spoken about in hepatitis C-related public health policy, particularly IDUs, generally do not belong to the aforementioned social networks that influence policy-making processes. In relation to drug policies, Duff (2004, p. 387) cites Wodak’s (2000) comment that: “‘Consumer groups’ have been largely excluded from the public policy process in Australia”. There are exceptions such as Ms Annie Madden who represents AIVL—the national peak body for state/territory IDU organisations—on the Hepatitis C Subcommittee of MACASHH (and on the former ANCAHRD committee). The advisory committee of Lowe and Cotton’s (1999) review also includes a representative of peer-based IDU groups. According to Madden (2002), AIVL is unique in receiving funding for its work on bureaucratic committees: “Most drug user organisations...only get funding to carry out peer education programs and activities”. IDU groups in the community sector are not alone with respect to the lack of Government funding available for them to engage in their advocacy role and activities to inform the public policy process. In the previously mentioned survey by the TAI completed by 290 NGOs—to find out NGOs’ perceptions of the barriers limiting their participation in public debate—76% of organisations received no Government funding to help them participate in Government consultation processes (Maddison, Dennis & Hamilton, 2004, pp. 32–33). Most of these groups undertook activities such as writing submissions to Government inquiries, yet the costs of this work were not Government funded, and were borne by the NGOs themselves.

Although Madden's professional role as a representative for IDU groups on hepatitis C-related bureaucratic committees is funded, she is conscious that IDU-representatives do not belong to the social networks that influence policy-making processes. In her opening plenary address at the 4th Australasian Hepatitis C Conference, Madden stresses that drug-user organisations are located on the periphery of, with only a minor involvement in, the social networks that influence policy directed towards people who inject drugs:

As far as AIVL is concerned, one of the main missing ingredients in our current response to hepatitis C in Australia is the lack of genuine engagement with and involvement of current or active injecting drug users. (Madden, 2004)

The participation of IDUs at research conferences, too, is limited and problematic as she tells the audience at the International AIDS Conference in Barcelona in Spain:

I would like to begin by telling you that I am a current or "active" injecting drug user. I have been a heroin injector for over fifteen years...I don't always identify as an active injecting drug user at international conferences such as this...It is dangerous for me...[A]s far as I know, I am the only 'out' injecting drug user at this entire conference. Think about it...an international conference on HIV/AIDS with over 15,000 people in attendance and I may be the only active injecting drug user speaking at or attending the conference. (Madden, 2002)

Madden's position as "the only 'out' injecting drug user" is in contrast to that of the gay community leaders and professionals listed by Dowsett (1998, pp. 186–188) in his description of the professionalisation of HIV/AIDS policy activism from 1983 to 1996. Workers from NGOs are conscious of the disparity in the status afforded by conference organisers to members of the biomedical community and that given to members of the hepatitis C community sector presenting at international research conferences in Australia. The following anecdote by a project officer of the Hepatitis C Council of Victoria about the 2002 annual conference of the Australasian Society for HIV Medicine reflects this inequality:

Miscalculating the shape of the hep C 'sector', the conference organisers placed the clinical streams in the largest rooms of the Masonic Centre, and the community/research streams in the smaller ones. While smaller rooms were crammed with enthusiastic community health oriented people spilling out into the foyers, the larger rooms had, by comparison, plenty of room for the few who occupied them. (Johnson, 2002, p. 6)

With the exception of Lisa Waller's (2004) personal perspective, "Living with Hepatitis C: From Self-Loathing to Advocacy", articles by IDUs (current or past) are infrequently published in the *MJA*. Waller's personal account carries less authority than that of contributors of medical research articles and editorials by medical experts published in the *MJA*. Newsletters of community sector organisations distributed to members, (often available on organisation websites), regularly publish personal stories written by hepatitis C-positive IDUs. While targeting the lay community, such newsletters have readers amongst health professionals who are members of the organisation. The AHC (n.d. (b)), for example, specifies "people with hepatitis C, Hepatitis Councils and health professionals" amongst the readership of its publication, *The Australian Hepatitis Chronicle*. The extent of the professional readership of lay hepatitis C-related publications, and the impact on figures in the social networks that influence policy-making processes, though, is not known.

As noted, participation of the hepatitis C-affected community in the development, implementation, and ongoing monitoring of the *Strategy* is firmly controlled via the bureaucratic network established for such purposes. Outlining the roles and responsibilities of partners implementing the *Strategy*, the Department emphasises "strong ties" within a hierarchical network—such as national and state and territory community-based organisations—for the diffusion of influence and information (Commonwealth Dept Health & Aged Care, 2000b, p. 55). The AHC and AIVL, as designated representative bodies on Ministerial committees such as MACASHH, are significant connections between groups of people. In such an arrangement, these national organisations may function as "bridges", that is, "a line in a network which provides the *only* path between two points" (Granovetter, 1973, p. 1364). At times, the AHC functions as a bridge between professionals and other hepatitis C organisations or between the Government and hepatitis C organisations. Similarly, AIVL functions as a bridge between various groups and IDU organisations. However, Granovetter's (1973) work on the cohesive power of "weak ties" in social networks provides insight into the diffusion of influence and information and community organisation, particularly in fragmented groups. As will be discussed in relation to Australian news media representations of hepatitis C, it is widely believed that hepatitis C-affected people do not form a cohesive group, and nor do hepatitis C-positive IDUs (Booth, 1999; Campora, 1999, p. 147; Krug & Hepworth, 1999, p. 104; MacDonald, Sullivan, Locke, Wodak & Kaldor, 1998). Public health professionals

consider that the structure of the hepatitis C-affected community blocks community organisation and is problematic to the public health sector. The following comment by Dr Michael Wooldridge on ABC radio's *PM* program illustrates this view: "It's been much easier to deal with HIV because the people involved have been much better organised than the hepatitis C groups" (Nolan, 2003b). Former Health Minister, Dr Neal Blewett (1997, pp. 177–178) similarly identified the absence of "a network of [IDU] communities stretching from the national to the local level" compared to the gay community. Regarding the "AIDS/IV drug interface" Blewett noted: "As Federal health minister I inevitably had much less sense of what was happening on this front" (p. 178).

While the Government has set up a bureaucratic network of committees, advisory groups, forums, and the like, to coordinate the implementation of the *Strategy*, there may be alternative configurations of the network of relations between the Government and community-based groups that offer advantages to the lay community. Given the importance of interpersonal paths in the diffusion of ideas and the adoption of innovations, the inclusion of and funding for local peer-based IDU groups in "dyads", (that is, each local group participating directly in such bureaucratic groups rather than national organisations representing them), may strengthen ties as people get to know each other better over a period of time. With regard to organising communities at the local level, the existence of multiple weak ties that form bridges may be particularly important in fragmented communities (Granovetter, 1973, p. 1375). This is relevant to community-based groups such as the Hepatitis C Council of WA (HCWA) with its small membership—135 financial members in December 2003 including health care and allied professionals (V. Brown, personal communication, December 12, 2003)—as it tries to organise the hepatitis C-affected community throughout the large state of Western Australia. The importance of the development of social networks is recognised by community-based groups. The Hepatitis C Council of Victoria, for instance, announced the establishment of a Membership Advisory Group (MAG) as a means of engaging its lay members (Connor, 2002, p. 7). Further study is required to determine the ways that hepatitis C-related community groups in Australia (including peer-based IDU groups) set up management committees, interact with their membership, organise the hepatitis C-affected community, and build social networks within and between groups within a splintered community (including interpersonal ties and the manipulation of direct and indirect contacts, and the importance of reciprocity) to influence population health policy.

“Selective” Consensus

At first glance, it seems that the development of the *Strategy* reflects a consensus easily come by, as the text does not depict any sense of conflict between stakeholders. However, Lowe and Cotton’s (1999, pp. 131–135; 139; 140; 169–176) report, which informed the development of the *Strategy*, reveals issues and concerns that may have been points of disagreement amongst informants and advisors. Examples of disagreement include: the mismatch between injecting drug users’ hepatitis C-related health concerns compared to health care professionals’ perceptions of the same; different views on the legal status of illicit drugs held by members of the professional community; arguments for and against doing more to “combat” hepatitis C; and models for a “strategic response”. Within the population health bureaucracy of the Department to which the discourse belongs, there is, in Fairclough’s (1989, p. 193) terms, a “struggle” for support between stakeholders or participants.

As previously stated, staff from a number of government departments (at state/territory and federal levels) and community sector organisations took part in the consultation process for the development of the *Strategy*, and negotiated their interests. Written documents such as the *Strategy* are important because of the selective nature of the information presented, which affects how hepatitis C will be regarded in the future. The graphic accompanying a Department article on the development of the second National Hepatitis C Strategy 2005–2008 portrays the *Strategy* as the bottom of two toy building blocks, supporting the second and subsequent strategies (Australian Govt Dept Health & Ageing, 2005a p. 9). Feldman (1989, pp. 91–92), writing of the American situation, argues

The written document establishes a frame that becomes part of an organisational memory...the structuring that occurs affects how future as well as current readers understand the subject of the written document.

Feldman’s (1989) argument is applicable to the consultation process for the development of the *Strategy* in Australia. “Concurrence” implies that participants reached agreement on the interpretation of issues and concerns in Lowe and Cotton’s (1999) report and in subsequent policy. The *Strategy*, therefore, reflects something of the different perspectives of the stakeholders involved in its development and the agreement that they came to on issues. For example, it includes the seemingly consumer-focused “Preventing Discrimination and Reducing Stigma and Isolation” in the four priority areas, and “Access and Equity” and “Harm Reduction” amongst the six

essential components of the response. The then executive officer of the AHC says of the consultation process related to the development of the *Strategy*

I was really happy about the consultation and development process for the national strategy. Community sector (AIVL and AHC) was involved on both the steering committee and on the writing group of the strategy and we did a lot of harm reduction on what could have been. (J. Wallace, personal communication, March 2, 2004)

Wallace—incorporating the rhetoric around injecting drug use to describe the consultation and development process—expresses his satisfaction with the community sector's influence on the sort of information that was included in, or omitted from, the policy.

While representatives of hepatitis C consumer/support groups and injecting drug user groups cooperated with, and informed, those engaged in the development of the *Strategy*, it is difficult to imagine that they were able to extensively determine and refine issues (the most important topics for discussion) or concerns (matters that affect or are of significance to people living with hepatitis C) represented in policy documents. Wallace's statement, however, suggests that community sector workers have an image of themselves as tempering the biomedical and bureaucratic responses to the hepatitis C epidemic and towards people living with hepatitis C. In this regard, representatives from the community sector can be said to contribute to agreement on issues that preserve significant aspects of the interests and concerns of the hepatitis C-affected community. It is important, though, to remember the asymmetric participation of hepatitis C positive IDUs compared to other social groups (including health care service providers) in the development of population health policy on which Madden (2002; 2004) notes participation in is critical.

As the *Strategy* defines or frames the nature of future policy about hepatitis C, so too it influences the nature of information collected and inventoried, and subsequently the kind of information produced by health policy staff and others in the partnership. As Feldman (1989, p. 91) explains, information production is a facet of information interpretation. Hence, the way in which concerns of significance to stakeholders are associated with the issues or topics discussed in the process of health policy development about hepatitis C is assumed to affect the sorts of problems that are identified, and their solutions. Moreover, the experiential value of the language or vocabulary of the *Strategy* (a cue to the way the text's producers experience and

represent the social world) affects the development of solutions to the problem (Fairclough, 1989, pp. 112–114; 1995b, p. 16; Feldman, 1989, p. 91). The interpretation determines such concerns as: which group or groups are considered affected by the problem; which group(s) or authorities are considered best able to deal with the problem; and how to judge the effectiveness of the *Strategy*. It is assumed, too, that those experts evaluating the *Strategy*—for example, ANCAHRD with its dominant representation of medical and scientific professionals—frame their analysis according to the interests that they represent.

How participation by the community sector should work is briefly outlined in Chapter Seven of the *Strategy*. As shown in the analysis of the *Foreword*, however, the notion of “community” is not elucidated, and the representativeness of groups representing hepatitis C-positive people is problematic and community participation is not guaranteed. Under the heading “Roles and Responsibilities” in Chapter Seven of the *Strategy*, community organisations are allocated the role of representing the hepatitis C-affected community. Community organisations are expected to engage in activities such as advocacy and the delivery of health promotion, care and support services (Commonwealth Dept Health & Aged Care, 2000b, pp.60–61). “Advocacy” in the text seems to assign to community groups the work of pleading the cause of hepatitis C-affected people: “Advocating for the interests of people affected by hepatitis C in decision-making and policy formation” (p. 60). However, it is not clear if the advocacy role that the Department envisages for community groups is a consultative role, or whether the term refers to “robust” debate of public policy in a bid to influence outcomes of public health decision-making and policy formulation. In hindsight, Maddison, Denniss and Hamilton’s (2004, p. 5) finding of the Federal Coalition Government’s negative response to robust debate of public policy by NGOs make the latter interpretation seem unlikely. The way in which the text frames other activities proposed for community groups from the perspective of public health service providers also suggests that advocacy refers to a consultative role for NGOs, rather than an invitation to robustly debate public policy (let alone openly express dissent).

NGOs to Conform to Professional Practices

NGOs are co-opted into the network of organisations that deliver hepatitis C-related public health services in Australia, and are expected to take on, or conform to, the practices of the professionals who provide health care services including health care managers and Department staff. The Department stipulates that service planners and providers are to take an evidence-based approach when undertaking research and developing health maintenance, care and support services, as distinct from clinical treatment services (Commonwealth Dept Health & Aged Care, 2000b, pp. 16 & 41). As previously discussed in regard to the *Foreword*, evidence-based health policy-making, as with evidence-based medicine, is intrinsically linked to health economics (Black, 2001, p. 275; Filc, 2004, p. 1278, Hanney et al., 2003, p. 2; Hepworth & Krug, 1997, p. 5). Health promotion activities, including peer education, are also to be “informed by the best available evidence and program logic” (p. 16). Discussing a drug users’ group presentation at a scientific conference on hepatitis C, Krug and Hepworth (1999) similarly found that, in order to speak in such contexts, community groups have learnt to mimic professional behaviour and language.

Generally, the text suggests that evidence-based practice is straightforward and that the utilisation of research, for example, proceeds for the most part in a rational fashion that follows a linear sequence. Community participation in research is to occur at each of the stages in the linear sequence: the setting of the research agenda; design of the research study; execution of the research; and dissemination of the results (Commonwealth Dept Health & Aged Care, 2000b, p. 16). However, the use or otherwise of scientific evidence in health services policy-making and service provision may be determined by other considerations including: competing evidence (such as the policy-makers’ personal experience); competing pressures from the electorate (see, for example, Körner & Treloar’s (2003) examination of news reports about syringe finds in a school grounds and the subsequent closure of a needle exchange); the research design most favoured by decision-makers; and the relationships between policy-makers and experts who constitute an “epistemic community”, which will affect, for example, what researchers examine and the kinds of questions they ask (Black, 2001, pp. 275–276; Hanney et al, 2003, p. 6; Hepworth & Krug, 1997, p. 5). The *Strategy* refers to the utilisation of evidence from research that Hanney et al (p. 6) broadly categorise as basic, clinical, and applied research:

The main branches of research contributing to the population health effort to address hepatitis C are epidemiology, basic scientific research, virology, clinical research, and social and behavioural research...Both investigator-initiated and commissioned research have a role in guiding the national response. (Commonwealth Dept Health & Aged Care, 2000b, p. 16)

Utilisation of evidence obtained through different research designs is also alluded to in the text:

Multi-disciplinary collaboration is encouraged. Community involvement is necessary in setting the research agenda, in the design and execution of research...Initiatives from within local communities are also recognised for their contribution towards developing innovative approaches. (pp. 16–17)

Words such as “contribution”, “multi-disciplinary”, and “collaboration” imply that the stakeholders in the partnership will work together to achieve the aims of the *Strategy*. In this partnership, lay participants are portrayed as partly responsible for achieving the goals of the public five-year project. This representation of research activity fits Trist’s (1972) category of “domain-based” or “policy-oriented” research summarised by Hanney et al (2003, p. 6), which is interdisciplinary and “entails wider reference groups, beyond the scientific or clinical communities.” Government expenditure on biomedical, social and behavioural research is considered in a later chapter.

As well as participating in research, community organisations are to participate in “developing, delivering and evaluating policies and programs” related to hepatitis C (Commonwealth Dept Health & Aged Care, 2000b, p. 60). This phrase is meaningful in terms of the approach to program development taken by professionals in fields such as health promotion and education. In particular, the phrase suggests the sequencing of activities familiar to such professionals, including: needs assessment; planning; program design; implementation and evaluation of outcomes (both formative and summative evaluation, that is, during and after program implementation). The phrase also points to the contracting of NGOs by mainstream public sector departments to provide programs or services to clients, or produce something. Programs, linked to a temporal cycle and funding, will be developed to achieve a goal or set of goals. The phrase also indicates that the outputs of NGOs and the results or outcomes of programs NGOs deliver are important to the Department and will be evaluated. The Department favours performance measures, such as data, that can be measured as indicators of the outcomes.

The earlier statement about the participation of community organisations in program delivery, however, belies the problems experienced by NGOs in relation to funding arrangements. The difficulty for those working in the hepatitis C non-government sector stemming from the uncertainty of Government funding is expressed in the opening to the president's message of the 2002–2003 annual report of the Hepatitis C Council of NSW:

The Federal Government allocated \$15.9 million over four years to hepatitis C education in the last federal budget on top of funding for needle and syringe programs and drug and alcohol services, but the states are still waiting to hear how the Federal Government will allocate that money and until that happens NSW Health will not commit to continuing a significant portion of the Council's funding. There is every hope and expectation that the funding will be renewed and that the Council may even receive a greater amount than it has in the past. (Waller, 2003, p. 1)

Those working in peer-based community groups representing IDUs express even greater frustration about the funding of programs as the following comment from the executive officer of AIVL indicates:

Over the past 5–8 years, NSPs [needle and syringe programs] have constantly had additional, and in the case of hepatitis C, significant public health agendas added to their responsibilities...without the adequate levels of resourcing to effectively address those issues. Furthermore, the fact that NSPs have been unable to 'work miracles' with the resourcing that they have, has then been used to attack the effectiveness of NSPs and the integrity of drug users. (Madden, 2003, p. 2)

Madden's experiences echo Lemke's (2001) commentary about the shifting of state responsibility for illness, for example, onto the individual and collectives under neo-liberal forms of government:

[Neo-liberalism] responds to stronger 'demand' for individual scope for self-determination and desired autonomy by 'supplying' individuals and collectives with the possibility of actively participating in the solution of specific matters and problems which had hitherto been the domain of state agencies specifically empowered to undertake such tasks. This participation has a 'price-tag': the individuals themselves have to assume responsibility for these activities and the possible failure thereof. (p. 202)

The uncertainty experienced by workers in NGOs in relation to Commonwealth funding of hepatitis C services is not conveyed in the *Strategy*. This uncertainty, however, is reflected in commentaries of those working in the state and territory public

health departments. The then senior policy and planning officer for the Sexual Health and Blood-borne Virus Program with the Department of Health in Western Australia (WA), highlights such funding constraints in her article about the public health response to hepatitis C in WA written for members of the Hepatitis C Council of WA:

The response to hepatitis C has been severely constrained by a lack of funding to support initiatives in this area. The National Hepatitis C Strategy 1999–2000 to 2003–2004 was released with no funding attached to it....A further Commonwealth funding initiative relevant (but not specific) to hepatitis C is a package of measures under the National Illicit Drug Strategy [the Commonwealth of Australian Governments (COAG) funded needle and syringe initiatives]. The Federal Government recently announced that this COAG funding will continue for another four years. It is anticipated that WA will be offered a proportion of this funding and it is likely that the Department of Health will request funding proposals from key stakeholders in the near future. (Bevan, 2003, pp. 2; 4 & 5)

The phrases “it is anticipated” and “it is likely” convey a measure of insecurity and vagueness on the part of the state department of health, which may be assumed will flow on to the NGOs it contracts to provide hepatitis C services.

The vocabulary of the *Strategy* suggests that community participation is straightforward. However, these comments from workers in NGOs and state public health indicate that the inclusion of hepatitis C NGOs in the planning, delivery and evaluation of public policy and programs, while benefiting the affected community, is not without its problems. The lack of detail on the subject of funds and resources to implement the *Strategy* undercuts the description in the introduction of the *Strategy* as providing for a “strong and inclusive response from all levels of government [and] community organisations” (Commonwealth Dept Health & Aged Care, 2000b, p. 1). Funding arrangements may hold NGOs back from delivering services (at least for a period of time) or restrict their activities. Any controlling effect that contracting hepatitis C NGOs to deliver public health services has on the free expression of these groups, as Maddison, Dennis and Hamilton (2004) suggest, requires further investigation.

Excluding Lay Voices

“Life is a struggle. It’s a real struggle physically, emotionally, um, probably mentally. When people imply that it’s all in my head I start to ask myself, ‘What if it is all in my head?’ How can I imagine this pain?...And I’ve done the rounds of the doctors and naturopaths and said, ‘Look, I’m not well. I’m tired all the time, and this is wrong and that’s wrong.’ I was told I was neurotic and to get a life and all sorts of things. I just continued to get sicker and sicker. Finally I got diagnosed. You know it wasn’t all in my head before I got diagnosed so how the bloody hell is it now it’s all in my head, that I’m imagining it? And even doctors say, ‘Oh you shouldn’t be so tired. That’s not your liver. It must be something else. Or, ‘That’s not the virus.’ What is wrong with me? I thought, ‘Something is wrong with me, things are happening to me and I’m sure this isn’t normal.’ But I was being told by the various doctors I went to, and they’d run tests, ‘Oh no there’s nothing wrong with you.’ But there is something wrong with me.”

– Carol, Interview, April 2003

The Government’s commitment to “preventing discrimination and reducing stigma and isolation” experienced by hepatitis C-positive people is portrayed in chapter six of the *Strategy*. Although clearly identifying injecting drug use as an illicit behaviour, the text also speaks about protecting the rights of IDUs to receive fair treatment from health care providers. The text is written from the third-person point of view. The author’s perspective is privileged as knowing what there is to know about hepatitis C-related discrimination and stigma, and people’s feelings and motives such as reasons to “avoid testing and deny or conceal their health status” (Commonwealth Dept Health & Aged Care, 2000b, p. 47). However, the people themselves remain invisible.

The third-person narrative constructs a perspective, and the judgments therein, that is authoritative. The Government is portrayed as speaking on behalf of those affected by hepatitis C from the following groupings: rural, regional and remote communities; Aboriginal and Torres Strait Islander people; culturally and linguistically diverse communities; people who inject drugs; workers in health care settings; those infected from blood products; and those co-infected with other blood-borne viruses (Commonwealth Dept Health & Aged Care, 2000b, pp. 48–52). In this style of narrative, the author reports on events and expresses the Government’s opinions about the actions of others. For example, the “prejudicial behaviour” of workers in health care settings towards people affected by hepatitis C is considered “regrettable” (p. 51).

However, unlike the introductory chapter of the *Strategy*, no references are cited in Chapter Six. Instead, the knowledge is anecdotal as in the report on health care providers: “It must be noted that workers in health care settings are repeatedly cited as a source of discrimination against people affected by hepatitis C” (Commonwealth Dept Health & Aged Care, 2000b, p. 51). Readers are not told the source of this information. The anecdotes reported in the text are not, for example, linked to research conducted within institutions—such as faculties of medicine or schools of public health at universities—that would give this knowledge validity outside of the immediate discourse. Nonetheless, the content of this chapter of the *Strategy* is valid knowledge in the sense that it forms part of the discourse within the discourse on hepatitis C. Hepatitis C-related discrimination is also spoken about in the context of, and categorised under, anti-discrimination legislation: “For the purposes of anti-discrimination legislation, hepatitis C infection is regarded as a disability in all Australian jurisdictions” (p. 52).

Since the release of the *Strategy*, there has been a change in the perceived status of anecdotal knowledge about hepatitis C-related discrimination, and the utilisation of such knowledge to inform policy development. The consultation draft of the 2nd *National Hepatitis C Strategy 2005–2008* (Commonwealth Dept Health & Ageing, 2004, p. 23) makes links between anecdotal knowledge and outside institutions with its citation of three references within the section “Addressing Discrimination and Stigma”. The works cited are the 2004 report of the Senate Community Affairs References Committee on hepatitis C and the blood supply in Australia; 2001 report of the enquiry into hepatitis C-related discrimination conducted by the Anti-Discrimination Board of NSW, and the 2000 paper commissioned by the Department that was co-written by then AHC staff Jeff Ward and Michaela Coleborne with the then Department staff member Tenille Fort. This does not, however, reflect a burgeoning of research in the area since the release of the *Strategy*. Although Ward, Coleborne and Fort (2000, p. 143) note that research and documentation of hepatitis C-related discrimination is lacking, they cite three Australian reports relevant to this area. It is assumed that Department staff producing the *Strategy* were also aware of these reports, one of which was published in 1996 by the National Hepatitis C Councils Education Reference Group (and was commissioned by the Department) and another in 1998 by the Parliament of NSW Legislative Council Standing Committee on Social Issues. The third 1999 unpublished report of the AIDS Council of NSW was at least known to Fort, from the HIV/AIDS and Hepatitis C Section of the Department’s Population Health Division (who also

reviewed the literature on discrimination related to injecting drug use and/or HIV or hepatitis C for the Department in 1998). The *Strategy* reflects a deliberate choice *not* to cite relevant studies, enquiries, or commissioned reports. The citations of documentary evidence of hepatitis C-related discrimination in the draft second national hepatitis C strategy goes some way towards acknowledging the utility of different types of research. However, this draft Government policy is introduced and framed, as is its forerunner, by scientific research from the biological and clinical sciences, rather than from the experiences of those living with hepatitis C.

Restricted Access to Professional Discourse About Hepatitis C

The exclusion of lay people from hepatitis C-related public health policy discourse, and the dominance of the professional perspective, is particularly evident in the economic analysis entitled, *Economic Analyses for Hepatitis C: A Review of Australia's Response* (Shiell, 1998), which was utilised in decision-making and the development of the *Strategy*. This exclusion of lay people from public health policy discourse “lowers their publicly acknowledged status” (Fairclough, 1989, p. 64).

The development of the *Strategy* was informed by Shiell's (1998) economic analysis. Its use in the policy-making process is explicitly referred to in the introductory chapter. An abridged version of Shiell's 39-page report forms Chapter Seven of Lowe and Cotton's (1999) review of Australia's response to hepatitis C. In the *Strategy*, it is subsequently reduced to the following single paragraph summary headed “The Economic Impact of Hepatitis C”:

The cost of hepatitis C to the Australian community has recently been calculated by Shiell (1998). Conservative estimates of direct and indirect costs in 1996–97 amount to \$107.5 million for people with existing infection, with costs rising by \$46.6 million (over 50 years) for every 1,000 new infections. Considering the high numbers of existing chronic infections in Australia, coupled with the current incidence of approximately 11,000 a year, this epidemic will continue to have serious implications for Australia's health care sector for many years. (Commonwealth Dept Health & Aged Care, 2000b, p. 7)

Sheill's (1998) economic analysis was used at the “central level” of the decision-making context (Drummond, 2004, p. 4), in which the Department makes decisions for the Australian health care system. The National Population Health Planning Branch of the Department commissioned the economic analysis and specified the type of economic data it required, including cost-effectiveness data (Shiell, 1998, p. 1), as part of the

larger review of Australia's response to the hepatitis C epidemic undertaken by Lowe and Cotton (1999, p. iii).

Prior to this point in time, policy and program developers were said to be "largely reliant on program logic in determining which approach to take" (Lowe & Cotton, 1999, p. xii). The commissioning of economic analyses to help with resource allocation decisions and policy-makings is in accordance with the Government's adoption of evidence-based medicine (EBM) in 1998. The then Minister for Health and Family Services, Dr Michael Wooldridge, launched the Medical Services Advisory Committee, which included experts in health economics and health administration and planning, to signal the formal adoption of EBM in Australia (Wooldridge, 1998). In terms of the technical characteristics of economic evaluations adapted from Drummond et al. (1997) by Walker & Fox-Rushby (2000, p. 685), Shiell's (1998) economic analysis incorporates both the health care provider perspective with its focus on the direct costs incurred by Commonwealth and state/territory health agencies, and a societal perspective with its consideration of some of the indirect costs to the Australian society from productivity losses due to hepatitis C infection. However, Shiell (1998) does not cover community and patient/client/consumer viewpoints apart from citing Burrows and Bassett's (1996) needs assessment and the survey data of the HepCare study (n.d.) regarding the adverse impact of hepatitis C infection on the quality of being productive. The diverse voices of the hepatitis C-affected community are thereby excluded.

Although Shiell's (1998) analysis is available to the general public on the Department's website—both the full version and the abridged version in Lowe and Cotton's (1999) review—access to the contents is constrained in certain ways. Features of this text that constrain access include: the methodology; terminology; the narrow perspective; and the use of statistics to give veracity to dubious data.

As research associate in the Department of Public Health and Community Medicine at the University of Sydney when he wrote the report, Shiell (1998) is connected with an educational institution to which, it is assumed, many lay readers do not have access. In much the same way, many lay readers would not have access to the university and its resources that I have as a researcher. Although the Commonwealth Department of Health and Aged Care's data archives are publicly accessible, not all members of the public have the knowledge, skills, time, resources, or inclination to browse and analyse documents (see previous discussion of constraints to access to

electronic information by laypersons). The discourse types that Shiell draws on include economics, health economics, public health, and medicine. In particular, the text reflects the formal and systematic approach of the fields of economics and public health, and associated special or professional knowledge, which would be unfamiliar to many lay readers.

Like the *Strategy*, Shiell's (1998) report requires that readers have a high level of literacy, and this puts constraints on who can read the document. It is not an easy document to read; its Flesch Reading Ease score of 29.7 indicates that it would be extremely difficult reading for lay members of the public. Readers require some academic ability, especially knowledge of economics. Readers also need an understanding of the complex language and content of the report, that is, the issues, topics, and questions in the report. There is, therefore, a role for researchers to mediate between institutions (such as the Department)—and the discourses that emanate from them—and the lay public, alongside or with community groups. This is a role that is not currently fulfilled by hepatitis C-related NGOs.

As noted in the analysis of the *Foreword*, the Minister has a “practical-operational orientation”, accommodating “emergent” knowledge in the development of public health policy related to hepatitis C. This extends to the economic analyses of direct and indirect costs of hepatitis C infection informing public health policy, which were based upon incomplete knowledge (Shiell, 1998, p. 1). It underpins the “portfolio approach” recommended by Shiell: “Allowing investment in interventions which are currently unproven but for which there is good reason to believe might be effective” (p. 29). The word “estimates” and similar terms are used frequently throughout Shiell's report indicating the provisional or incomplete nature of information or evidence upon which his economic analyses is based, as the following examples show.

Although Shiell (1998) transparently identifies his sources of data, the tentative nature of the available data upon which he bases his economic analyses is not explicit in the *Strategy*. Instead, Shiell's analysis is heavily summarised and takes on a life of its own in the *Strategy* stripped of his qualifying statements. The information network, of which the hepatitis C surveillance system is a part, was refined with separate funding for improvements in hepatitis C surveillance introduced in 1997. At the time of Shiell's report, though, such costs were not readily available. Shiell uses both primary cost data and secondary sources of cost data. In his discussion of hepatitis C-related treatment costs, he informs the reader that certain data were hard to find, and that care in the

interpretation of available data is necessary in light of the methods and measures employed. He uses adverbs such as “likely” and “probably” and the modal verb “may” to indicate that although the data is insufficient, incomplete, or undifferentiated, the calculations or conclusions are likely to be true. The following selection of excerpts from Shiell’s (1998) report, *Economic Analyses for Hepatitis C: A Review of Australia’s Response*, illustrate his logic:

The AIHW database suggests that there were over 2,400 hospital separations for HCV-related diagnoses in 1996/97, nearly 60% of which were same day separations. It is not possible to infer from this information the number of individual patients since repeat admissions are each counted separately. (p. 6)

The estimate of treatment costs was based on the first 282 participants recruited to the HepCare trial...This relates to the total health care needs of the people participating in the trial and therefore it overstates the costs of hepatitis C...It is not possible to break down this aggregate cost of treatment by stage of disease. (p. 8)

Given the time frame for this review it was not possible to carry out a detailed patient-based costing...Instead, an estimate of the total costs of treatment during 1996 – 97 has been derived by multiplying an estimate of the number of people in each clinically important stage of the disease in receipt of treatment by costs of treating that stage and summing the result across disease stages. (p. 9)

By 1997, there had been 100,000 notified cases of HCV infection, of which an unknown proportion were repeat notifications...As the rate of under-notification is not known it is not possible to estimate accurately how many people may be receiving treatment for HCV. (p. 10)

The categorisation of hepatitis C-related pathology tests for which Medicare benefits were available did not distinguish between two different hepatitis viruses thus requiring estimation:

The cost of pathology testing for HCV infection is difficult to estimate accurately since tests for the different forms of hepatitis often carry the same item number... An estimate of the share of the cost of those items which cover different forms of hepatitis has been based on a clinical judgement of the proportion of tests relating specifically to HCV. (p. 4)

Moreover, estimates of hepatitis C-related pathology testing only considered costs funded by the Government under the Medicare Benefits Schedule (p. 5).

Readers need to be familiar with, or able to understand, the type of data that Shiell (1998) uses as the basis for his conclusions as well as the methods or systematic techniques used in economics (such as measures of productivity), and health economics (such as the practice of discounting future costs in estimates). For example, in his calculation of the costs and cost-effectiveness of antiviral treatment for hepatitis C, Shiell brings together data from patient records, clinical trials, expert groups, and models of disease progression. His calculations include estimates from the empirical literature of the ratio of patients with “compensated to decompensated cirrhosis”, and the proportion of patients in different states of “decompensated cirrhosis”. He outlines the derivation of treatment episode costs for patients with hepatitis C infection as follows:

The disease-stages specified by the Projections Working Group do not exactly match those recognised as clinically significant. In particular, ‘cirrhosis’ covers a number of separate clinical conditions including compensated cirrhosis as well as different manifestations of decompensated cirrhosis, such as ascites, variceal bleeding, and hepatic encephalopathy. Each of these conditions has different costs implications. To get around this problem, an expected cost for a ‘representative’ case of cirrhosis was derived by taking a weighted average of the unit costs of each of the ‘cirrhotic’ states where the weights reflected the proportion of patients likely to be in each of the component states. (Shiell, 1998, pp. 10–11)

Readers are expected to understand, therefore, that the cost of treating individual patients is estimated on the basis that they will share characteristics with typical patients of a particular kind.

Sources in the economic analysis (Shiell, 1998) include Brown and Croft’s (1998) predictions of health care costs associated with the continued spread of hepatitis C virus among injecting drug users in Australia. Shiell (1998) does not explicate the Markov model used in these predictions, which is a probability simulation that uses “successive hypothetical cohorts of 1,000 patients as they develop the sequelae of HCV [hepatitis C] over an extended period of time” (Brown & Crofts, 1998, p. 384). Although Shiell (1998, pp. 16–17) notes that the model used by the Hepatitis C Projections Working Group (1998) differs from that used by Brown and Croft (1998) to estimate incidence-based direct—he reports having done a sensitivity analysis (but does not provide details)—he does not critique the problems with either economic model. Nor does Shiell model costs in different parts of Australia. Discussing modelling for cost-effectiveness analysis in the United States, for example, Russell (1999, pp. 3239–

3240) recommends that the validation of costs take into account variations across the country. Applying this reasoning to the Australian context, the costs of hepatitis C treatment for patients in remote and regional North West Western Australia instead of Perth, for example, may have an impact on cost-effectiveness that is not reported by Shiell (1998). Moreover, since Shiell's analysis there have been demands for equitable resource allocation for treatment, care and support services "for communities bearing a high disease burden" (Levy, Baum & Thomas, 2002, p. 90).

As previously noted, the predominant perspective in Shiell's (1998) economic analysis is that of the health care provider. Indirect costs of treatment, including costs to patients are not calculated (pp. 15–16). The need for alternative models of service delivery for people living outside urban centres to improve their access to treatment is acknowledged in the *Strategy* (Commonwealth Dept Health & Aged Care, 2000b, p. 34). This call for alternative models of service delivery, however, is considered from the health care provider point of view. Citing studies of alternative models of service delivery in developing nations, Walker and Fox-Rushby (2000, p. 689) demonstrate that the inclusion or exclusion of costs borne by patients will redefine the cost-effectiveness of the respective models.

In the review of the *Strategy* commissioned by the Commonwealth Minister for Health and Ageing, Levy, Baum and Thomas (2002, p. 118) call for the re-commissioning of Shiell's (1998) economic analysis. The review of the *Strategy* received written submissions and heard oral presentations from a range of organisations including eight hepatitis C-related support or consumer groups and peer-based organisations for people who use(d) illicit drugs (organisations are listed in Appendices B and C of Levy, Baum & Thomas, 2002, pp. 138–140). However, in the report summary of Levy, Baum and Thomas's review—which is also published on the Australian Hepatitis Council's website—the review team's list of the constraints on the implementation of the *Strategy* includes the following:

Lack of information about the economic impact of hepatitis C infection, especially in terms of the implications of the future cost of treatment and care to the community. (Levy, Baum & Thomas, 2002, p. 84)

The review team can be said to recommend cost-benefit analysis from a societal perspective. There is, therefore, scope for those undertaking economic analyses to take a patient/client/consumer perspective and/or a community perspective.

Reviewing the usefulness of economic evaluation in health care decision-making, Drummond (2004, p. 4) quotes the United Kingdom's House of Commons Health Committee's (1992) stance that consideration of the cost-effectiveness of treatments should take into account: "the wider costs and benefits to the public purse of reduced benefit dependency and [patients'] improved ability to work". The economic impacts of hepatitis C infection for individuals and the broader Australian community are described as "profound" in the *Strategy*:

Hepatitis C illness can force some people out of the workforce, either temporarily or permanently, and can contribute to or exacerbate poverty. (Commonwealth Dept Health & Aged Care, 2000b, p. 40)

However, while unemployment is linked to decreased living standards (Parham, 1999, p. 25) Shiell (1998, pp. 21–22), in his economic analysis, notes that hepatitis C infection is unlikely to impact on productivity performance of the Australian economy and the living standards of the Australian community as a whole. Commenting on the indirect costs related to lost productivity, Shiell cites data from two surveys of current injecting drug users, an Australian study of HIV and injecting drug use by Loxley, Carruthers and Bevan (1995) and a five-year cohort study of the incidence of blood borne virus infection in 626 IDUs in Victoria undertaken by Crofts and Aitken (1997):

Consideration also needs to be given to the role that estimates of indirect costs ought to play in determining health priorities. This is a normative question rather than a technical one. If value is placed on reducing indirect costs, the priority ought to be given to those conditions which affect high income earners. Given the low rates of employment participation among the biggest group of people infected with HCV [that is, injecting drug users], the disease is unlikely to rate highly by this criterion. (Shiell, 1998, p. 22)

This ethical dilemma, noted by Shiell, is not articulated in the *Strategy*, and is at odds with Brown and Crofts' (1998) position that

IDUs in Australia are an extremely heterogeneous group, represented across all socio-economic strata, and that many of the people presenting now with endstage liver disease are those who injected only once or a few times in the 1970s and not since...the cost consequences detailed here are conservative from the viewpoint of the Commonwealth Government (as opposed to Medicare), as an estimated 20% of people with chronic hepatitis and 40% of those with cirrhosis may be unable to work as a result of their illness and entitled to disability pensions. (p. 388)

Shiell (1998, p. 22), nonetheless, assigns a monetary value to health outcomes. He estimates the value of lost productivity from hepatitis C-related disorders for 1996/97 and undiscounted lost earnings per person over 50 years. He does not, however, include a valuation of quality of life, or of quantity of life, in the range of outcome measures often included in economic evaluations (Walker & Fox-Rushby, 2000, p. 685).

Shiell (1998, p. 26) identifies the need for further research about the impact of hepatitis C infection and its treatment on people's quality of life. Subsequent published economic evaluations, such as the report *Return on Investment in Needle & Syringe Programs* (Health Outcomes International, 2002, pp. 18–20), include valuations of outcomes such as quality of life effects (QALY) of needle and syringe programs, including life years gained. Walker and Fox-Rushby (2000, p. 686), however, found that economic evaluations of health programs (including communicable disease interventions) in developing countries between 1984 and 1997 used valuations of quality of life derived solely from the opinions of professionals. This creates bias as it “can lead to over estimates of the severity of a disease and may be consistently different to the opinions of the general public” (p. 690). It also reinforces the dominance of the health care provider perspective.

In a study of 504 people with hepatitis C in New South Wales (including 54 current injecting drug users), Hopwood and Treloar (2003, p. 6) note the dearth of information about the impact of hepatitis C infection on quality of life. The majority (56.8%) of participants of this study “reported their current health status as either ‘poor’ or ‘fair’” in a self-administered questionnaire (p. 59). Alternatively, 73.8% of participants reported their current health status as either “Fair” or “Good” (the study authors collapsed the four categories into “Poor-Fair” and “Good-Excellent”). Overall, 7.3% of participants in Hopwood and Treloar's study reported that hepatitis C infection limited their ability to work “a lot of the time” and at least double that proportion reported that the disease affected their everyday physical activities and limited their participation in social activities (p. 59). If biases such as those in valuations of quality of life “serve the interests of particular groups”, as Walker and Fox-Rushby (2000, p. 690) suggest, then the impact of hepatitis C infection warrants further critical evaluation. Stepping outside of the dominant health paradigm as Galbally (1996, p. 185) advocates could lead researchers and consumer groups to take a holistic perspective. Instead of focusing on illness, Galbally recommends promoting “resilience”, an approach that considers “how people survive with reasonable health under very adverse conditions.”

A concept such as resilience offers an alternative perspective to that of Shiell's (1998) economic analysis upon which the *Strategy* relies.

The *Strategy* (Commonwealth Dept Health & Aged Care, 2000b, pp. 12–13) incorporates social concerns such as social inequalities in health in prioritising the use of public resources, reflecting the trend in health policy decision-making (Drummond, 2004, p. 7; Duthie, Trueman, Chancellor, & Diez, 1999, p. 144; Murray, Evans, Acharya & Baltussen, 2000, p. 236). But of at least equal importance in resource allocation decisions is concern for the wellbeing of the Australian community generally, and the economic impact of hepatitis C on future generations. That the economic impact of the hepatitis C epidemic is an imperative in decisions at the central level is echoed by Brown and Crofts (1998, p. 384) when they conclude: “[T]here is an even more pressing need to halt or slow the current epidemic of HCV infection among IDUs on fiscal grounds alone.” The focus on the return on investment in the economic analyses that inform the *Strategy* is of great, though understated, import. Concern about the impact of the hepatitis C epidemic on the health care budget over a 50-year period is central to decision-making and policy-making in relation to, for example, Government-subsidised treatment of hepatitis C infection and the provision of needle and syringe programs.

Evaluation of return on investment to, or value for money for, the Australian community is implied in the *Strategy* (Commonwealth Dept Health & Aged Care, 2000b, p. 9) to build a case for needle and syringe exchange programs (NSPs), which are described as a cost-effective, “blue-chip investment”. In business, return on investment analysis—a form of cost-benefit analysis—means “decision-makers evaluate the investment potential by comparing the magnitude and timing of expected gains to the investment costs” (Solution Matrix, 2004). The term blue-chip investment is Shiell's (1998, p. 30) metaphor for preventive NSPs believed to reduce the rates of needle sharing: “offering high health returns, financial savings and other benefits at very low risk”. The term “blue-chip” came into use in the early 1900s, and is associated with the game of Poker (“a blue counter...of high value”), and the stock exchange (“a share considered to be a fairly reliable investment”) (Oxford University Press, 2005). The term has connotations of dependability, soundness of investment and minimal risk. Shiell (1998) describes the returns from NSPs, in relation to their part in controlling the hepatitis C epidemic, as a “free-good” piggybacking off NSPs established to prevent the transmission of HIV/AIDS. He tentatively predicts reductions in the incidence of hepatitis C infection related to NSPs. In this he concurs with Brown and Crofts (1998,

p. 388) who cite Hurley, Jolly and Kaldor's (1997) study of the effectiveness of NSPs in reducing the incidence of HIV infection among injecting drug users. Brown and Crofts (1998, p. 388) conclude: "On economic grounds alone such investment [in NSPs] would repay itself many times over."

However, while Shiell (1998, pp. 20 & 29) acknowledges the difficulty in matching health returns with costs of associated public health resources, and that it was not possible to calculate changes in indirect costs (such as employment or performance at work) caused directly by interventions, the limits of the economic analyses that support the decision-making process are not foregrounded in the *Strategy*. The Department characterises harm reduction interventions, such as NSPs, as "balanc[ing] the cost to the community and to individuals of illegal or risk behaviours where those behaviours are associated with transmission of blood borne viruses such as hepatitis C and HIV" (Commonwealth Dept Health & Aged Care, 2000b, p. 14). However, the conditions created by "harm minimisation", the Government's approach to drug use, are not explored in the *Strategy*.

In the excerpt from Shiell's (1998) economic analysis about the derivation of treatment episode costs for patients with hepatitis C infection, cited previously, readers are expected to understand medical terminology such as "cirrhosis", "compensated cirrhosis" and "decompensated cirrhosis", and to be familiar with the major sequelae of cirrhosis. Readers require considerable knowledge of the Australian health care system, such as hospital inpatient classification schemes and costing of patient care. The data on hepatitis C-related treatment costs that Shiell presents, for example, assumes reader familiarity with the Australian Institute of Health and Welfare's (AIHW) National Hospital Morbidity Database and Diagnosis Related Groups (DRGs). In this instance, they also need to know something about resource consumption in the management of patients with cirrhosis. Readers are also expected to understand methodologies in scientific modelling such as "sensitivity analysis", a method for determining the quality and strength of a model: "[H]ow the model depends upon the information fed into it, upon its structure and upon the framing assumptions made to build it" (European Commission, n.d.). Lay readers are unlikely to notice that Shiell (1998) considers the direct costs and cost-effectiveness of hepatitis C education (a general assessment), prevention (NSPs and methadone maintenance programs) and treatment but does not, for instance, compare interventions between groups within a population and does not

consider “allocative inefficiencies” (Murray, Evans, Acharya & Baltussen, 2000, p. 236).

Not everyone involved in the development of the *Strategy*—for example, those who participated in the public forums of the national consultation process (Commonwealth Dept Health & Aged Care, 2000b p. 11)—would understand the approach taken by Shiell (1998) to predict the economic impacts of hepatitis C and the cost of action. According to Drummond (2004, p. 7), Duthie, Trueman, Chancellor and Diez (1999) attribute the limited use of economic evaluations by decision-makers at the local level to a: “[L]ack of understanding of the methodology of economic evaluation and economists’ jargon.” NGOs in the field of hepatitis C publish current information about hepatitis C-related policy. The AHC, the national peak organisation for state/territory based Hepatitis C Councils, publishes on its website what it describes as “consumer-friendly 2 [*sic*] page summaries of key national hepatitis C reports” (AHC, n.d. (c)). The New South Wales Hepatitis C Council announced the launch of the *Strategy* on the cover page of its Spring 2000 newsletter, and included excerpts from the first chapter of the *Strategy* in the “Feature” section of the same edition (Hepatitis C Council of NSW, 2000a & b). The Hepatitis C Council of South Australia announced the *Strategy* in a three-paragraph article (Hepatitis C Council of SA, 2000). In essence, though, these documents are either report-summaries taken from the original reviews, strategies and reports, or media release-style articles. The NGOs, themselves, do not offer a critical examination of the original documents as outlined in this chapter. Hence, the NGOs do not offer a counterpoint to the dominating professional voice.

Conclusion

The process of making hepatitis C-related population health policy in Australia involves public scrutiny of proposed policy, and consideration of groups in the community who will be most affected by the policy. Such consultation is said to reflect a “well-functioning democracy” (Maddison, Dennis & Hamilton, 2004, p. vii). Representatives of hepatitis C NGOs and peer-based IDU groups were included in the acquisition and creation of information that informed the development of the *Strategy* during the consultation and concurrence processes for the 1999 review of Australia’s response to hepatitis C conducted by management and health services consultants Lowe and Cotton. However, professionals from state/territory and federal government sectors

(particularly public health and population health) and medical, scientific, and health care institutions/communities (including researchers) dominated the process. The influence of experts, key individuals from a small set of institutions, who are members of expert committees, subcommittees and advisory groups is reflected in the networks that characterise the development and implementation of the *Strategy*.

While public health managers (including economists), health care professionals, and the scientific community are given a voice in the vocabulary and organising structures of the text, the affected community is spoken about, confirming Hepworth and Krug's (1997, p. 5) assertion that affected individuals are "the objects upon whom action is [to be] taken" by the scientific, medical and public health communities. However, advocates working within peer-based injecting drug user groups such as AIVL can competently contribute to the work of bureaucratic committees established to inform hepatitis C health policy-making and, given the opportunity and proportional representation, are able to speak for themselves and identify issues and concerns.

Social networking by representatives of NGOs with these experts offers a way of getting their ideas incorporated into public policy, though this is not guaranteed. Changing the ratio of the categories of participants in the policy-making process, in the future, may affect the types of issues raised, the particular way in which problems are understood and framed, and who should be involved in solving problems. In this option, it is important to involve active drug users more fully such that *their* expertise frames the review and report writing process, and policy development.

To read, interpret, and critique hepatitis C-related public policy, and associated texts such as the analyses and evaluations that inform its development, requires considerable knowledge (including knowledge of antecedent texts), and high-level literacy skills. The public health discourse about hepatitis C constrains access by the lay community. The language and construction of such texts tends to sideline lay readers. Yet representatives of the lay community in hepatitis C-NGOs tend to re-present the texts (including the templates therein). Discourse analysis offers a means by which NGOs can rewrite policy and work at changing the policy agenda, if so desired, to represent the affected community (see Jones, Lee & Poynton, 1998, pp. 147–150).

The next chapter is concerned with how social action by NGOs is absorbed into a strategically-oriented approach that is reliant on the expertise of institutions of the biomedical sciences (including epidemiology, public health), the language of which reflects the problem-solving and technical methods of these expert sites.

CHAPTER SIX

A SKEWED PERSPECTIVE ON HEPATITIS C

The Hepatitis C Council of NSW is an independent, community-based, non-government organisation funded by the NSW Health Department to provide information, support, referral, education and prevention services for people in NSW affected by hepatitis C...We were pleased to have entered into our third three-year funding and performance agreement with NSW Health, as this allows us to plan with certainty up till the end of 2004 – 05.

– Hepatitis C Council of NSW, Annual Report 2002–03

Introduction

The *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) published by the then Commonwealth Department of Health and Aged Care (2000b) (the Department) for the Federal Coalition Government (the Government) is the inaugural national strategy “targeting” the “hepatitis C epidemic” in Australia. Three distinct types of language were discernible in the analysis of the vocabulary of the *Strategy*: the first, the language of government; the second, the language of public health; and the third, the language of the scientific and medical communities. As discussed, the language of government conveys a strategically oriented approach that links the Government’s goals and priorities for safeguarding the Australian community from the hepatitis C epidemic to the performance of the public sector and its agents. It was shown that the *Strategy* is a blueprint for professionals dealing with the hepatitis C-affected community and the epidemic, in which the attributes of the text constrain access to the discourse by, and participation of, the lay community. While the hepatitis C-affected community participates in the development, implementation, and evaluation of Government policy, in keeping with the espoused principle of “partnership”, the

Strategy reflects the dominance of the professional perspective. This chapter continues the examination of the language of public health that frames the *Strategy*. It is argued that the skewed public health perspective, which reflects an evidence-based approach and concern for performance measurement, restricts the enterprise of the hepatitis C-affected community.

At Australian universities, “public health” or “population health” schools or divisions are found under the umbrella of “health sciences”—often within faculties of medicine—and epidemiology and health promotion are found within public health. In addition, the academically and administratively coherent health sciences—variously called faculty, division, or college—houses specific centres, such as those for health promotion research and public health economics research. The *Strategy* reflects the scientific method and problem-solving paradigm promoted in the teaching and learning and research of public health at universities, particularly, an “evidence-based approach” that tertiary institutions such as the University of Western Australia (2004) promote in population health programs and health research. The Department’s representation of the hepatitis C epidemic and those affected by the virus particularly reflects the perspective of managers in the public health sector. The key users of the text are those responsible for planning, managing and evaluating public health services for the prevention, control, and treatment of hepatitis C, and service providers implementing major decisions of the Department. This is reflected in the following aspects of the text: the classification schemes evident; the emphasis on quantitative measures of outcomes, and on what is not measured; standardisation of data collection and accountability; connotations of the word “challenges” and deficiencies in public health services and the behaviour of service providers that this metaphor disguises; the dominant health paradigm; and the way that control of the affected individual’s behaviour is couched in euphemisms.

Privileging What can be Seen and Measured

The *Strategy* defines, or frames, the nature of future policy problems. It will influence the nature of information collected and inventoried, and subsequently the kind of information produced by public health policy staff and others in the partnership. Hepatitis C is cast as a threat to population health. Drawing on epidemiological data, the disease is designated “the most commonly notified communicable disease in Australia”, and the Department seeks to “prevent exposure to the virus” by all Australians (Commonwealth Dept Health & Aged Care, 2000b, p. 1). The purpose of the *Strategy* is

“to promote and support the health, safety and wellbeing of all Australians in relation to hepatitis C” (p. 1). Its two primary aims are:

- To reduce the transmission of hepatitis C in Australia [and]
- To minimise the personal and social impacts of hepatitis C infection. (p. 1)

The four priority areas for action are:

- Reducing hepatitis C transmission in the community;
- Treatment of hepatitis C infection;
- Health maintenance, care and support for people affected by hepatitis C; [and]
- Preventing discrimination and reducing stigma and isolation. (p. 2)

The six essential components of Australia’s response to hepatitis C are:

- Developing partnerships and involving affected communities;
- Access and equity;
- Harm reduction;
- Health promotion;
- Research and surveillance; [and]
- Linked strategies and infrastructures. (pp. 2 & 11)

The text draws upon classification schemes associated with business management such as public sector management, particularly key performance indicators (KPIs). The Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) is to report to the then Minister for Health and Aged Care (the Minister) on “specific performance indicators” (p. 57)—not published in the *Strategy*—and Commonwealth – state/territory funding agreements rest on these performance indicators (p. 63). Performance management and reporting allows comparisons of Australia with other countries, between states/territories, and at functional levels within states/territories. Hence, the progress of the implementation of the *Strategy* will be tracked.

The nation-wide performance of the public health sector in relation to hepatitis C is rated according to measures of effectiveness, such as the rate of transmission of the hepatitis C virus (Commonwealth Dept Health & Aged Care, 2000b, p. 15). Knowledge from this point of view derives from measurable data. In the *Strategy* the terms “outcomes” and “health outcomes” collocate with “measuring”, “monitoring”, “evaluation” and “the best available evidence”. The ideological and dominant assumptions (Fairclough, 1989, p. 114) embedded in such language are commonly

found in professional sites such as biomedical institutions (including public health) and those of business or commerce. What can be seen and measured is considered legitimate and is privileged over what is spoken, heard and felt or intuitive. The written word is also privileged over the spoken. This, in turn, constrains the types of activities or practices and types of data that are monitored and evaluated and, hence, promoted and funded within Commonwealth – state/territory funding arrangements (and subsequent Commonwealth funding arrangements with non-government organisations (NGOs) and state/territory–NGO funding arrangements). As one consultancy group, which specialises in web-based management reporting services, says of KPIs: “What you can measure you can manage—and—what you can manage you can leverage” (Consolidata, 2003).

Although the *Strategy* stipulates what is to be accomplished, it does not detail specific service outcomes and quality. The demands that the Department makes as a condition of its funding agreements with state and territory governments and national and state hepatitis C organisations are couched as “Challenges”. For example, in Section Four “Treatment of Hepatitis C Infection” the following challenge is identified:

To provide the best treatments available, supported by patient education and counselling, to reduce current and long-term morbidity, particularly for people with hepatitis C who are likely to progress to advanced liver disease. (Commonwealth Dept Health & Aged Care, 2000b, p. 35)

In this instance, the Department specifies what it hopes will be achieved: the provision of cutting-edge treatment for people infected with hepatitis C; patient education; patient counselling; and a reduced rate of occurrence of sickness associated with hepatitis C.

The approach to expected outcomes is predominantly quantitative. Service providers are to focus on collecting what is measurable. There is to be uniformity and standardised outcomes or “agreed indicators”, although specific indicators are not detailed in the *Strategy*. Subsequently, the lack of detail regarding plans for implementing the *Strategy* and performance indicators for monitoring it is considered one of the main constraints to its implementation (Levy, Baum & Thomas, 2002, p. 83). However, key organisations involved in monitoring and evaluation are named: ANCAHRD; the Communicable Diseases Network of Australia and New Zealand; the national centres in HIV and hepatitis C research; the national centres for alcohol and other drug research; and the Department itself (Commonwealth Dept Health & Aged Care, 2000b, p. 66). The National Centre in HIV Epidemiology and Clinical Research,

for example, collects longitudinal national surveillance data such as the long-term outcomes of hepatitis C infection including the number of liver transplants performed annually. It follows that Commonwealth – state/territory contracts of funding agreements include measures of the provision of such services.

The corollary that only what is measurable, measured, and reported may receive funding warrants study. As Hatry, Gerhart and Marshall (1994, S18) caution in their guide to performance measurement in the public sector: “What is measured and reported gets attention” and, by implication, what isn’t, doesn’t. Respondents in a survey by The Australia Institute (TAI) indicate that Government funding of NGOs has had a negative impact on public debate on certain issues, particularly in relation to women and youth in Australia (Maddison, Dennis & Hamilton, 2004, pp. 1 & 2). The majority of responding NGOs report that the relationship between NGOs and the Federal Coalition Government is increasingly characterised by “micromanagement” that undermines the notion of partnership between NGOs and the Government (p. 1). This is of particular importance for hepatitis C-NGOs, which receive primary funding from mainstream Government departments to employ staff and to deliver contracted services.

“Monitoring and Evaluation Mechanisms” reflect the standardisation of data collection and reporting that the Department requires for making comparisons between state and territory governments, to hold them accountable. Comparative data on the performance of state and territory governments is to be collected and displayed publicly: “The publication on the Department of Health and Aged Care’s website of State and Territory governments’ performance information against agreed indicators in their respective Public Health Outcome Funding Agreements” (Commonwealth Dept Health & Aged Care, 2000b, p. 66). Uniformity, too, enables the Minister to make global comparisons: “Australia is leading the international community in responding to the hepatitis C epidemic...Australia is recognised as a world leader in developing and implementing effective population health responses to other blood-borne viruses” (Wooldridge, 2000a, p. iii). An underlying assumption, therefore, is that not only is it possible to compare state and territory governments and Departments of Health, but it is possible to compare the quality of public health services in Australia with that of other nations. This enables the ranking of Australia in relation to other nations.

Performance information referred to in the *Strategy* does not, however, describe the individual experiences of consumers and the effects of the particular practices of service providers on the quality of consumers’ experiences. In Section Six of the

Strategy, titled “Preventing Discrimination and Reducing Stigma and Isolation”, it is acknowledged that people with hepatitis C may be subjected to discriminatory practices of workers in health care settings:

[I]t must be noted that workers in health care settings are repeatedly cited as a source of discrimination against people affected by hepatitis C. Regrettably, this discrimination is often initiated at the point of clinical diagnosis. Discrimination may be extreme, as in the case of discouraging or refusing service, or it may be less direct, in the form of judgments made on the basis of known (or imputed) current or past behaviours. (Commonwealth Dept Health & Aged Care, 2000b, pp. 50–51)

The focus of monitoring and evaluation mechanisms, however, reflects a narrow range of data and not the whole performance of service providers. Service quality, for example, is not specifically referred to as a category of performance indicator. Instead, the need to develop, trial and implement case management models to improve the quality of service delivery is listed as one of the challenges for service providers (p. 43). As a case management model may be satisfactory for some groups of people with hepatitis C and not for other groups, and in some places but not other places, NGOs can work towards ensuring that monitoring and evaluation activities reflect the values of the communities that they represent.

Casting the Hepatitis C Epidemic as Intractable

In the foreword to the *Strategy*, previously discussed, the Minister uses the word “challenge” to represent the test that the hepatitis C epidemic poses to the collective intellectual abilities of the scientific and medical communities in Australia, and to summon these communities into action such as developing new technologies (Wooldridge, 2000a). This polysemantic word is used to such an extent in the *Strategy*, and in other texts—(for example, Hopwood and Treloar (2004, p. 526) use the term in the introduction to their research report: “The hepatitis C epidemic represents a significant challenge to public health in Australia, both in terms of preventing further transmission and managing future social and economic impacts”)—that it is worth considering again. In the *Strategy*, the usage of “challenge” as a term, or coined expression, masks the lack of existing hepatitis C-related services and funding. It also obscures questions of agency and responsibility around certain issues, and excludes the personal perspective of those who experience discrimination, particularly in health care settings. Each of these is discussed in turn.

In *Hepatitis C: A Review of Australia's Response*, Lowe and Cotton (1999, p. 137) identify five “principal challenges”—“challenges for the future”—which structure much of the content of the *Strategy*:

1. Reducing the number of new hepatitis C infections;
2. Improving treatment and care for people living with hepatitis C;
3. ‘Getting the research right’;
4. Extending partnerships; [and]
5. Clarifying structures, roles and responsibilities.

In the *Strategy*, the word “challenges” is used as a section heading in four of the nine chapters, and can have a number of interpretations. The items listed under this term (and the term “Objectives”) are concerned with performance indicators such as inputs; efficiency; quality of services; and outcomes. One of the connotations of the word is that of an invitation to managers to put in place programs to achieve desired outcomes (short term, intermediate term and long term). Organisations providing public health services will be called to account for outcomes. As well as representing a test, “Challenges” is a positive term with emotional overtones, suggesting strong and decisive action by public health managers and elected Government officials who will “take up the challenge”.

The term “Challenges” hides the information that resources budgeted by the Government to implement the *Strategy* are limited. It implies a test of a different sort—a resource-poor situation that will test the abilities of public health managers to implement the specified public health services. This is evident in Chapter Four, “Treatment of Hepatitis C Infection”, in which 17 challenges are listed in relation to the provision of hepatitis C testing and treatment-related health care services, health care worker training, consumer education, and basic and clinical research programs (Commonwealth Dept Health & Aged Care, 2000b, pp. 35–36). A further 11 challenges are listed in Chapter Five in relation to health maintenance, care and support services that fall outside of specialist hepatitis C clinical services (p. 43). The term conceals the lack of details regarding the available funding, or funding dedicated for such services. News coverage about hepatitis C in Australia reports that health care and support services for those affected by the disease are considered under-funded by workers in the hepatitis C community sector (as will be discussed later). The then Executive Officer of the Australian Hepatitis Council cites the “lack of dedicated funding” as one of the

“fundamental barriers to the effective implementation of our national response to hepatitis C” (Wallace, 2002, p. 1). Similarly, the “lack of resources for implementation” of the *Strategy* is one of the main findings of the review requested by the Federal Minister for Health and Ageing (Levy, Baum & Thomas, 2002, p. 83).

The lack of existing services is disguised by use of the term “Challenges”. In this sense, challenge is a euphemism for “problem”. The dearth of health care services outside the metropolitan areas is one instance in which shortcomings in the provision of public health services is disguised as a challenge: “To provide appropriate health care services with a continuum of care in regional, rural and remote Australia through developing and testing innovative service delivery models” (Commonwealth Dept Health & Aged Care, 2000b, p. 43). The vocabulary of the *Strategy* is deliberately chosen by its producers to cast problems in health care and public health services in such a way as to influence readers positively towards the Government’s policies rather than for readers to find fault with, and deficiencies in, existing public health services. While readers might ask why, for instance, health care services outside the metropolitan area have deteriorated, agency and responsibility for such deficiencies are not elucidated.

Grammatical features of the text also reinforce the way in which the producers of the *Strategy* avoid discussing agency, causality, and responsibility. The provision of “adequate” needle and syringe programs, considered essential to reducing hepatitis C transmission in the community (Commonwealth Dept Health & Aged Care, 2000b, p. 21), illustrates this. Needle and syringe programs are represented as essential, yet “custodial settings” in Australia are depicted as follows:

Within custodial settings access to education, the means of preventing transmission and infection control is severely limited. There are also restrictions on the distribution of a number of personal hygiene items such as razors and scissors, and infection control within prison hairdressing facilities needs improvement. Sterile tattooing and injecting equipment is not available, and the means to clean such equipment is limited. As a result, sharing and re-using of unsterile equipment is common. Acts of violence involving blood-to-blood contact are also common and pose an additional threat to all within these settings. (p. 25)

In this excerpt, the producers leave agency unclear (regarding agency, see Fairclough, 1989, pp. 51 & 120–123). While the hepatitis C virus is transmitted via blood-to-blood contact between inmates engaging in activities such as sharing injecting equipment, someone has not provided health education and hepatitis C prevention programs to

inmates to reduce the likelihood of blood-to-blood contact. Who is the agent limiting inmates' access to education? Who restricts the distribution of personal hygiene items? Who does not provide sterile injecting equipment? Who limits the means to clean tattooing and injecting equipment? Agency is suggested in the fifth chapter of the *Strategy*, as readers are told that health authorities in custodial settings—not the Department—are responsible: “Health authorities operating in custodial settings have a duty of care for people in these settings” (Commonwealth Dept Health & Aged Care, 2000b, p. 42). By attributing responsibility to these health authorities in custodial settings, the Department disguises the Government's responsibility. As with the provision of other health care services, it is a *challenge* to “support the implementation of nationally consistent standards for hepatitis C education and prevention in custodial settings” (p. 28).

The preponderance of unsafe injecting practices in custodial settings is acknowledged in the second National Hepatitis C Strategy, the *National Hepatitis C Strategy 2005–2008* (Commonwealth of Australia, 2005), as is the absence of NSPs in prisons (p. 6). It is specified in this second hepatitis C strategy (p. 15) that the approach to providing services related to drug use in custodial settings is to be found in the *National Drug Strategy: Australia's Integrated Framework 2004–2009*. The National Drug Strategy was prepared for and endorsed in May 2004 by the Ministerial Council on Drug Strategy, described as “the peak policy and decision-making body on licit and illicit drugs in Australia” (Commonwealth of Australia, 2004, p. 1). It is an influential text that is “intertextually incorporated” (Fairclough, 2003, p. 13) into the second Hepatitis C Strategy, just as the previous National Drug Strategic Framework was incorporated into the previous hepatitis C strategy. Responsibility for reducing the risks associated with drug use and hence drug-related harms is attributed in this document to a conglomeration of: “Governments at all levels, the non-government sector, business and industry, communities, research bodies, families and those who use drugs or other substances themselves” (Commonwealth of Australia, 2004, p. 7). However, there is no guarantee that the expansion of the availability of and access to NSPs, as specified in the priority action areas of the second Hepatitis C Strategy (Commonwealth of Australia, 2005, p. 16), will extend to custodial settings. Instead, in the sole reference to custodial settings, the National Drug Strategy states that “a comprehensive approach to the management of drug use and related harms in correctional settings” will be developed within the five-year period of the strategy (Commonwealth of Australia,

2004, p. 7). This is another example of the skewing, whereby the lack of needle and syringe programs for injecting drug users (IDUs) in custodial settings is couched in, and masked by, the promissory language of public health.

The term “Challenges” in the *Strategy* disguises inadequacies in the manner in which health care workers interact with patients or clients, particularly people who inject drugs. It also illustrates the absence in the text of the voices of people who inject drugs or did so in the past. Prior to the list of challenges is a general description of the types of discrimination that health care workers’ may employ against people affected by hepatitis C:

Discrimination may be extreme, as in the case of discouraging or refusing service, or it may be less direct, in the form of judgments made on the basis of known (or imputed) current or past behaviours. (Commonwealth Dept Health & Aged Care, 2000b, p. 51)

This categorisation of behaviour lacks the power expressed in, for example, Lisa Waller’s (2004, p. 293) personal perspective written for the *Medical Journal of Australia (MJA)*:

In 2000, my doctor’s response to my request for an HCV test was “you wouldn’t have that”. My subsequent admission of injecting drug use all those years ago was met with silence, but she ordered the test. When I went back for the results it seemed that she didn’t want to know about me or my illness, despite the fact that I was very sick. She offered almost no information at all about the virus, explaining that she “just doesn’t see it” in her surgery...I felt that my GP’s diagnosis was not that I had a serious liver disease, but an untreatable moral malady...I didn’t go home filled with righteous indignation and contempt for my doctor that day. I was consumed with self-loathing—I felt like a piece of human debris, unclean and totally unworthy.

This peer-reviewed medical journal frequently publishes articles under the heading “Personal Perspective”. This section of the journal includes illness narratives (Frank, 1995; Hawkins, 1999) written by individuals who are, or have been, patients in the health care system. Such stories are a way of repairing the “narrative wreckage” arising from illness, to reconstruct past experiences, construct new paths and identities (Frank, 1995, p. 53; Riessman, 1993, p. 2). The section also contains commentaries by health care professionals about various aspects of their professional practice or aspects of the health care system that have an impact on their practice. Waller’s two-page personal perspective on living with hepatitis C appears in a general issue of the journal, and is unrelated to other topics in the issue. She recounts the narrative of her illness as

an introduction to her comments, as the President of the Hepatitis C Council of NSW, about the NSW Anti-Discrimination Board's enquiry into hepatitis C-related discrimination and the Australian Government's proposed Disability Discrimination Amendment Bill.

The heading "Personal Perspective" has implications for the modality of Waller's (2004) article. Waller's first-person account of her diagnosis, with verbatim quotes of her doctor's response, relates to the "expressive modality" (Fairclough, 1989, pp. 126–127) of the text, and establishes her authority as someone providing an accurate portrayal. However, the heading clearly separates personal accounts and personal commentary from medical research articles and editorials written by medical experts. In terms of "relational modality" (p. 126) then, Waller may be viewed as having less authority than other contributors to the journal. Producers of the *Strategy*, too, differentiate texts on the basis of relational modality by choosing a formal style of writing that appears authoritative, and by excluding other styles such as the personal narrative.

Persons like Lisa Waller are the "targets" of health care service providers. The challenges related to discrimination in implementation of the *Strategy* are listed as: "To ensure that health care services are accessible to and tolerant of the individual needs and dignity of people affected by hepatitis C" and "To train and support health care workers to ensure that they do not engage in discriminatory behaviour towards people affected by hepatitis C" (Commonwealth Dept Health & Aged Care, 2000b, p. 52). Although it is conceded in the text that the discriminatory practices of health care workers are wrong and unacceptable, the term "challenges" makes such practices seem less intractable.

The Department notes that the association of hepatitis C with injecting drug use is reported as "the single most common cause of discrimination, stigma and isolation experienced by people affected by hepatitis C" (Commonwealth Dept Health & Aged Care, 2000b, p. 50). In its enquiry into hepatitis C-related discrimination, the Anti-Discrimination Board of New South Wales (2001, pp. 100–102) similarly found

The stigma associated with injecting drug use is closely linked to hepatitis C, and discrimination on the basis of hepatitis C or current, past or assumed drug use are so closely associated that they may be indistinguishable.

The Enquiry found discrimination on the basis of drug use or presumed drug use commonly arose within health care settings (p. 32). As Byrne (2002, p. 7) from the Australian Injecting and Illicit Drug Users League (AIVL) writes:

One of the biggest problems for drug user groups is that by the time an individual receives a hepatitis C diagnosis they are so imbued with the negative responses and overt discrimination due to their drug use that they are inclined to accept this behaviour. The expectation then is that such attitudes within the health care/medical community will continue in the context of future treatment.

The focus of the discussion by the Anti-Discrimination Board of New South Wales (2001, pp. 32–35) about the relationship between hepatitis C and drug use discrimination is on whether or not drug dependency is considered a disability under the state's Anti-discrimination Act 1977 (NSW) legislation and the federal legislation, the Disability Discrimination Act 1992 (DDA). Debate about this issue can also be found at the website entitled *Disability Discrimination Act Amendments 2003* (n.d.). The principal organisations supporting this website are: the National Association of Community Legal Centres; the Public Interest Law Clearing House; AIVL; the Family Drug Support; People With Disability; and the Australian Federation of AIDS Organisations. Other listed supporters are: the AHC; the NSW Users & AIDS Association; the Council of Social Service of New South Wales; the Hepatitis C Council of NSW; the VivAIDS; and the Australian Nursing Federation. These organisations contest the Federal Coalition Government's proposed amendment to the DDA said to reflect: "the Government's 'Tough on Drugs' strategy, the proposed amendment is designed to ensure a person's drug addiction cannot be the sole basis of a claim of unlawful discrimination."

That the list of challenges in the *Strategy* does not specifically speak of ensuring that health care workers do not engage in discriminatory behaviour towards IDUs—regardless of whether or not both drug dependency and hepatitis C are considered disabilities—is ideological, reflecting the Government's prevailing values and beliefs, which reflects (to a greater or lesser extent) those of the wider community. The proposed amendment to the DDA makes this ideologically-based omission the more apparent, and discrimination against IDUs within health care settings likely to continue. Despite acknowledging that IDUs have rights, a sense of immorality attaches to IDUs infected with hepatitis C. Injecting drug use runs contrary to the moral principles espoused by the Federal Coalition Government, involving issues of right and wrong,

and how individuals should behave. This stance is highlighted by the Minister's foreword to the second National Hepatitis C Strategy:

The Government is committed to its "Tough on Drugs" strategy which was launched by the Prime Minister in November 1997...This commitment represents the largest single initiative ever undertaken in this country to reduce the supply of, and demand for, illicit drugs. It brings together law enforcement, health, education and family portfolios and the non-government sector in the pursuit of a government agenda around a reduction in the use of, and ultimately abstinence from, illicit drugs. (Commonwealth of Australia, 2005, p. v)

The repeated use of certain verbs, or "overwording" (Fairclough, 1989, p. 115), in the lists of challenges in the *Strategy* portrays the Government as intending to do something about the lack of services and the manner in which service providers interact with patients or clients. The verbs and near synonyms "establish", "develop", "provide" and "implement" suggest that an array of needed services do not exist but that these services should be made available to people with hepatitis C. There is also a sense of security and permanence associated with these verbs that attaches to the provision of services. However, the portrayal of the Department, and hence the Government, as taking the appropriate action or steps to provide the services required by people with hepatitis C is undercut, to some extent, by the heading "Challenges". The term obscures the incumbency of the provision of services.

Controlling People and Containing the Disease

As stated at the start of this chapter, the *Strategy* primarily addresses those responsible for planning, managing, implementing and evaluating public health services to prevent, control, and treat hepatitis C. The verb "ensure" is used often in the lists of challenges. Like the verbs discussed above, "ensure" signals that the Department, on behalf of the Government, can be depended on to take action. The *Strategy* is the Government's guarantee that it is taking steps to make the Australian community safe from hepatitis C, and safe from "risks" associated with injecting drug use. It is a promise to provide specified hepatitis C-related services. The collocation of "ensure" with the noun "access" is a guarantee that people with hepatitis C will have the use of the specified services. In particular, it wants to *ensure* that people with hepatitis C who inject drugs *access* the primary health care sector (Commonwealth Dept Health & Aged Care, 2000b, p. 36). Government "support" for peer education of, and access to

treatment by, people with hepatitis C who inject drugs is linked in the text with preventing the transmission of the virus and reducing illness associated with the disease.

The perspective of the *Strategy* reflects the dominant health paradigm, of which Galbally (1996, p. 184) is critical, with its focus on transforming bodies to approximate the “norm”, postponing death and changing the individual’s “high-risk” behaviours, in particular, by aiming:

- To enhance the capacity of and support peer educators and peer based drug user groups to reduce the transmission of hepatitis C in the context of holistic health and wellbeing;
- To ensure equivalent access for people with hepatitis C seeking treatment, regardless of their social, cultural, economic or geographic circumstances;
- To provide the best treatments available, supported by patient education and counselling, to reduce current and long-term morbidity, particularly for people with hepatitis C who are most likely to progress to advanced liver disease; [and]
- To support comprehensive peer education programs to encourage people with hepatitis C who inject drugs to engage with the primary health care sector. (Commonwealth Dept Health & Aged Care, 2000b, pp. 28 & 35)

In the dominant health paradigm it is seen as important to the health of people with hepatitis C, particularly those who also inject drugs, to locate them within specific places and/or spaces.

The impact of space and place in the delivery of health services to hepatitis C-positive people is outside the scope of this study. However, Foucault’s (1977, p. 144) depiction of the control within medical institutions, such as hospitals, that comes from a system that demarcates the “therapeutic space” and regulates the “comings and goings” of patients, suggests that hepatitis C-positive patients will have limited autonomy within the healthcare system. Analysis of “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), televised on the ABC’s *7.30 Report*, in Chapter Nine, outlines the way in which health professionals control the contextual aspects (Van Dijk, 1993, pp. 259–260) of their interactions with patients or clients with hepatitis C, whether it is the time, place or setting of an outpatients’ department attached to a tertiary treatment centre or a primary health care clinic. As the Anti-Discrimination Board of New South Wales (2001, pp. 35–57) reports in *C-Change: Report of the Enquiry into Hepatitis C Related Discrimination*, health care settings are more than physical places or locations within which particular spaces are located for the testing, diagnosis, health monitoring, and treatment of hepatitis C-positive people. Rather, health care settings imply social relations, and those entering health care settings will have a “sense of place”, that is,

“the meaning, intention, felt value and significance that individuals or groups give to particular places” (Curtis & Jones, 1998, p. 647; 653–654). None more so than hepatitis C-positive drug users who experience discrimination within health care settings such that they consider these locales the antithesis of places of “care” (Byrne, 2002, pp. 7–8; Jewell, 2003, pp. 3–5; Madden, 2004).

The *Strategy* speaks about the systematic use of peer support to change the behaviour of IDUs, helping IDUs behave in a responsible manner. Peer-based IDU groups (a type of NGO) are named in the “Guiding Principles” and challenges, of Chapter Three of the *Strategy*, as one of the institutions involved in observing and gathering information about IDUs, and working to change their behaviour or conduct:

Health promotion activities for specific communities are best developed and delivered by those communities through peer based initiatives in partnership with governments, health professionals and researchers...To enhance the capacity of and support peer educators and peer based drug user groups to reduce the transmission of hepatitis C in the context of holistic health and wellbeing. (Commonwealth Dept Health & Aged Care, 2000b, pp. 22 & 28)

Peer-based IDU groups are to play an intrinsic part in the reconstruction of IDUs as responsible citizens. Phrases such as “enhance the capacity of...peer educators and peer based drug user groups” (p. 28) suggest that workers in peer-based IDU groups will be trained to be “useful forces” (Foucault, 1977, p. 217) in the normative control of IDUs. Terms such as “social circles” imply that much of the work of IDU peers will be conducted in the social spaces and geographical places where injecting occurs and/or IDUs interact. Although IDUs engage in illegal behaviour, they are expected to conform to less dangerous injecting practices, exhibiting the form of governmentality associated with self-control and self-care (Lemke, 2001, p. 201). IDUs are expected to behave in such a manner so as *not* to produce disturbing indices, such as the incidence of hepatitis C over the operational period of the *Strategy* or the prevalence of hepatitis C among IDUs.

Barriers to the availability of medical treatment are acknowledged in statements about the limited access to treatment for a “range of people” (Commonwealth Dept Health & Aged Care, 2000b, p. 33), and the provision of “equitable access” to health care services, including antiviral treatment, is portrayed as a challenge. Health care services providers are encouraged to “explore options” in arrangements of the system of health care delivery in relation to the delivery of treatment. The word “options” suggests

choice, or enabling someone to make a choice, such as the patient choosing his/her doctor. However, it is health care service providers, rather than patients, who are to investigate changes to the established system of service delivery. The goal is to “augment capacity” (p. 34), that is, to increase the number of hepatitis C-infected people treated (the output) and/or the productivity of the treatment centre, and to “improve access”. At the same time, treating general practitioners and specialists are to follow the prescribing criteria of for Section 100 Items of the Highly Specialised Drugs Program in the Pharmaceutical Benefits Schedule (Commonwealth Dept Health & Ageing, 2003d), and patients are to comply with the treatment protocol as discussed in Chapter Nine. “Limited access” to treatment is framed as a problem to be solved by health care service providers, and control by patients is not mentioned. The experiences of advocates for hepatitis C positive IDUs embody the inequality in power relations between health care service providers and patients suggested in the text. In the *Strategy’s* fifth year, Madden (2004, pp. 5–6) of AIVL, bemoans the small number of current injectors accessing hepatitis C treatment and calls for structural changes in the provision of treatment to create client-centred treatment and health care services.

The use of the verb “support” in the lists of challenges has more than one interpretation. “Support” signals the Government’s assistance to the hepatitis C “community”, for example, by providing funds for peer education programs for people with hepatitis C who inject drugs. The Department makes it clear that the Government gives its support to a particular course of action, that is, harm reduction interventions, including needle and syringe programs (Commonwealth Dept Health & Aged Care, 2000b, p. 14). It is at pains to cite research conducted in Australia and the United States that shows the effectiveness of needle and syringe programs in reducing the transmission of blood-borne viruses, and squash any beliefs that such programs promote injecting drug use. However, the Government’s support is not intended to strengthen the position of IDUs, or to uphold their choice to engage in injecting drug use. Instead, the provision of support for particular programs, can be read as a means of controlling the behaviour of IDUs in order to contain the spread of hepatitis C from one person to another through the sharing of injecting equipment:

A variety of interventions appropriate to the particular contexts where risk-taking behaviours occur will be supported and promoted under this Strategy. The primary focus for these interventions is to reduce transmission of hepatitis C. (p. 14)

The producers of the text have chosen to express strategies for controlling people and containing the disease through words that imply negotiation and good will rather than coercion. Examples of “soft” verbs used repeatedly in the *Strategy* include: “enhance”; “promote”; “foster”; “encourage”; and “facilitate”. Without seeming authoritarian, these verbs are also used when informing health and public health professionals how to behave and how not to behave, and what the Department requires of them.

Competing discourse types around hepatitis C and injecting drug use are evident in the text. Fairclough, (1989, pp. 138–139) argues that the audience’s familiarity with “naturalised” conventions of a genre masks other elements. In this case, the reader would expect the Government to explicate the links between the *Strategy* and other programs. The Government’s policy in relation to illicit injecting drug use, which links with this population health *Strategy*, therefore, may not be scrutinised:

The *National Drug Strategic Framework 1998–99 to 2002–03* states that governments do not condone illegal behaviours such as injecting drug use but they do acknowledge that these behaviours occur. It also states that governments have a responsibility to develop and implement population health measures designed to reduce the injury that such behaviours can cause, both to individuals and to the community. (Commonwealth Dept of Health and Aged Care, 2000b, p. 14)

However, the *Strategy* contains evidence of oppositional discourse that gives another perspective on injecting drug use. In the priority area, “Preventing Discrimination and Reducing Stigma and Isolation”, the bulleted list of “Opportunities” related to the *National Drug Strategic Framework* includes the following statement:

To support initiatives to promote the diversion of people who use illicit drugs away from incarceration into alternative, non-custodial options where the risks of hepatitis C transmission are reduced. (Commonwealth Dept of Health and Aged Care, 2000b, p. 53)

This same opportunity—almost word for word—is also listed in the priority area “Reducing Hepatitis C Transmission in the Community” in relation to the National Drug Strategic Framework (p. 29). Two readings are possible: firstly, that there are contesting discourses within Government around the Government’s drug policy in which injecting drug use is regarded as criminal behaviour. Secondly, the Government’s drug policy that sees people who use illicit drugs incarcerated contributes to the transmission of hepatitis C within custodial settings and the broader community, as custodial settings are acknowledged “incubators” of the virus (pp. 24–25). In both

readings, it can be inferred that the *Strategy*'s producers frame the social behaviour of injecting drug use, and people who inject drugs, from a health-illness and communicable disease perspective. This is not unexpected as Lowe and Cotton (1999, p. 30) report, in their review of Australia's response to hepatitis C, that a communicable diseases framework is the model for a strategic response to hepatitis C preferred by the majority of stakeholders who reviewed options during the consultation process. Also, state and territory health departments identified the illegality of injecting drug use as "a major barrier to the delivery of appropriate preventive services and education" for the period October 1994 to March 1998 (Lowe & Cotton, 1999, p. 118). Whether the Government's policies relating to illicit drugs, particularly law-enforcement measures, undermine the gains to be made with the *Strategy* is an area requiring further study.

Conclusion

As outlined previously, the positive image of the Federal Coalition Government constructed in the *Strategy* is that of a government that is efficient, accountable, transparent, and consultative. Moreover, it is of a *federal* government that provides leadership to the states and territories, and holds the purse strings. Written from the third-person point of view, the text has an authoritative and omniscient air. It draws on the language of public health privileging what can be seen and measured. What the vocabulary of the text obscures is the failure to nominate agency and responsibility for problems in the health care sector. The word "challenge", meant to rouse members of the partnership to action, masks the following problems: the lack of dedicated funding to implement the *Strategy*; the lack of existing services; and the shortcomings in the manner in which health care professionals interact with hepatitis C-infected IDUs.

While links with national drug programs are acknowledged, the *Strategy* reflects the conception of the hepatitis C epidemic primarily as a health issue, and its location within the Commonwealth Department of Health and Aged Care. Representation of the disease as an individualised medical problem sees people who are infected with the hepatitis C virus encouraged to seek medical treatment. IDUs have rights in a health policy that adopts the disease concept of addiction. Hence, professionals—health care professionals, biomedical researchers, academics, and public health professionals—are to work towards removing stigma and discrimination that attaches to a hepatitis C diagnosis. It is not known how many health care professionals are aware of the *Strategy*,

and apply its guiding principles to their work practices. The challenge of changing the entrenched practices of health care services providers generally provides a rationale for reorientating health policy discourse so that it is framed by discourse on discrimination and social justice, alluded to by Hepworth and Krug (1997, p. 5), with the biomedical discourse taking a back seat. It is noted, however, that the second National Hepatitis C Strategy mimics its predecessor in listing “Addressing Discrimination and Stigma” as one of the seven priority areas for action, though not as one of the three central focal points for action. Nor does this second hepatitis C strategy alter the primary framing established in the inaugural strategy.

Notwithstanding this conception of the hepatitis C epidemic as a health issue, the health policy discourse about the epidemic is linked to the dominant ideology of the Government, specifically zero tolerance for drugs. The text talks around the problem of injecting drug use, and does not address underlying assumptions such as the Government’s perspective on injecting drug use that will stymie the implementation of the *Strategy*. The *Strategy* is, therefore, a testament both to the influence of experts who informed the making of this health policy (and to their sensitivity to the hepatitis C-affected community), and to the power of health economics that convinces decision-makers to invest in hepatitis C-related services now to forestall the “burden” of future health costs and indirect costs.

The way in which the text draws upon the vocabulary and organising structures of biomedicine to represent the natural and social worlds follows. The next chapter extends the argument that, despite the rhetoric of partnership, the *Strategy* secures the dominance of biomedical power for dealing with the hepatitis C epidemic in Australia.

CHAPTER SEVEN

CONTINUING THE RELIANCE ON THE BIOMEDICAL PERSPECTIVE IN HEPATITIS C PUBLIC HEALTH POLICY

“You’d have to drag me kicking and screaming to get me anywhere near that treatment.”

– Leanne, Interview, April 2003

Introduction

The analysis of the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b) in preceding chapters depicts this document as a blueprint for professionals dealing with the hepatitis C-affected community and the hepatitis C epidemic in Australia. Consequently, the potential reading audience of this document is limited. From its development to its implementation, hepatitis C public health policy discourse is primarily framed by the discourse patterns of the biomedical and public health institutions. It is from this perspective that people living with hepatitis C are spoken about, and about whom action is taken. The Federal Coalition Government (the Government), constructed in the text as efficient, accountable, transparent, and consultative, defers to experts from a relatively small set of institutions. The Government strategically manages the participation of non-government organisations (NGOs) representing the hepatitis C-affected community in the policy development and implementation processes. Limited to consultation, involvement of the affected community is not fully participatory.

That the *Strategy* reflects the language of scientific and medical research communities, and that of health care professionals, is to be expected given the relationship of public health to medicine within academic institutions. Although the socio-economic causes of ill health are noted, and there is consideration of, for example, prevention, occupational health issues, and health promotion, the *Strategy* nonetheless emphasises the “medical model”, particularly in relation to treatment, research, and technology. In this chapter I consider the Department’s attempt to present medical language in lay terms and the way in which the organising principles of the text reflect the discipline of medicine. The dominance of biomedical power is also considered in relation to the emphasis on treatment, the medical research paradigm, and surveillance to accumulate knowledge about, and depict, the hepatitis C epidemic.

Organising Structures Reflect Medicine

*“I just turned fifty. I didn’t think fifty would be a big deal but I really feel like an old lady. And I resent that. I resent that I feel old. That I ache all over, that I don’t sleep very well, that [sighs] I don’t have any energy and when I do have some energy it doesn’t last long. Yeah, I sort of feel that my life’s **not** beginning at fifty. Not the great life it should be, you know? Anyway, that’s the way it is...It’s [hepatitis C] always there. It’s sort of colouring your whole life...I’m sad for myself. It isn’t sort of what I saw as my life. My partner is really physical. I sort of think one of the answers is being fit and the more physical I can be, the fitter I can be, the better I can become. But I don’t have the time or the energy to sustain an exercise program. The mornings are horrendous for me and I find it very hard to get out of bed, I’m really sluggish, I’m stiff, I ache...I don’t have a visual image of it. It’s this thing that drags me down.”*

– Carol, Interview, April 2003

The Department as the producer of the *Strategy* attempts to translate medical language in the text into everyday language meant for the lay reader and non-medical professionals. The boxed information entitled “How Hepatitis C Affects Individuals and the Community: A Summary” (Commonwealth Dept Health & Aged Care, 2000b, p. 4), found in the introductory chapter, is an example of this (see Figure 3). In this device, too, the reader is introduced to the particular perspective of the world portrayed by the *Strategy*.

On first reading, the text seems tailored to the lay reader. The phrases “Hepatitis C infection involves an initial (acute) phase of infection” and “around 65 to 85 per cent of people infected will develop a long-term (chronic) infection”, for instance, give definitions of the medical terms “acute” and “chronic”, which those with the virus are likely to come across. In this example the medical terms are given in parentheses following the common term, as is the practice in medical references written for a lay reading audience such as *The Merck Manual of Medical Information—Second Home Edition* (Beers, 2004b). The Department though, is inconsistent in its bid to translate medical concepts into everyday language. The text is stripped of extremely complex information and technical terminology, such as information about laboratory findings in hepatitis C-infected patients. However, it does retain terms that may not be familiar to the lay reader including “immune response”, “antibodies”, “cirrhosis”, “liver failure”, and “abdomen”.

How hepatitis C affects individuals and the community: a summary

Hepatitis C infection involves an initial (acute) phase of infection, which is often asymptomatic and usually lasts from two to six months. During this phase levels of the virus in the blood rise dramatically until the body’s immune response starts producing antibodies. Although these antibodies fight the virus, around 65 to 85 per cent of people infected will develop a long-term (chronic) infection and could transmit the virus to others. Many people with a chronic infection stay healthy for a long time. Some people develop symptoms of liver disease, among them tiredness, lethargy, nausea, headaches, depression, aches and pains in joints and muscles, and discomfort in the upper abdomen area. After many years a number of people with chronic infection will develop serious liver illness, such as cirrhosis, liver failure and liver cancer.

The hepatitis C virus is believed to have been in the Australian community for many years, possibly since the 1960s. Current estimates suggest that more than 200 000 Australians have been infected with the virus and that 11 000 new infections are occurring each year. In 1997 it was estimated that the cost of the hepatitis C epidemic in Australia was \$107.5 million, rising by \$46.6 million (over 50 years) for every 1000 new infections. With high numbers of existing chronic infections and most people with hepatitis C not yet seeking treatment or experiencing serious liver illness, compounded by the number of new infections occurring, hepatitis C will continue to have serious implications for Australia’s health care system for many years.

Figure 3. Boxed information “How hepatitis C affects individuals and the community: a summary” in introductory chapter of the *Strategy*

Source: Commonwealth Department of Health and Aged Care. (2000b). *National hepatitis C strategy 1999–2000 to 2003–2004*. Canberra: Publications Production Unit (Public Affairs, Parliamentary and Access Branch).

The boxed summary information in Figure 3 is organised in the fashion of medical references, such as *The Merck Manual* and its “home edition” (Beers, 2004a & b). Hepatitis C is cast as a particular type of disorder, namely, an infectious disease: “More than 200,000 Australians have been infected with the virus and...11,000 new infections are occurring each year.” This summary box, like other pages in the text, contains a host of assessments and estimates, such as the estimate of the number of Australians infected, the number of new infections, and the economic costs associated with the epidemic. Information in the box also covers causes, symptoms, diagnosis (suggested without specifying diagnostic tests and procedures) and prognosis, and omits prevention and treatment. The liver is specified as the organ that the virus targets: “Liver disease...liver illness, such as cirrhosis, liver failure and liver cancer.” The following lines of text suggest the prognosis, or likely course or outcome of hepatitis C:

Many people with a chronic infection stay healthy for a long time. Some people develop symptoms of liver disease...After many years a number of people with chronic infection will develop serious liver illness, such as cirrhosis, liver failure and liver cancer.

Symptoms of liver disease are listed as: “Tiredness, lethargy, nausea, headaches, depression, aches and pains in joints and muscles, and discomfort in the upper abdomen area.” The organising structure common to medical references, evident in the summary box, is threaded throughout the *Strategy* with sections on: epidemiology; the classification of viral hepatides; transmission risk factors; prevalence and incidence; natural history of the virus; clinical treatment; and testing. Although more colloquial language is employed in section headings—for example, “How Many People have Hepatitis C in Australia?” in place of “The Prevalence and Incidence of Hepatitis C”—the *National Hepatitis C Strategy 2005–2008* (Commonwealth of Australia, 2005) follows suit in terms of the organising structure and the content of sections.

As mentioned in a later chapter on news coverage of hepatitis C, a number of news stories personify the hepatitis C virus as a secretive and insidious opponent or combatant, and the disease as an epidemic by stealth, which has crept up on health authorities in Australia. The language of the *Strategy* is similarly embellished with metaphors that shape meaning. Words denoting warfare and the Government’s response as a military operation were discussed in Chapter Three about the foreword to the *Strategy*. The *Strategy* elaborates on the war metaphor, which Sontag (1988/2001, p. 97) argues is a common attribute of modern medicine:

Military metaphors have more and more come to infuse all aspects of the description of the medical situation. Disease is seen as an invasion of alien organisms, to which the body responds by its own military operations, such as the mobilizing of immunological “defenses,” and medicine is “aggressive”.

Phrases like “antibodies fight the virus” (Commonwealth Dept Health & Aged Care, 2000b, p. 4) provide an image of the battle waging in the host’s immune system between defending antibodies and the invading hepatitis C virus (the primary “object” about which the *Strategy* speaks). The host’s defences are found lacking in the majority of cases of hepatitis C: “Although these antibodies fight the virus, around 65 to 85 per cent of people infected will develop a long-term (chronic) infection and could transmit the virus to others” (p. 4). A logical relationship is apparent in the text between the large percentage of people remaining infected who “could transmit the virus” and the imperative for newer, improved treatment: “[The] improvement in our ability to suppress or even eradicate certain subtypes of the virus in particular individuals elevates the place of treatment in the list of strategies for dealing with hepatitis C” (p. 31). The virus, can now be detected through nucleic acid testing, the “latest technology” (p. 27), to amplify its genetic material and make it visible. This cutting edge technology is in use in “securing the blood supply” (p. 26), and is one of the tools for diagnosing infection in people (p. 33).

Figurative language that continues the military theme, such as “vigilance”, “threat”, “security”, “surveillance” and “targeted”, suggests that the virus poses a danger to the uninfected as well as to those who are hepatitis C positive. The word “effective” in phrases like “most effective way to reduce harms to individuals and the community” and “an effective national response to hepatitis C will be responding to the challenges” (Commonwealth Dept Health & Aged Care, 2000b, pp. 1 & 2), has connotations of a military unit that is equipped and ready for action. While it is “social, cultural and occupational practices” and “risk behaviours” that may expose a person to hepatitis C-infected blood that are referred to in the text (p. 23), the hepatitis C-positive person, as will be discussed further on, is positioned as a source of the virus, a source of danger. This can be inferred, for example, in the previous quote: “65 to 85 per cent of people infected will develop a long-term (chronic) infection and *could* [italics added] transmit the virus to others” (p. 4). It follows, as discussed in Chapter Nine, that the doctor wielding high-technology treatment is positioned as the “hero”.

The dominance of biomedical power is fixed in the *Strategy* through the emphasis on high technology diagnostic testing, high technology treatment, and the application of the medical research paradigm. As will be discussed, the emphasis in the *Strategy* is on biomedical research—basic, virological and clinical—to develop hepatitis C treatment: “new and improved treatment”; “a broader range of treatments”; and “post-exposure prophylactic therapies” (Commonwealth Dept Health & Aged Care, 2000b, pp. 32 & 36). Not surprisingly, breakthroughs in medical treatment for hepatitis C rank in the top ten topics of news items on hepatitis C examined for this study. Complementary and alternative therapies are also to be subjected to the testing and research paradigm associated with the high-technology medicines supplied by pharmaceutical companies. The brief mention of complementary and alternative therapies in the *Strategy* reflects the appropriation of these modalities by conventional medicine. The statement, “the use of complementary and alternative therapies is widespread among people with hepatitis C” (p. 35), at first seems to indicate recognition and accommodation of consumer health care choice.

This trend in consumer choice is acknowledged in professional journals published subsequently. In an article for the *Medical Journal of Australia (MJA)*, Bensoussan and Lewith (2004, p. 331) report: “About half the Australian population use complementary and alternative medicine (CAM)...[and] preliminary research indicates that CAM may be useful in treating hepatitis C infection.” In the *Strategy* acknowledgment of the “use” of CAM is qualified: “The limited body of research into complementary therapies shows that such therapies have limited effect on viral activity but more success in alleviating the symptoms of infection”. Readers are told that the consumption of complementary therapies provides some benefit in “alleviating the symptoms of infection”. Readers are also told that complementary therapies can be consumed solely for the purpose of relieving symptoms, as these therapies are not antivirals and not curative. The vocabulary, therefore, fits the medical concept of a palliative remedy or medicine. While the use of complementary therapies is described as “widespread”, for some—particularly current drug users who are hepatitis C positive—usage may reflect their hitherto lack of access to curative medical treatment as much as any exercise of consumer choice.

The use of complementary and alternative therapies, however, is not worded from the perspective of lay people, or from the perspective of people who may oppose the biomedical model. The sentence, “The use of complementary and alternative

therapies is widespread among people with hepatitis C”, is worded from the perspective of health care service providers. It is an observation about the health care practices of people infected with hepatitis C of which doctors should be aware. The research concerns expressed in the text lie with the primary object, the hepatitis C virus, and the natural history of the virus: “There is need for further research into and more information about the impact of these [complementary] therapies on hepatitis C infection and liver function generally” (Commonwealth Dept Health & Aged Care, 2000b, p. 35). The text, therefore, reflects the perspective of conventional Western medicine with its call for research into the prognostic value of complementary and alternative therapies. It is assumed that the benefit to consumers of such therapies in alleviating symptoms fails to impress the medical community as the consultation draft of the second strategy (Commonwealth Dept Health & Ageing, 2004, pp. 17–19) did not include discussion of complementary and alternative therapies in the priority action area, “Diagnosis, Access, Treatment and Support”, and nor does the *National Hepatitis C Strategy 2005–2008* (Commonwealth of Australia, 2005).

The Government sought specialist understanding of the hepatitis C epidemic when developing its hepatitis C population health policy. While “expert” members of the social networks that influence hepatitis C-related policy may share a broad set of values, they may not advocate the same policies. For the most part, though, the knowledge that these experts generate comes from biomedicine, the dominant health paradigm:

Biomedicine considers illness and disease to be located in the individual and views treatment as predominantly surgical or pharmacological. This paradigm explains disease mostly by mechanical causality and with reference to explanatory models as close to the molecular level as possible. (Filc, 2004, p. 1276)

With its representation of hepatitis C as an individual health problem that is amenable to medical treatment, the *Strategy* reflects the normalising focus of the dominant health paradigm criticised by Rhonda Galbally (1996), the former director of the Victorian Health Promotion Foundation. In this text, those who are hepatitis C positive are to be encouraged to seek a cure through treatment:

Treatment options for hepatitis C infection have greatly improved in recent years...This significant improvement in our ability to suppress or even eradicate certain subtypes of the virus in particular individuals

elevates the place of treatment in the list of strategies for dealing with hepatitis C. (Commonwealth Dept Health & Aged Care, 2000b, p. 31)

The second National Hepatitis C Strategy retains this focus: “The second Strategy will also focus on areas such as encouraging people with hepatitis C to access treatment” (Australian Govt Dept Health & Ageing, 2005a, p. 8).

Focusing on treatment is of particular concern for health consumers who are disabled, chronically ill or ageing as the health care imperative of “normalising” bodies serves to isolate them (Galbally, 1996, p. 184). It is also of concern to hepatitis C positive injecting drug users (IDUs) who have experienced, or anticipate, discrimination in health care settings. According to AIVL’s education manager Jude Byrne (2002, p. 8), IDUs “feel they cannot face current mainstream health services” due to the discriminatory behaviour by health care workers. Reporting on AIVL’s submission to the review of the *Strategy*, AIVL education project worker Skye Jewell (2003, p. 4) also cites systemic discrimination within the health care setting as a barrier to IDUs accessing treatment:

Drug users are voting with their feet when it comes to accessing health services generally, and hepatitis C treatment services specifically...Many drug users simply cope with hepatitis C symptoms as best they can rather than going to see a doctor and having to deal with the inevitable judgements and unfair treatment...Too often, drug users are denied critical health monitoring and new treatment options in relation to hepatitis C, simply because the health system appears unable or unwilling to change the ways it thinks about and treats current drug users.

Galbally (1996, p. 185) believes that it is in consumers’ interests to become independent of, or “disengaged” from, the health care system. As mentioned, in the new paradigm proposed by Galbally, research would focus on understanding “how people survive with reasonable health under very adverse situations”.

An alternative to the dominant health paradigm of biomedicine is that expressed by Leanne [name changed] in her description of her life with hepatitis C. In this excerpt from an unstructured interview conducted for this study, Leanne, an academic in her late 40s, describes how she incorporates the hepatitis C virus that resides in her body into her life philosophy of ecofeminism. Leanne starts her story of living with the virus by recalling an old friend of hers who is also hepatitis C positive:

Quite early on somebody I know who is hep C positive, who found that out before I knew that I was, made an interesting correlation. I think that he had first belonged to the Council [Hepatitis C Council of WA] and felt that the kind of close association with HIV stuff and what sort of seemed like a bit of doom and gloom kind of atmosphere around it, he pulled back from that for a while. He came to terms with it by sort of saying, “Things live under rocks. Things live everywhere.” And that always stayed with me. It stayed with me a lot because in my own studies, in my own storytelling, and in my own philosophical orientation, it’s come around to being quite an ecofeminist one, and my interest in things. (Leanne, Interview, April 2, 2003, Lines 6–15)

Leanne relates two past events that involve significant others, her brother and her friend with hepatitis C, weaving these with her current thoughts and approach to living with the virus. She finds aspects of her friend’s and her brother’s ideas and approaches to life that help her live with the virus:

It was a couple of years later that I had, completely accidentally, found out that I was positive. So I was fortunate that I was with [my husband] but also this comment of this friend...I felt able to take a different sort of sense of it *or* at least work on, at least have a space for that kind of sense of it. There’s stuff floating around a bit these days that some of the autoimmune diseases that people have is because they’re too blood clean [laughs]. There’s a certain level of living with viri, microbes of what-have-you, which can be okay. It’s a sort of long-term symbiosis rather than something that’s going to take you over. People might see it [hepatitis C] as a parasite but I’m not seeing it in that way in my system. (Lines 27; 39–45; 48–53)

I’ve got a spectrum of things and there’s one end where it’s this terrible, devastating thing...It [hepatitis C] might rear its head if I’m feeling particularly low...Yeah, my system functions well so these days I just don’t feel [pauses] I have a sense that well it’s in there under the rocks, you know, it’s in the ecosystem of my whole body...I try to make healthy choices. I certainly make healthy choices around my food. I’m not by any means perfect but I just keep an eye on things. I kind of live a fairly balanced approach to it...There’s many ways in which it’s a *non-issue*... (Lines 206–210; 228–234)

Because it’s a blood borne thing, I tend to think of it more in my blood. That’s the site it’s going to have the most impact on. I tend to have a sense of it being in my system because it’s in my circulatory system. And that’s okay. That *is* okay. My brother wrote a song for me once many years ago after I had this terrible, terrible heartbreak and grief that lasted for years when a relationship ended. He had lines, some lines in it that went, “As meteor showers sculpt the face of the moon so the beauty of an old jarrah comes from its ancient wounds.” And it kind of connects up with that. There is a rough and tumble in life, in organic life – not inorganic life but *in* organic life – that means that things live on other things and under other things and within other things. That up to a

certain point, if that system is in balance, yeah, okay it's damaged but it can contribute to a richness in a way. To use an ecological metaphor again, if it's out of balance then it goes completely like a compost heap that goes off, do you know what I mean? There's that problem. But it's in an ecosystem where other things are functioning well then...you can consider it damage but you can also consider it dues for being alive, for being human and in the end then dying. (Leanne, Interview, April 2, 2003, Lines 251–272)

In the coda (Labov cited in Riessman, 1993, pp. 18 & 59) of this narrative segment of the interview, Leanne returns the perspective to the present:

This [living with hepatitis C] is just one part of the spectrum of who I am. And who I am is, and what I am is, connected to the community, and in connection to ecosystems. It's world connected and bodily embodied, and your perspective is always relational to those other things that are out there. Those other things are the other things in the more than physical ecosystem, in the social ecosystem or in the whatever, that makes it this one thing that's in this mixture of many healthy and vibrant things and therefore it doesn't take over and be the rotting compost. Which it could do if there weren't these other multiple things. (Leanne, Interview, April 2, 2003, lines 390–396)

Not all hepatitis C-positive IDUs will identify with Leanne's sense of herself as just one organism amongst many in an ecosystem, nor with her acceptance of her own mortality. However, an ecofeminist critique of relationships of domination may resonate for those who have negative experiences of zero-tolerance policing practices (see Day, Woolcock & Weatherall, 2003, pp. 70–71; Southgate et al., 2003, p. 88), or who have experienced discrimination within the health care setting.

Many hepatitis C-positive IDUs will not fit Galbally's (1996, p. 185) notion of people surviving "with reasonable health under very adverse situations". Instead they may live "with chronic pain, serious illness and poor general health as a routine part of life" as Madden (2004) describes. Notwithstanding this, IDUs may have a holistic view of health as Southgate et al. (2003, p. 89) note in their summary of Kimber and Day's (2003) pilot study of quality of life among a small sample of IDUs in four Australian cities. Those seeking the inclusion of IDUs in political rights, access to health care and the transformation of the hierarchical and professional-dominated and controlled public health system may find ideas in alternative paradigms as Galbally (1996) suggests.

Surveillance: Knowing the Epidemic and People at Risk

“Just before the year 2000 I was sitting on a tropical island three degrees south of the Equator. Sitting there with my missus thinking, ‘Well this is it.’ I had everything. I had a really good job, just got me third promotion. Had me two older girls in boarding schools, in quite good boarding schools. I thought, ‘What could go wrong?’ And a month later I was sitting up there nearly in tears. I’d been diagnosed with hep C. So it changed my life from that diagnosis. Very, very much. The first thing I noticed was me circle of friends, they’ve changed quite dramatically. Soon as people realised that I had hep C. I used to play touch football, squash, go diving. I was really involved in everything. Ah, people just didn’t want to play any sports with me. I was on a ship and no-one’d ever come and say ‘Giddy’ to me. People’s attitudes and everything just changed, basically overnight sort of thing. They thought ‘cause I had hep C my wife had hep C and all the family would have hep C. So she got alienated as well. Women wouldn’t let their kids come around and play with our kids. They wouldn’t come around and associate with my wife. She was outcast ‘cause it’s only a very small community – you’re talking about 40 expat people there. And, ah, she found she wasn’t positive for hep C and none of the kids were positive for hep C but still it never changed anything and it got so bad that I actually got the company to take my family off the island and go back to Australia. Just the ridicule, the pressures of life and that...It was just basically that bad. The first thing they did, my boss called me in and he expected me to resign on the spot because of it. Because as he indicated, ‘We can’t afford to have an epidemic on the island’ sort of thing. And I refused. I said, ‘No. I want treatment.’ You know sort of, ‘Why should I give up my job and resign because I’ve got it?’”

– Trevor, Interview, July 2003

Obtaining and accumulating knowledge about the hepatitis C virus and people infected with hepatitis C is a major goal of the *Strategy*. The listing of “Research and Surveillance” as one of the six essential components of Australia’s response to hepatitis C (Commonwealth Dept Health & Aged Care, 2000b, p. 11) establishes the goal of obtaining knowledge—to add to an “incomplete” body of knowledge—as an extensive publicly funded undertaking. The types of research that will furnish data to inform public health policy-making and public health practice are categorised by their specialised fields: “Epidemiology, basic scientific research, virology, clinical research, and social and behavioural research” (p. 16). The collection of sets of data over time is portrayed as most important for constructing an accurate picture of the “hepatitis C epidemic”. This section about surveillance of the hepatitis C epidemic covers the

following: the use of the word “risk”; the artificial separation of the surveillance of people from that of the epidemic; changing “high-risk” behaviours and “self-surveillance” by hepatitis C-positive individuals; and the imperative to forestall illness and postpone death.

As an essential component, “Research and Surveillance” becomes a sub-heading in Chapter Two of the *Strategy*. The vocabulary about surveillance is measured. The three stated functions of surveillance are: “To monitor the prevalence and incidence of hepatitis C in our community, to identify those at risk of infection and so enable accurate targeting of prevention and care interventions, and to provide data to assist in the evaluation of these interventions” (Commonwealth Dept Health & Aged Care, 2000b, pp. 17–18). Research and surveillance provide the “evidence base” to justify public policy and programs, clinical treatments, and hepatitis C-related services (p. 16). Surveillance is linked with risk, a term that is used in more than one way in the text. Risk is a technical calculation of probability that pervades science (Douglas, 1990, pp. 2-3). In the *Strategy*, it is the calculation of the probability of a person becoming infected with the hepatitis C virus and its attendant negative outcomes. It remains a concern of the second national hepatitis C strategy, which is highlighted in the executive summary of that document: “Knowledge of the characteristics of the hepatitis C epidemic in Australia remains incomplete. Improvements to the current surveillance system are needed to give a true picture of the extent of the epidemic, and of the behaviours and contexts which place people at risk of hepatitis C” (Commonwealth of Australia, 2005).

The use of the term “risk” in the *Strategy* gives a veneer of scientific precision to its other meaning, “danger” (Douglas, 1990, pp. 3–4), and is used to justify the Government’s decisions and actions, working to portray the Government as accountable. Contrary to Krug’s (1995, p. 305) finding, those in power—governments and the biomedical, scientific and public health communities—are taking hepatitis C seriously. “Risk groups” for hepatitis C transmission are indicated in phrases such as: “risk factors”; “very high risk factor”; “high risk context”; “elevated risk”; “those at risk of infection”; “people at risk of hepatitis C”; and “population groups at risk”. Risk behaviours are referred to in phrases such as: “risk of transmission”; “risk of hepatitis C transmission”; “hepatitis C transmission risks”; “high risk behaviours”; “risk-taking behaviours”; and “risk-related behaviours”. The term occurs 113 times in the second national hepatitis C strategy (compared to 83 occurrences in the first strategy). In the

second strategy another category of risk is apparent in the phrases “transmission risk to others” and “the risk of passing the virus on to others” (Commonwealth of Australia, 2005, pp. vii; 8 & 17). The seemingly “neutral” vocabulary of risk nevertheless reflects the “moralising and politicising [of] the dangers” of hepatitis C (Douglas, 1990, p. 5) as discussed later.

The *Strategy* speaks about measuring the occurrence of hepatitis C in population groups at risk with surveillance and monitoring interventions. Surveillance most often refers to descriptive or analytic research, with measures of occurrence, such as the measurement of the occurrence of hepatitis C in populations at risk, and measures of association such as the calculation of risk ratios. In place of the visual observation of people’s behaviour associated with panoptic institutions and earlier disciplinary techniques, epidemiologists monitor the end-product or indicators of behaviour, such as the incidence and prevalence of hepatitis C, and make projections for the future. Surveillance is a public health management tool for calculating both the outputs and costs of, for example, public medicine (discussed in Chapter Three), and is used for planning and evaluating services. It encompasses the collection of data by centres of observation, such as the National Notifiable Diseases Surveillance System maintained by the Surveillance Section of the Australian Government Department of Health and Ageing, for judging the performance of hepatitis C service providers, as previously discussed, in educating hepatitis C-positive persons (and those at risk of infection) to conform so as to reduce the transmission of hepatitis C, with the Minister at the apex of the reporting hierarchy. Surveillance reveals categories of people who are not conforming to the established norms. In a self-perpetuating cycle, failure to contain the hepatitis C epidemic gives various institutions (including public health, medical, scientific, academic, government, and NGOs) a reason to continue their activities.

The surveillance of the hepatitis C epidemic rather than surveillance of hepatitis C positive people is spoken about in the *Strategy*. This phrasing seems to distance the infected person from the process of continual observation, and may encourage the hepatitis C-positive person to feel less subject to surveillance by others. Similarly, the definition of surveillance in the *Strategy’s* glossary refers to hepatitis C the disease as the object upon which attention is focused:

The continuing scrutiny of all aspects of the occurrence and spread of a disease. The main purpose is to detect changes in trends or distribution in order to initiate investigative or control measures. (Commonwealth Dept Health & Aged Care, 2000b, p. 72)

This definition is similar in wording to that of the World Health Organisation quoted by the national surveillance section of the Department: “Continuing scrutiny of all aspects of the occurrence and spread of disease that are pertinent to effective control” (Communicable Diseases Australia, 2004, p. 98). Hier (2003, p. 402) says of contemporary surveillance systems: “It is not the personal identity of the embodied individual but rather the actuarial or categorical profile of the collective which is of foremost concern.” However, as Hier shows in relation to the monitoring of welfare to single mothers in Ontario in the mid-1990s, the information collected can be “redirected back towards the body [the individual] for a multitude of reasons.”

It is important to consider how a distinction can be made in practice between surveillance of the epidemic and that of hepatitis C-positive people as implied in the *Strategy*. Although testing, described as “a primary tool in diagnosing infection” (Commonwealth Dept Health & Aged Care, 2000b, p. 33), is not linked in the text to surveillance, it is about this point in time that testing occurs that mandatory notification for surveillance purposes becomes an issue for the patient. Health care practitioners are to conduct “adequate pre-test discussions and offer post-test counselling”, and a national hepatitis C testing policy is to be developed “incorporating guidelines for pre-test discussion and post-test counselling” (p. 33). A guarantee of anonymity of test results and patient privacy accompanies the mandatory notification of hepatitis C infection. Hepatitis C is notifiable by all doctors in all states and territories of Australia:

In Western Australia, it is a legislative requirement that *doctors* notify certain infectious diseases to the Department of Health. Hepatitis C virus (HCV) became a notifiable disease in 1993. In all other Australian States and Territories, *except* WA, notifiable diseases legislation also requires *laboratories* to report positive test results to the State/Territory health department...For a chronic disease such as hepatitis C, it is important to follow the long term trends and patterns of disease. To learn more about risk factors for ongoing transmission of the disease, it is necessary to distinguish recent infections from those that were acquired in the past, often years ago. (Atthowe, Thompson & Giele, 2002, p. 1)

Doctors are the instruments of surveillance conducted by the public health bodies, which are concerned with populations (Foucault, 1997) and the individual as a “case”, rather than the personal stories or experiences of the individual.

In WA, doctors completing the Hepatitis C Enhanced Surveillance Form, when notifying hepatitis C virus infection to the Department of Health, Government of WA (2004), can read the accompanying privacy statement. The privacy statement available

at the WA Department of Health's website states that "notified information is held securely and kept strictly confidential" and that the notification does not breach the *Privacy Act (Commonwealth)* 1988. The letter to doctors introducing this form includes a box for supplying patient details. The statement "strictly confidential" is printed beside the heading "Patient Details". The reporting doctor also has the option of supplying a "name code" in place of the patient's name. However, on the notification questionnaire, the patient's name and address must be supplied in full, as well as details of occupation. The doctor has the option of notifying the Department of Health by post, telephone, or facsimile. Although procedures are in place to protect the patient's privacy and ensure confidentiality of a hepatitis C diagnosis, the individual diagnosed with hepatitis C infection is, nonetheless, fully implicated in mandatory notification. While notification to the Department may be treated confidentially, Rowe (1999, p. 69) quotes from an interview conducted by Burrows and Bassett (1996) that illustrates a breach in confidentiality during the delivery of a hepatitis C diagnosis to a prisoner. The individual bearing the hepatitis C virus is notified to the Department of Health, not an anonymous person. The diagnosis of a person with hepatitis C infection identifies that person as hepatitis C positive.

The feelings and intuitions of persons who are diagnosed with hepatitis C virus infection, whose test results are notified to the state/territory's department of health as required by legislation and regulations for statutory or mandatory medical notifications, are absent in the *Strategy*. It is noted in the consultation draft of the second national strategy that "the diagnostic event shapes how people with hepatitis C understand their infection [and it] is essential that diagnosis is handled sensitively" (Commonwealth Dept Health & Ageing, 2004, p. 17), yet the relationship between diagnostic testing and surveillance is not explicated. The definition of surveillance in the *Strategy*, which refers to surveillance external to the individual, says nothing overt about the infected person's relations with his/herself. Nor does this definition speak about the relations of the hepatitis C-positive person to others following diagnosis. In the previously mentioned interview with Leanne, she describes the "darker side" of dealing with instances of possible blood contamination after finding out that she was hepatitis C-positive:

For me it tends to be I'm Typhoid Mary or something, and yes, the notion of contaminating somebody else. Its corollary is, of course, that I'm contaminated and therefore, there is, particularly when I was menstruating, this ever-present contaminating somebody else...I haven't lived much of a self-abusive life. I've mostly exercised and I've mostly eaten pretty good food and stuff. So I'm kind of well. So the issue's been more along the line of what if I give it to somebody else who's not so lucky? Do you know what I mean? What if their system's frail in some other way or they go down with some of the worse consequences of it? That's where the contaminatory stuff comes in. (Leanne, Interview, April, 2, 2003, Lines 68–71 & 84–90)

In the *Strategy* the producers speak about governing the disease hepatitis C, but the disease is not accessible outside of the laboratory (Krug, 1997, p. 94), except via the people infected with the hepatitis C virus. The text is characterised by a level of abstraction and mystification, as though the disease and the virus are disembodied from the people infected with it. This is an artificial divide. Moreover, words like “detection” found in texts such as the NHMRC (1997) document *A Strategy for the Detection and Management of Hepatitis C in Australia*, and the word “identify” in the *Strategy*, suggest that the infected individual will be exposed or revealed, and set apart from others. Others may suspect the individual who tests positive for hepatitis C of injecting drug use at some point in time, and react in a discriminatory fashion (as previously discussed). The identification of an individual as hepatitis C-positive may also arouse in that person an awareness of the possibility of infecting others, such that he/she engages in self-surveillance.

Nonetheless, the text represents surveillance in general terms, without insights into the experiential qualities of surveillance. Surveillance is not brought home to the reader's own experience. This reflects a deliberate choice on the part of the producers of the *Strategy*. While surveillance and the practice of testing and diagnosing hepatitis C infection are also considered as separate issues in Lowe and Cotton's (1999) report, which informs the *Strategy*, the time of diagnosis, spoken about in the chapter by Rowe (1999, pp. 67–74), illustrates these practices with samples of concrete events. Rowe represents the subject matter of diagnosis so that readers can experience it. The “snapshots” presented by Rowe, which are excerpts of interviews from secondary sources, connect readers to the experiences of people tested for, and diagnosed with, the hepatitis C virus. Rowe's text connects readers to events that exist in place and time, and evokes an emotional response in readers. Producers of the *Strategy*, by comparison, omit concrete details to suggest that instances of, for example, being tested for and

diagnosed with hepatitis C, exist in many different places at many different times, for many different people. It seems that the producers of the text assume that the experiences of hepatitis C-positive people are similar enough that their experiences can be compressed and represented abstractly. This assumes, also, that readers either share experiences in common with those who have been tested for and/or diagnosed with hepatitis C infection or can intuitively understand. However, this style of writing may exclude, for some readers, the “salient” knowledge embedded in the “day-to-day lived experience” of persons living with hepatitis C (Hepworth & Krug, 1997, p. 5).

Surveillance in the *Strategy* does not relate to the *physical* confinement of segments of a society. It is not a reference to the sequestering of infected persons, as in Foucault’s (1977, pp. 195–199) description of the “technique of disciplinary partitioning” associated with the “tactical” segmentation of plague victims in France at the end of the seventeenth century, and the nineteenth century segregation applied to lepers. Nor does hepatitis C surveillance in Australia currently relate to the confinement of individuals infected with hepatitis C in a place or space under visual observation (or the perceived threat of visual observation) as in punitive panoptic institutions (Foucault, 1977, pp. 200–203). However, not so long ago, hepatitis C-positive patients *were* physically set off from other patients as the following excerpt from Krug’s (1997, p. 97) study shows:

Patients in the Royal Prince Alfred Hospital in Sydney were “tagged” with yellow armbands if they were positive for HCV, HIV, tuberculosis or other diseases to indicate their status to hospital workers. Similarly, at the same hospital, international biohazard warning stickers were placed on the patients’ files.

While Lianos (2003, p. 427) cautions against projecting Foucault’s analyses onto studies of social behaviour in modern societies (since the 1970s), the concept of a generalised “panoptic schema” (Foucault, 1977, pp. 205–209) is still relevant to this analysis of the *Strategy* as the risk of infected individuals transmitting the virus to others remains a central concern of the *Strategy* that requires some form of surveillance of the health of populations. The *Strategy*, produced by the Department on behalf of the Government, seeks to mediate activity between people. Moreover, contrary to Lianos’s (2003, p. 416) contention regarding institutional control, the testing and diagnosis of a person as hepatitis C-positive involves the *consciousness* of that individual and of the treating doctor.

To place the hepatitis C epidemic under surveillance requires diagnosis and notification of individuals infected with the virus. To this end the *Strategy* has the imperative of testing for the virus, identifying the hepatitis C virus, diagnosing the infected individual and registering that person within the surveillance system. In WA, for example, the mandatory notification form and the hepatitis C enhanced surveillance form documents the person's: name; sex; date of birth; country of birth; ethnicity; address; occupation; date of test; test results; previous hepatitis C testing results; estimate of when the person acquired hepatitis C; reasons for testing; risk factors; where the infection was acquired; overseas travel; and other clinical details (Dept Health Govt WA, 2004). The Department of Health, Government of WA, like the health authorities in all states and territories, updates the National Notifiable Diseases Surveillance System fortnightly (Australian Govt Dept Health & Ageing, 2003a), thereby adding data to the body of knowledge about hepatitis C.

Testing, identifying, and diagnosing pave the way for self-surveillance, targeted prevention and care interventions, and the much-emphasised treatment to cure the infection (Commonwealth Dept Health & Aged Care, 2000b, pp. 17–18). Testing for, and diagnosis of, hepatitis C is the equivalent of an inspecting gaze that the infected individual is expected to internalise such that that individual exercises control over his/her own behaviour (as will be discussed). The identification, diagnosis, monitoring, and treatment of persons infected with hepatitis C requires that health care professionals conduct themselves in a non-discriminatory manner so that, in particular, IDUs are tested, receive information, seek treatment to clear the virus, and do not transmit the virus to others. As previously discussed, changing the discriminatory behaviour that health care professionals may display towards people infected with hepatitis C, especially in interactions with IDUs, and effecting a moral detachment from the diagnosis of hepatitis C, is itself a “challenge”.

Population surveillance for hepatitis C sees a shift away from the physical confinement associated with diseases that have visible markers of illness. Hepatitis C infection is an invisible disease, and the *Strategy* is imbued with a sense of pathology as it moves beyond markers visible to the eye, beneath the surface of the body to the cellular level via antibody testing and nucleic acid testing, high technology applications. Mandatory reporting of hepatitis C infection provides data to furnish statistics, managed by professionals in public bureaucracies. Mandatory reporting is also the point at which the burden of responsibility of the infected individual is documented. While the marker

for hepatitis C is invisible, the moral overtone attached to the disease brings stigma, and social partitioning. This can be seen in news reports, such as the *Herald Sun*'s page two story "Bad Blood Blamed for Deaths" (Carter, 1999), in which hepatitis C-positive people are often grouped together on the basis of morality, and according to the biomedical concept of risk factors for the transmission of the virus specified in the *Strategy*. Social partitioning is signified in media reports such as the television news segment "Hepatitis Treatment" (Ward, 2005), broadcast on the ABC. This news report of the launch of "National Hepatitis C Treatment Awareness Week" is to educate people and doctors of the advances in treatment of the disease. In this report, footage of injecting equipment—a needle and syringe being used to draw up a solution from a teaspoon—signifies drug culture and IDUs as Krug (1997, p. 99) previously noted. A photographic image of a buffed male torso behind the hepatitis C-positive male interviewee can be read as a signifier of gay culture and a possible reference to those homosexuals or bisexuals co-infected with hepatitis C and HIV (see O'Brien, Misson & Grierson, 2002, p. 3).

Although hepatitis C surveillance in the *Strategy* refers to the surveillance of the virus not to surveillance of people, it does involve categorising people according to their behaviour(s) or actions. Such categorisation is itself a form of social segmentation and partitioning. The third chapter of the *Strategy*, entitled "Reducing Transmission of Hepatitis C in the Community", outlines the approach of focusing on reducing the risk behaviours that individuals engage in (Commonwealth Dept Health & Aged Care, 2000b, p. 21). The concept of "risk behaviours" is considered less stigmatising of groups of people than the term "risk groups" (AHC, 2001, p. 26; Widdus, Meheus & Short, 1990, p. 183). Nonetheless, judgments are made about people based on their actions. The guiding principles in the third chapter of the *Strategy* both individualise the person infected with hepatitis C and hold the individual accountable to the community:

Obviously, individuals can play an important part in reducing the transmission of hepatitis C—for themselves and in the broader community—by avoiding risk behaviour such as injecting drug use... Each person must accept responsibility for taking action to avoid becoming infected and for preventing further transmission of the virus. (Commonwealth Dept Health & Aged Care, 2000b, pp. 21 & 22)

"Risk behaviour" is a reference to behaviour that is considered dangerous, in this instance injecting drug use, an illegal behaviour that "governments do not condone" (p. 14). Contrary to Douglas's (1990, p. 7) description of dialogue about risk in the United

States as having moved “away from protecting the community and in favour of protecting the individual”, discussion of risk in the Strategy is directed at both the community and the individual. Hepatitis C-positive individuals, particularly IDUs, are portrayed as having a moral obligation to control and/or change their behaviour(s) in the interests of both their own health and for the collective good.

The tone of the news headlines of stories of the three news sources examined in Chapter Eight is predominantly negative. The majority of these headlines and accompanying lead paragraphs similarly portray hepatitis C infection as potentially harmful, a risk to the health of the infected individual and to the Australian community generally. In these headlines, words connoting “contamination” and “taint” are applied to the hepatitis C positive people as a statement of identity. The *Strategy* also has examples of judgments about the current state of affairs with regards hepatitis C, the threat to the community, and the threat to individuals. The *Strategy* represents the “community” as possibly threatened by the hepatitis C virus transmitted by those infected with the virus, particularly the behaviour of IDUs. Hence, the Government acts to “secure” the national blood supply by screening donors and blood products, setting standards and auditing the industry (Commonwealth Dept Health & Aged Care, 2000b, p. 27). At the same time, the Government intensifies its monitoring and surveillance “mechanisms”, including “identification of those at risk of infection” (pp. 17–18).

Persons infected with the hepatitis C virus from blood products contaminated with the virus are “vulnerable to the misbehaviour of the individual” who acquired the virus by means such as illicit injecting drug use, invoking the notion of “sin”, a moral or ethical offence (Douglas, 1990, p. 7). The notion of sin within a religious context, as a violation of the teachings of one’s religion, holds true for some persons infected with hepatitis C:

The early philosophical questioning actually contributed to some past-IDU participants’ depression. These participants experienced thoughts along the lines of retribution, that is, being punished by a higher power, for example, by God, for their past injecting drug-use behaviour. (Faye & Irurita, 2003, p. 99)

Although Douglas (1990, p. 8) contends that the “risk rhetoric” moves away from talking about the “collective good”, Australian news media representations of hepatitis C portray two divergent groups: “Innocent Victims” in the community who are, to use Douglas’s words, “sinned against”; and those who are the “cause of harm” or “expose

the others to risk” (pp. 7 & 15). With such media representations, it is not surprising that non-IDU participants in Faye’s study sought to avoid the stigmatisation associated with hepatitis C infection contracted through illicit drug use by explaining how they acquired the virus: “When disclosure was considered by those participants as unavoidable, or desired by them, they made an absolute point of explaining their noninjecting drug-use mode of HCV transmission” (Faye & Irurita, 2003, p. 101).

As well as impacting on the health of the “Australian community”, the hepatitis C epidemic has an economic impact on the community, the magnitude of economic costs estimated over 50 years (Commonwealth Dept Health & Aged Care, 2000b, p. 7). Proposed information and education programs “target” those with, or at risk of, hepatitis C infection, particularly, IDUs and patients undergoing treatment, rather than all members of society. Even though it is said that “blood awareness” (p. 53) will be promoted in the community, the community is to be protected as much from illicit injecting drug use as it is from the hepatitis C virus. The *Strategy* reflects the Government’s bid to control illicit injecting drug use as expressed in statements such as: “support efforts to reduce the prevalence of risk behaviours such as injecting drug use” (p. 29).

The word “risk” is found throughout the *Strategy* in conjunction with other words that emphasise the danger of hepatitis C such as: “risk developing advanced liver disease”; “increased risk of cirrhosis”; “risk of liver failure”; and “risk of liver cancer”. As these phrases suggest, hepatitis C as an infectious disease poses the possibility of real danger. Such a sense of danger is tangible to those who find out that they are hepatitis C-positive. Participants in one study felt “that they had been sentenced to a future that could include illness, disease, and premature death” (Faye & Irurita, 2003, p. 93). The *Strategy*, then, is also a proposition to protect the health of individuals, including IDUs, from the danger of cirrhosis, liver failure and liver cancer that may threaten the health of those with chronic hepatitis C infection. Hence, the *Strategy* reflects institutional control that many would consider beneficial, not solely constraining (Lianos, 2003, p. 415).

As well as speaking about interventions for measuring the hepatitis C epidemic, a range of interventions and institutions are spoken about for changing the behaviour of individuals that would otherwise lead to the transmission of hepatitis C, including: peer-based drug user health promotion; needle and syringe programs; the development of national occupational health and safety industry standards; research and training

programs (Commonwealth Dept Health & Aged Care, 2000b, pp. 22 & 28). Interventions to reduce injecting drug use, specified as a high-risk behaviour for acquiring hepatitis C, are central to the *Strategy* (p. 21). The *Strategy* sets a course for the infected person: testing for and identification of the hepatitis C virus; diagnosis of hepatitis C infection; notification to the state/territory health department; monitoring; and treatment (if the person is eligible and agreeable to treatment). The hepatitis C-positive individual is expected to be an active participant, taking on the maintenance of his/her health, based on information from health care service providers, to stave off liver disease that may eventuate some time in the future, and the consequently “bleaker prognosis” (p. 41). The individual is expected to engage in self-surveillance that reflects both “the care of the self” and “self-monitoring” (Vaz & Bruno, 2003) as implied in statements such as: “Consumption of alcohol in harmful or hazardous quantities will also predispose a person with hepatitis C to advanced liver disease” (Commonwealth Dept Health & Aged Care, 2000b, p. 41). Thus the text constructs the hepatitis C-positive individual as responsible, moral and rational in accord: “Subjects whose moral quality is based on the fact that they rationally assess the costs and benefits of a certain act as opposed to other alternative acts” (Lemke, 2001, p. 201). The medical diagnosis of hepatitis C infection establishes an identity for the patient, which includes self-surveillance. Once identified, persons infected with the virus will be “informed”, “educated” and, in the case of IDUs outside of “custodial settings”, given “sterile equipment” to prevent further transmission, thereby protecting others in the community (Commonwealth Dept Health & Aged Care, 2000b, p. 22). Whether with diagnosis, health monitoring, health maintenance and support alone, or in conjunction with treatment (and possible cure), the *Strategy* aims to improve the health and wellbeing of individuals (pp. 39-40), their longevity, and hence their usefulness as citizens.

The creation or maintenance of healthy individuals who are able to work, look after themselves and provide for themselves, is discussed later in relation to the current affairs story, “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) televised on ABC’s *7.30 Report* program. In the *Strategy*, “investment” in expensive antiviral treatment to prevent serious illness and reduce the number of infectious individuals is considered cost-effective for the future. The National Strategic Development Officer of the AHC, the coordinating organisation for the first national hepatitis C awareness campaign, notes: “Hepatitis C infection will not progress to serious liver disease or cause debilitating symptoms in *most* [emphasis added] people” (Paterson, 2005a, p. 23).

Yet this campaign in May 2005—five-years after the launch of the *Strategy*—bears the title, “National Hepatitis C Treatment Awareness Week”. This event is depicted in the newsletter of the Hepatitis C Council of NSW as follows:

The emphasis for this week will be on the pharmaceutical treatments available for hepatitis C and their attendant issues. So rather than educate the public with regards to hepatitis C, the week will seek to inform those living with the virus about their possible (pharmaceutical) options for treatment. (Patterson, 2005b, p. 21)

Both the *Strategy* and the first national hepatitis C awareness campaign fit Vas and Bruno’s (2003, pp. 274; 284) argument that the concept of risk in contemporary medicine helps creates individuals who “accept restricting their behaviour in order to care for their health even and principally when they experience well-being”. Despite the “temporal gap” between infection with the hepatitis C virus and health problems, and knowing that most people with chronic hepatitis C will remain otherwise healthy, it is *not* knowing which individuals will progress to serious liver disease that heightens the sense of risk of hepatitis C-related health problems, making it a concern to all hepatitis C-positive individuals. However, the impact of the anticipation of illness by those diagnosed with hepatitis C, in the space between diagnosis and future illness, is not canvassed in the *Strategy*.

As previously discussed, the foreword to the *Strategy* establishes the social identity of the responsible IDU. In its proposition to protect the health of individuals, the *Strategy* focuses on the individual exercising self-control in relation to injecting drug use. In the sentence, “Each person must accept responsibility for taking action to avoid becoming infected and for preventing further transmission of the virus” (Commonwealth Dept Health & Aged Care, 2000b, p. 22), the phrase “must accept responsibility” represents the conduct of individuals infected with hepatitis C, and those who inject drugs, in moral terms rendering their actions right or wrong, and the individual accountable for his/her actions. The individual is expected to identify with this normalizing judgment. Each person “carr[ies] the blame for what happens to them” as is common in an individualistic culture (Douglas, 1990, p. 16). Such a belief can be pervasive:

Stigma was seen to be a form of punishment, and was specifically related to injecting drug use. This punishment was seen as a consequence of some people having done ‘the wrong thing’ (P11) according to someone else’s or a group’s point of view. The data indicated that some participants felt a sense of deservedness of penalisation for those who had contracted HCV [hepatitis C virus] via injecting drug use. (Faye & Irurita, 2003, p. 97)

As previously noted, informants in Faye’s (2000, p. 102) study undertook self-surveillance so as not to contaminate others. The verb “must”, in the Department’s directive “each person must accept responsibility” (Commonwealth Dept Health & Aged Care, 2000b, p. 22), suggests that the producers of the *Strategy* consider individuals morally accountable for their actions. Those infected with hepatitis C, and those at risk of infection, are expected to monitor their own behaviour and to take “action to avoid becoming infected and for preventing further transmission” (Commonwealth Dept Health & Aged Care, 2000b, p. 22). An underlying assumption is that the individual given a diagnosis of hepatitis C infection, and *knowing* himself/herself infected, will assume responsibility for his/her self-surveillance. The language divides people according to binary opposites such as Responsible/Irresponsible, and classifies behaviour, particularly in relation to injecting practices, as High-Risk Behaviour/Low Risk Behaviour. The moral imperative in the *Strategy* confirms that the “medicalisation of the self” noted by Krug (1995, p. 315) is entrenched: “Requiring people to take responsibility for the spread of the virus as well as for the dissemination of information to other people in their lives”. Hence, overt surveillance by public health authorities of the hepatitis C-positive individual is unnecessary.

The use of seemingly neutral terms like “risk” and “high-risk behaviour”, which are considered less likely to imply “membership of a particular group” (AHC, 2001, p. 26), creates a text that seems less divisive, and less likely to be construed as negative criticism of IDUs. The reader is reminded throughout the *Strategy* that it is the Government’s intention to include marginal groups such as IDUs through partnership with community groups, including peer-based IDU groups. Policy-makers appear knowledgeable about injecting drug use practices and to have utilised research in this area. Although “sharing and re-using injecting equipment” is spoken about in the abstract in the *Strategy* (Commonwealth Dept Health & Aged Care, 2000b, p. 23), it is evident that the Department has gathered information about injecting drug use by

different people, in varied circumstances. The sentence, “The meanings and rules of sharing and re-using—including the items shared and the social circles where the sharing takes place—will vary across communities and social contexts” (p. 23), is a reference to the rituals of injecting, social rules and cultural meanings discovered through sociological or anthropological research. The utilisation of such research makes the Department appear sensitive to cultural meanings that may attach to injecting practices. It is IDUs and workers in peer-based IDU groups who provide access for researchers to IDUs and an entrée into the “meanings and rules” of injecting within groups and/or places. The importance of IDUs to the research process is apparent in summaries of research projects published on the Department’s website such as project number 19, “Initiation into Injecting Drug Use—Hepatitis C Education Needs Assessment and Resources Design/Production”, funded by Queensland Health and completed in 1997, which utilised peer interviewers to recruit participants. Given the centrality of IDUs to the Government’s response to the hepatitis C epidemic, the predominance of hepatitis C-related research from the biological and clinical sciences, and the relative dearth of research from the social sciences, warrants consideration.

The Pre-Eminence of Biomedical Research

Amongst the principles underpinning hepatitis C research, the *Strategy* calls for hepatitis C research from “many branches of research”, investigator-initiated research, commissioned research, multi-disciplinary and collaborative research, and the involvement of the affected lay community (Commonwealth Dept Health & Aged Care, 2000b, p. 16). The expression of such principles, however, does not diminish the pre-eminent position given to medical practice and biomedical research.

While the Government’s allocation of resources to biomedical research and its expenditure on social and behavioural research is not elucidated in the *Strategy*, the register of Australian hepatitis C research published on the Department’s website is an indicator of Government expenditure on hepatitis C research. The register, which was last updated in August 2002, lists a total of 194 completed research projects, and the then ongoing research projects, partly or wholly public-funded (Australian Govt Dept Health & Ageing, 2002). The research projects are categorised as “Social”, “Virological and Immunological” or “Epidemiological and Clinical” (shown in Table 3). By comparison, the register of hepatitis C research published by the AHC (2004a) comprehensively lists hepatitis C research undertaken in Australia from 1994 to 2004.

Projects in this register of research are firstly categorised under the four national hepatitis C strategy areas: “Reducing Hepatitis C Transmission”; “Treatment of Hepatitis C Infection”; “Health Maintenance, Care and Support”; and “Preventing Discrimination and Reducing Stigma and Isolation”. Research within each of the four areas is then listed under “Plain Language Articles” (mainly from community based publications), “Journal Articles”, or “Reports” (such as national policy documents). The majority of research listed in this register is also partly or wholly public-funded, with researchers drawn from institutions such as the National HIV Research Centres, Schools of Public Health in Universities, National Drug Research Centres, and public hospitals. For this study, only those 230 research projects published in peer-reviewed journals, listed under “Journal Articles” in the AHC register, were considered (also shown in Table 3).

Table 3

Australian Hepatitis C Research Listed by Category on the Australian Government Department of Health and Ageing’s (Department) Australian Hepatitis C (HCV) Research Register (August 2002) Compared with the Australian Hepatitis Council’s (AHC) Hepatitis C Research Register Version 2 (March 2004)

Research category	Department		AHC	
		Refer to IDU ^a		Refer to IDU
Social	83 (42.7%)	24 (28.9%)	82 (35.6%)	44 (53.6%)
Epidemiological/clinical	79 (40.7%)	17 (21.5%)	139 (60.4%)	36 (25.9%)
Virological and immunological	32 (16.5%)	0	9 (3.9%)	0
Biomedical (epidemiological/ clinical and virological and immunological combined)	111 (57.2%)	17 (15.3%)	148 (64.3%)	36 (24.3%)
Total reference to IDU	41 (21.1%)		80 (34.8%)	

^a IDU: Injecting drug use[r]

In the background to their study of the social and psychological experience of hepatitis C infection, Faye and Irurita (2003, p. 92) note the relative abundance of epidemiological and physiological research on hepatitis C compared to research on the social and psychological aspects of hepatitis C infection. Such an imbalance has implications for NGOs. For instance, in its submission to the review of the *Strategy*, AIVL (2002, p. 7) states that the lack of emphasis on social research has “hampered the

flow of funding resources to critical peer education and prevention programs due to an absence of a comprehensive evidence base for action". In the Department's research register there is a slight discrepancy between the total number of biomedical research projects and the number of social research projects, with the former exceeding the latter. This discrepancy is more marked in the AHC research register. There is a reference to injecting drug use in more than fifty percent of "Social" research projects in the AHC register compared to just under one-third of "Social" research projects in the Department register; and almost one-quarter of "Biomedical" research projects in the AHC register compared to just over 15 percent in the Department's register. Overall, injecting drug use or injecting drug users are referred to in a greater percentage of project titles in the AHC register (approximately one-third), compared to the Department's register (just over one-fifth).

A limited "summary" of Government expenditure on hepatitis C research is also published on the Department's website. National Health and Medical Research Council (NHMRC) research grants total \$8 million for the period 1999 to 2005 (Australian Govt Dept Health & Ageing, 2005b). Additionally, the Government funds the four National HIV Research Centres with \$8 million a year "for HIV and hepatitis C research combined". This research funding is distributed between HIV research and hepatitis C research, and then re-distributed between the areas of hepatitis C social research and biomedical research (virology, epidemiology and clinical). The principle of "multidisciplinary" and "collaborative" research that involves stakeholders (including the lay community), espoused in the *Strategy* (Commonwealth Dept Health & Aged Care, 2000b, p. 16), characterises descriptions of two of the four national centres, the National Centre for HIV Social Research and the Australian Research Centre in Sex, Health and Society (Australian Research Centre Sex, Health & Society, 2004; National Centre HIV Social Research, 2003).

The NHMRC is nominated in the *Strategy* as the "guiding" and "funding" body of hepatitis C research in Australia, while ANCAHRD is to "review" and "balance" research priorities (Commonwealth Dept Health & Aged Care, 2000b, p. 17). These decision-making expert groups or bodies "act as gatekeepers that determine what kinds of information are admitted to the discussion" (Hepworth & Krug, 1997, p. 5). The NHMRC calls for "an evidence-based approach to medicine and public health" (NHMRC, 1998). Some time after the publication of the *Strategy*, the majority of NHMRC grant funding for the period 2003 to 2005—which is listed on the NHMRC's

(2005) website—was allocated to research categorised under the two broad research areas of “Basic Science” and “Clinical Medicine and Science”. Research categorised under the broad research area of “Public Health”, which also receives a substantial proportion of overall NHMRC funding, mainly fits into the sub-category research field of “Epidemiology”. Sixteen of the 20 NHMRC grants for hepatitis C research for 2003–2005 are classified as “Basic Science” (almost all from the field of “Medical Virology”) and “Clinical Medicine and Science” (from fields such as “Gastroenterology and Hepatology”, “Infectious Diseases” and “Transplant Immunology”). The broad research area of the four remaining grants is “Public Health”. The fields of research for grants listed in “Public Health” include a study from “Nutrition and Dietetics”, one from “Epidemiology”, another from “Social and Community Psychology”, and two in which the field of research is not specified. The disproportion between NHMRC funding of hepatitis C biomedical research compared to social research is more marked than that listed in the Department’s research register and the AHC’s research register. The relationship between the make-up of decision-making groups such as the NHMRC and ANCAHRD and the production of information for use in hepatitis C health policy development reflects this disparity.

A number of statements in the *Strategy* suggest that Government commissioned or funded research will favour biomedical research, including the following:

- The development of new and improved treatments requires continuing, sustainable basic, virological and clinical research;
- To develop a broader range of treatments for hepatitis C infection;
- To investigate the development of post-exposure prophylactic therapies and promote access to these therapies for people with acute infection;
- To investigate the impacts of multiple hepatitis C infections on morbidity and mortality and promote the development of suitable therapies; [and]
- To support international cooperation in the field of hepatitis C basic, virological and clinical research. (Commonwealth Dept Health & Aged Care, 2000b, pp. 32 & 36)

As IDU peer-based NGOs have a critical role in reducing the transmission of hepatitis C by providing IDUs with information and skills, undertaking health promotion interventions (p. 22) and encouraging IDUs with hepatitis C to “engage with the primary health care sector” (p. 36) and seek treatment, Government expenditure on research in the area of prevention and education to bring about behavioural change warrants further study. As IDUs are encouraged to engage with the primary health care sector (p. 36), and as “equitable access” to hepatitis C treatments for all people with

hepatitis C (p. 32) is a guiding principle of the *Strategy*, Government expenditure on research in this area also warrants further study.

The vocabulary of the *Strategy* also suggests that knowledge produced by each of the different types of health research has equal status. However, just as the Minister stresses that a community of experts validates the evidence, the problem, and the course of action, as discussed in relation to the foreword to the *Strategy* in Chapter Three, the *Strategy* itself reflects the dominance of scientific research from the biological and clinical sciences. This is in accord with the view of Hanney et al. (2003, p. 6) that health-policy-makers are “more likely to place more confidence in the strictly controlled natural sciences than in the more eclectic social sciences.” It also concurs with Hepworth and Krug’s (1997, p. 4) editorial comment that “[r]esearch about hepatitis C virology and epidemiology has been employed to address all aspects of hepatitis C and has come to dominate political and public health discussions” in Australia. Moreover, spokespersons for Government agencies, departments and advisory bodies, medical experts, academics and/or researchers, particularly, medical researchers and epidemiologists, and medical publications, are the main sources of information for journalists reporting on hepatitis C in Australia greatly influencing media narratives, as will be discussed in a later chapter.

The dominance of biomedical research in the *Strategy* is particularly evident in section 1.2 of the introductory chapter entitled, “The Epidemiology of Hepatitis C in Australia”, which frames the *Strategy*. The sub-section “Viral Hepatides”, for instance, briefly details the importance of nucleic acid testing, “a new technology”, for early identification of the virus (Commonwealth Dept Health & Aged Care, 2000b, p. 3). The sub-section “Risk Factors” presents statistics of the percentage of people infected with the hepatitis C virus following its transmission during activities such as: sharing injecting equipment; mother-to-child transmission during pregnancy and delivery; and blood transfusions (pp. 4–5). This, and subsequent sub-sections—“Incarceration: A High Risk Context”, “The Prevalence and Incidence of Hepatitis C” and “The Natural History of the Virus”—include multiple citations of research and technical reports including: articles published in peer-reviewed medical journals; national surveillance reports; research reports of the national peak ministerial advisory body on hepatitis C; research reports of the NHMRC; and reports of research commissioned by the Department. The emphasis, as the term “epidemiology” in the section title suggests, is on classification and measurement related to the virus, for example: “types”;

“genotypes”; “strains”; “prevalence”; “estimates”; “projections”; “rate of infection”; and the calculation of risk (previously discussed). In the introductory chapter of the *Strategy*, the framing of the text from the perspective of the scientific and medical research communities is tempered by a single paragraph that refers to the discrimination and stigmatisation experienced by people with hepatitis C, though without reference to social and behavioural research in this area. However, the section, “The Epidemiology of Hepatitis C in Australia”, concludes with the sub-section, “The Economic Impact of Hepatitis C”, in which Shiell’s (1998) economic analysis, commissioned by the Department, is cited in text. Measurement is also the focus of this sub-section, with calculations of the current and projected direct and indirect costs of chronic hepatitis C infections used to substantiate evidence-based medicine.

Conclusion

In this chapter I described the way in which the language of the scientific and medical communities frames the *National Hepatitis C Strategy 1999–2000 to 2003–2004* published by the then Commonwealth Department of Health and Aged Care (2000b) for the Federal Coalition Government. This extends from the organising principles derived from the discipline of medicine, through the medical paradigm focused on treatment, to the dominance of biomedical research, and the bid to know the epidemic and account for those infected and those at risk.

As previously outlined, the Government (and the Department) uses research networks, commissioned studies (including commissioned research and reviews or evaluations) as well as independent research to inform its decision-making and policy-making. The Government has mechanisms in place that promote the utilisation of research evidence in policy-making, and in the “conceptualisation” of research (Black, 2001, p. 278), setting the research agenda and priority setting. Biomedical research (virological, epidemiological and clinical research), along with technical analysis of evaluative economic studies, were heavily utilised to inform hepatitis C policy-making confirming Hepworth and Krug’s (1997, p. 4) earlier assertion that “policies and implementation strategies remain largely based on medical and scientific models of disease.”

The biomedical perspective that frames the *Strategy* percolates down to the very organising structures of the text. While the performative strategically-oriented approach of Government readily incorporates hepatitis C NGOs and peer-based IDU NGOs as representing the hepatitis C-affected community within both hepatitis C policy development and service delivery, NGOs are required to adopt the evidence-based approach of biomedicine (including public health), and conform to the practices of the public health sector. The emphasis on evidence-based policy-making and evidence-based practice in the *Strategy*, focusing on the measurable, is open to contestation (Black, 2001, p. 277). Peer-based IDU groups, for example, may consider other sorts of evidence to that favoured in the *Strategy* and which governs the provision of services. NGOs have a role to play in bringing into the debate, which informs policy development, research findings that are outside the dominant perspective of policy-makers. To this end, NGOs might seek to bring research, such as Australian and international research findings on the theme of injecting rooms, to the notice of the media and the public to increase understanding of issues and influence the utilisation of such research in policy formulation. Re-orientating hepatitis C-related public health policy more towards social and behavioural research, and moving the focus away from its biomedical research orientation, warrants consideration.

Hepatitis C is represented as an individualised medical problem, and people who are infected with the hepatitis C virus are encouraged to seek medical treatment. The disease is also represented as a danger to the Australian community. Injecting drug use remains a behaviour that is marginalised by normative judgments in Australia, and the *Strategy* speaks about IDUs infected with hepatitis C, in particular, as having to behave responsibly. Not only are public health and health care professionals to work towards bringing marginalised IDUs into the mainstream of health policy formulation and implementation, but IDUs are to be transformed, retrained to function in Australian society, both as providers of hepatitis C-related services and as citizens displaying “responsible” injecting practices.

The next part of this thesis outlines the discursive practices of the news media in coverage of hepatitis C. It outlines the major news topics in news stories about hepatitis C, the main suppliers and sources of information, and the dominant discourses in the media coverage of hepatitis C in Australia from January 1999 to December 2003.

CHAPTER EIGHT

AUSTRALIAN NEWS MEDIA REPRESENTATIONS OF HEPATITIS C: A CASE OF BAD BLOOD

Recognising that Australian media are at best ambivalent towards hepatitis C, the Australian Hepatitis Council decided to raise the level and quality of media coverage of issues faced by people with hepatitis C...[S]tories had to reflect the experiences of people affected by hepatitis C in their daily lives, and were not to become vehicles for the promotion of public health policy.

– Peter Perfrement, Policy Officer,
Australian Hepatitis Council, 2002

Introduction

The inaugural national hepatitis C strategy—the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b)—outlines the Federal Coalition Government’s (the Government) strategic approach to managing the “hepatitis C epidemic” in Australia. The *Strategy* calls for health care professionals to change their behaviour, particularly their discriminatory practices towards injecting drug users (IDUs). The likelihood of effecting such change, though, is cast as a “challenge” that will not be readily achieved. It is the Government’s bid to increase the number of IDUs accessing health care services and treatment—in order to reduce the transmission of hepatitis C and the subsequent economic “burden” to the Australian community—that provides the impetus to change health care professionals’ ways of acting. At the same time it calls for people living with hepatitis C, and those at risk of hepatitis C infection, particularly IDUs to take individual responsibility for the care of themselves and of others. The *Strategy* is framed by the notion of “partnership” between the hepatitis C-affected community, the non-government sector, government at all levels, public health institutions, and the

scientific, medical and research communities. The *Strategy* seems to reflect a democratic form of policy-making with non-government organisations (NGOs) representing the hepatitis C-affected community, and affected individuals, participating in deliberation and discussions, and contributing to agreement at a national level on the definition of issues and concerns to guide the Government's decision-making about the hepatitis C epidemic. However, the stakeholders in the partnership are not on equal footing. The *Strategy* reflects the maintenance of power by professionals with experts from the medical and scientific communities dominating the public health discourse about hepatitis C.

As the Government's policy on hepatitis C, the *Strategy* "works simultaneously on representations and classifications of reality, and representations and classifications of people" (Fairclough, 1995b, p. 182)—namely, the hepatitis C virus, the epidemic, those living with hepatitis C, and those whose behaviour places them at risk of hepatitis C infection. Like the official public health policy discourse, news media discourse in Australia portrays events, constructs, and circulates meanings about hepatitis C and infected individuals, forming or shaping, in part, the individual's lived experience of hepatitis C. News media producers share the *Strategy's* predilection for talking about risk in terms of protecting the community from the threat of the hepatitis C epidemic as well as protecting the individual whose health is at risk from hepatitis C infection. The individual person infected with hepatitis C is held accountable to the community, and judgments are made about people based on their actions. Just as the complex that constitutes the partnership of the *Strategy* adopted the professional voice, pushing the lay voice to the margin, so news media discourse reflects the dominance of the biomedical perspective, and demonstrates inequality of power relations between experts and the hepatitis C-affected community despite the inclusion of select voices of hepatitis C-affected people in texts. News media representations of hepatitis C reproduce biomedical discursive formations, contributing to the way that people affected by hepatitis C, and others, make sense of their world. Chapters Eight and Nine depict the regularity in the discourse practices of public health and news media producers in representing hepatitis C.

Chapter Eight extends Krug's study (1997) of the reporting of hepatitis C in the Australian media, (television news reports, current affairs shows, and newspaper articles), between 1994 and 1995. It reports systematic qualitative and quantitative content analyses of the news coverage about hepatitis C published in the Australian

Broadcasting Corporation (ABC) news services (television, radio and on-line), *The Australian* newspaper and the *Herald Sun* newspaper during the period 1996 to 2003. The applicability of the descriptive stage of Fairclough's (1989; 2001) analytic procedure for critiquing the language of news texts about hepatitis C is discussed in relation to hepatitis C support groups in Australia.

Working in Italy, Vento and Cainelli (2002, p. 303) state that the hepatitis C virus has been incorrectly "portrayed in the media as a silent killer". Australian media reports saw the Australian Red Cross Blood Service (ARCBS) criticised for putting "tainted" blood and "contaminated" blood products into circulation (Mazzocchi, 2002). In the same week, other media reports extolled the life-giving properties of blood: "[Blood] keeps all of us alive, this river of life" (Forbes, 2002, p. 2). Similarly, the letter of thanks sent by the ARCBS to first-time blood donors in Western Australia includes phrases such as "gift of life" and "blood donors are life savers" (A.J. Keller, personal communication, July 7, 2002).

Participants in Faye's (2000) study stated that the media's reporting on hepatitis C in Australia does not have a good effect; it does not promote well-being. This suggests that people living with hepatitis C may experience problems with the symbolic message(s) about the disease much as Treichler (1987, p. 291) noted with regards to AIDS. Krug (1995, p. 210) expected that hepatitis C would become a signifier of disease or contagion. Whether hepatitis C is as much an epidemic of meanings or significations (Treichler, 1987, pp. 263–264) as it is an epidemic of a transmissible disease is of interest to this study.

Medical specialists and general practitioners are the main authorities on medical issues, and the medical profession has significant cultural and social authority reflected in the news media in Australia (Galvin & Pearson, 1994; Lupton & McLean, 1998). As Krug (1997) outlines, media coverage of hepatitis C makes use of common elements in the construction of stories: renowned medical expert; the human element (the "victim" or the thing affected by hepatitis C); and the journalist. The addition of "research" to this list completes the well-used formula in media stories acknowledged by journalist Jane Hansen (2002).

Reporting continues to focus upon the moral discourse of intravenous drug use noted by Krug (1997). Injecting drug use is conspicuously cited as the main means of transmitting hepatitis C in almost one-fifth of news articles in Cummings' (2004) study of 11 daily newspapers published in New South Wales and Victoria from January 2000

to May 2002. However, in her qualitative content analysis Cummings does not elucidate the discursive strategies employed in the construction of the newspaper articles, thereby limiting analysis to the obvious rhetorical devices (Lupton, 1992, p. 147). Newspaper reports, published in February and March 2002, covering finds of *unused* syringes by students attending a Sydney primary school—located adjacent to a needle exchange—speak about “potential risk” and “potential harm” (Körner & Treloar, 2003, p. 49). While the meaning of “risk” and “harm” is not explored, Körner and Treloar conclude that: “Negative judgement values are...deployed for IDUs as ‘addicts’” (p. 52).

In this and the next chapter, representations of hepatitis C in the Australian news media are examined to find out if hepatitis C is still depicted as Krug (1997) outlined, that is, dominated by the powerful discourse of medicine. Do medical practitioners and medical researchers define the disease, and construct the messages about hepatitis C? In what ways has participation in media coverage by spokespersons of NGOs, representing people living with hepatitis C, altered the form and content of texts (including the configuration of speaking positions and social relations between news actors)? How has the language and meanings attached to hepatitis C developed since 1995?

Major News Topics: Negative Headlines for Hepatitis C

Twenty-five of the 53 headlines in the ABC news stories analysed specifically referred to “Hepatitis C” or “Hep C” by name, and two included “Hepatitis” (referring to hepatitis C). *The Australian* and *The Weekend Australian* included the words “Hepatitis C” or “Hep C” in 21 headlines and “Hepatitis” or “Hep” (referring to hepatitis C) in a further six headlines (just under half the 53 articles in total). Twenty-five of the 98 headlines in the *Herald Sun* and its Sunday edition included “Hepatitis C” or “Hep C”, and a further 12 headlines included “Hepatitis” referring to hepatitis C. Major topic categories for ABC and *The Australian* news stories are shown in Appendix J. Those for the tabloid *Herald Sun* are shown in Appendix K. A combined listing of topic categories for the three news sources is shown in Appendix L.

In terms of a “news peg”, hepatitis C achieves news value by virtue of the large number of people infected with the virus, and even more that could be. Stories emphasise the magnitude of the “hepatitis C epidemic” with phrases such as the “fastest growing disease in Australia” heard on the ABC’s *Radio National Breakfast* story “Hep C Update” (2001); and “225,000 Australians already carry the *insidious* [italics added]

hepatitis C” in the introduction to Vincent’s (2000) report “Australian Hepatitis C Epidemic” broadcast on ABC radio’s *The World Today* program. The finding of “Hepatitis C Statistics” as the third ranked topic category for the combined media sources is consistent with Galvin and Pearson’s (1994, pp. 116–7) finding that the incidence of disease is a dominant topic in health-related news stories.

The news media’s focus on the incidence of hepatitis C is understandable when surveillance data pertaining to the occurrence of hepatitis C is compared to that of HIV/AIDS in Australia. In its annual surveillance report for 2002, the National Centre in HIV Epidemiology and Clinical Research (2002, p. 5) estimated that 157,000 people were living with hepatitis C infection in Australia that year, the majority with chronic hepatitis C infection and “a further 53,000 had hepatitis C antibodies but were not chronically infected”. There were 587 diagnoses of newly acquired hepatitis C infection in 2001, “a small fraction of the estimated 16,000 cases that were estimated to have occurred” in the same year (p. 12). By comparison, there has been a decline in the incidence of HIV (the virus that leads to AIDS), in Australia since the mid 1980s, and a decline in the incidence of AIDS. It is estimated that 12,730 people were living with HIV/AIDS in Australia in 2001, with 178 AIDS diagnoses in that same year. There are between 150–200 diagnoses of newly acquired HIV infection annually, with an estimated 450 new HIV infections (p. 5).

Biomedical and public health texts refer to hepatitis C as an epidemic, widespread—affecting many people throughout Australia—and rapid in its spread. In the news media medical experts warn that the hepatitis C epidemic threatens public health in Australia. Journalists report expert projections of liver disease—such as liver cancer—linked to hepatitis C in Australia, and the expected shortage of livers available for transplantation.

Medical experts sound warnings, and lobby the government via the media for treatments to control the spread of the disease that has been “neglected”. Galvin and Pearson (1994, p. 117) consider that government spending on a disease is “always a newsworthy issue”. However, “Funding for Hepatitis C” and the “Cost to Taxpayers”—ranked 10 and 16 respectively in the combined rankings—were not dominant topic categories in the media coverage of hepatitis C. Stories such as, “Hepatitis C Forgotten at the Expense of HIV”, in *The Australian* (Hickman, 1999) are exceptions. In this story hepatitis C is depicted as the “poor relative” of HIV/AIDS, a view that holds sway amongst those working in the field of hepatitis C. Executive officer of the Australian

Hepatitis Council (AHC), Mr Jack Wallace (2002, p. 1), acknowledges both the inadequate funding to implement the national hepatitis C strategy and the lack of media profile and political support for dealing with the disease.

Despite being a statistically prevalent threat, hepatitis C is generally regarded by those working in the field as under-funded and ignored by government. This perception is now established as representing the reality of the situation. In the story, “Hepatitis Needs Greater National Attention: Hepatitis Council”, broadcast on ABC radio’s *PM* program, for example, reporter Tanya Nolan (2003a) asks the president of the AHC, Mr Stuart Loveday, “So you don’t believe that hepatitis C has been given enough attention in the past?” Loveday replies, “We still maintain that hepatitis C is the poor cousin of HIV and AIDS”. The mode of this sentence is declarative; Loveday is the giver of information. As president of the AHC Loveday speaks with some authority, and can be expected to be speaking the truth. Any concern that Loveday’s is a partisan representation of the truth can be set aside as the next day on ABC radio’s *The World Today* program Kirk (2003) reports on “the Government’s release of a long awaited review, which says the fight against hepatitis has been under-resourced”. The cumulative effect of the media’s use of authoritative sources across individual stories establishes hepatitis C as the poor relative, or “poor cousin”, of HIV/AIDS in Australia.

Hepatitis C is closely associated with injecting drug use that is illicit in nature. In what we are told is a “hidden epidemic”, stories of the “Hepatitis C Sufferer” introduce the reader or audience fleetingly to individuals (not necessarily by their real names), who have hepatitis C and what they did to get the virus. Although the hepatitis C sufferer provides the human interest news peg upon which these stories are hung (Whitaker, Ramsey & Smith, 2000), people living with hepatitis C—ranked 17 overall—do not have strong news value. This contrasts sharply with a study of the Australian metropolitan press by Lupton, Chapman and Wong (1993) in which they found the content category “People Living with AIDS (Non-Celebrities)” received the most press attention. Given the incidence of hepatitis C compared to that of HIV/AIDS, the lack of visibility of people living with hepatitis C in the news media warrants comment. In an interview on ABC radio’s *PM* program Dr Michael Woodridge says of his time as federal health minister: “It’s been much easier to deal with HIV because the people involved have been much better organised than the hepatitis C groups” (Nolan, 2003b). Labor’s Minister for Health in the preceding decade, Dr Neal Blewett, was of a similar opinion:

The great strength of the homosexual position was the organisation of the gay community...the gay community had leaders...organisations, established networks and a sense of community, or perhaps communities. This much facilitated a government approach based on the development of policy in cooperation with the affected groups. These points contrast starkly with the position of intravenous drug users. (Blewett, 1997, p. 177)

As those working in the field of hepatitis C know, a diagnosis of hepatitis C may be all that people with the disease may have in common (Booth, 1999; Campora, 1999). Hepatitis C is increasingly associated with injecting drug use in Australia (Krug & Hepworth, 1999, p. 104) yet this is not a homogenous grouping. Prevalence studies, such as a small-scale survey of trawler crews by MacDonald, Sullivan, Locke, Wodak and Kaldor (1998), emphasise the diversity of the injecting drug user population in Australia. The heterogeneous nature of “members” of hepatitis C groups is one characteristic that diminishes their power to lobby. The construction of the hepatitis C sufferer in the Australian media also includes those who were infected from blood products contaminated with the hepatitis C virus. The circumstances of their infection are found in news items around the topic “National Blood Supply”, though their stories, as individuals, are absent.

It is in the news headlines and the lead paragraph that the thesis of the news story is found, what the story is about. News headlines containing “sub-textual” meanings may be the sole source of information for readers, viewers or listeners who only glance at, or attend to, the headlines expecting to get the substance of the news story (Fairclough, 1989, pp. 137 & 144; Lupton, Chapman & Wong, 1993, p. 7). The style of writing in the news headlines from the three news sources examined is, on the whole, negative. There is a constant sameness in the choice of words, in descriptive terms, in the tone of writing, and in the prevailing character in the headlines examined.

News headlines found in ABC news services, *The Australian* and the *Herald Sun* were classified as “Negative”, “Positive”, or “Neutral” in tone. The results are shown in Table 4. Negative tone emphasises the potential for harm, a marked deviation from a healthy state, or a state that is unfavourable to individuals and/or the community. Positive tone emphasises an advantage to, or the promotion, improvement or safeguarding of, an individual’s health, or that of the community generally. When news stories provide straightforward information about hepatitis C the tone is usually neutral, as in the ABC story “Hep C Update” (2001) broadcast on *Radio National Breakfast*, and the *Herald Sun* article, “Hep C Risks Known” (Carter, 1997). Similarly when journalists

report on events or action taken in response to local events as in the *Herald Sun* article “Council Considers Needle Machines” (Dargan, 2002).

Table 4

Tone of Headlines in News Stories on Hepatitis C in the Australian Broadcasting Corporation News Services, The Australian, and the Herald Sun, 1 January 1996 to 31 December 2003

Tone	Positive	Negative	Neutral
ABC news (N=53)	10 (18.86%)	34 (64.15%)	9 (16.98%)
The Australian (N=53)	13 (24.53%)	31 (58.49%)	9 (16.98%)
Herald Sun (N=98)	20 (20.4%)	62 (63.26%)	16 (16.32%)
Total (N=204)	43 (21.07%)	127 (62.25%)	34 (16.66%)

The language in the majority of headlines examined has negative connotations as described in the analysis of the *Herald Sun* article, “Bad Blood Blamed for Deaths” that follows. Negative phrases like “bad blood”, “tainted blood”, “blood contamination”, “hepatitis C crisis”, “hepatitis C epidemic”, and “hep C fear” emphasise the risk to health, the threat of death, danger, fear, alarm and deceit around hepatitis C and people with hepatitis C. The potential for hepatitis C to result in death is reflected in headlines and lead paragraphs containing phrases like “potentially fatal liver disease”, “potentially lethal virus”, “life-threatening”, and “deadly”. This occurs to such an extent that the topic category, “Hepatitis C Sentence”, was assigned in appreciation of Faye’s (2000) findings.

Negative words pervade the news headlines of the ABC, *The Australian*, and the *Herald Sun*. A complete listing of news headlines is provided in Appendix M. The language tends towards simplistic notions of good and bad. The public may not know what hepatitis C is, but they are assumed to know what the words “bad”, “contaminate” and “tainted” mean. The qualities or characteristics that such words denote are applied to hepatitis C and to people with hepatitis C as a statement of identity.

In Fairclough’s (1989, pp. 24–26) framework for critical discourse analysis textual analysis is an aspect of discourse analysis. Analysis of discourse involves consideration of both the “social conditions of production and social conditions of interpretation” (p. 25). The analysis of a communicative event such as a news text involves the analysis of the “*text, discourse practice* [processes of text production and

consumption], and *sociocultural practice*” (Fairclough, 1995, p. 57) to varying degrees. The meaning of news texts in this schema, then, comes from the interplay between the producer(s), the audience, the text, and context (see Fairclough, 1989, pp. 24–27; 1995, pp. 57–62). Values systems are inherent in texts. The context in which a text is received includes the reader’s moral and social values. Context also includes the value systems of Australian society and cultural myths such as stereotypes. It is assumed that people who are hepatitis C positive are constructed in particular ways in the news media, and that hepatitis C is represented in particular ways. The construction of news texts “fixes” people with hepatitis C in a particular manner, establishing their position in relation to others, and encourages particular responses in readers towards hepatitis C and people with hepatitis C. News articles do not simply present facts about hepatitis C, but reveal particular attitudes to people and events through the selection of information and language (Lupton, Chapman & Wong, 1993, p. 6). Language, structure, and the selection of detail shape each article about hepatitis C and influence interpretations of the events reported.

To uncover how representations of hepatitis C and of people with hepatitis C are brought to life in the language of news stories, a sample news article from the first ranked topic category, “National Blood Supply”, was selected for further analysis. Linguistic analysis of the text was undertaken utilising the descriptive stage of Fairclough’s (1989; 2001) analytic procedure for critical discourse analysis. This entailed focusing on linguistic features, including whole-text organisation or structures, grammar and vocabulary.

Contamination of the National Blood Supply

Revelations in the press that blood supposedly contaminated with the hepatitis C virus (HCV) was used in Australia to make blood products in 1990 and 1998 gave rise to the first ranked topic category, “National Blood Supply”. Contamination of blood bank supplies and the subsequent safety of the national blood supply in Australia form the major context in which hepatitis C appears in the news media from January 1999 to December 2003. In this context, persons who became hepatitis C positive from receiving tainted blood or blood products contaminated with HCV are cast as “victims” or “blood victims”. Stories are framed in terms of the scrutiny of the ARCBS, the then

federal government-owned Commonwealth Serum Laboratories (CSL), the formal inquiries, possible criminal proceedings and compensation claims.

“National Blood Supply” is a topic category that has a trajectory spanning several years, sometimes covered by more than one journalist in the same media organisation. A class action centred on the allegation that, in 1990, contaminated blood gave group members hepatitis C. This was reported in news stories such as, “Hepatitis Sufferers Sue Over Bad Blood”, in *The Australian* (Kerin, 2002) and Nick Grimm’s (2002) story, “Red Cross Blood Bank Facing Class Action”, broadcast on ABC radio’s *AM* program. News services throughout Australia reported on the outcomes of the federal government inquiry. Under the headline “Hep C Concern”, for example, Frenkel (2003b) follows up previous *Herald Sun* investigations of the deaths of Victorians infected with hepatitis C after receipt of tainted blood that seems at odds with the report tabled in parliament in 2003, which found thousands had been exposed to HCV-infected blood supplies in 1990, but there was “no evidence that anyone contracted hepatitis C.” In “Tainted Blood Reports” on ABC radio’s *PM* program Mazzocchi (2003) flags revelations in the same Government inquiry that “the use of infected blood plasma was a deliberate policy, endorsed by state and federal authorities as well as the Australian Red Cross Blood Service.” Also on ABC radio, Knight (2003) reports on the Tainted Blood Action Group’s dissatisfaction with findings of the inquiry.

Stories apprise readers of the “state of scientific knowledge” that informed the ARCBS’s decision to use the blood of donors testing positive for HCV. An example is the ABC’s *News Online* report, “Health Dept to Investigate Infected Blood Claims” (2002), in which readers are told that the ARCBS believed that “heat treatment would destroy the virus”. This is reiterated in Mazzocchi’s (2002b) report, “Inquiry into Blood Contamination”, on ABC radio’s *AM* program, in which she states that the Red Cross asserts it acted in accordance with what was known at that time, that is, the authoritative body of scientific knowledge available in 1990. Reporting goes beyond the 1990s incident, the precipitating event, to consideration of public health responses to hepatitis C including policy and funding as in “Stopping the Rampant Flow of Hep C” written by Don Baxter (2002), executive director of the Australian Federation of AIDS Organisations, for *The Sydney Morning Herald’s* online news.

Representations of Hepatitis C and of People with Hepatitis C

From January 1999 to December 2003 the topic category “National Blood Supply” has received the most media attention with articles that brief the public about events leading up to the allegations against the ARCBS: the number of people infected; investigations by the New South Wales (NSW) Health Department; the Federal Coalition Government inquiry; the bringing of a class action; the findings of the inquiry chaired by Professor Bruce Barracrough; and calls for a full judicial inquiry. A detailed examination of one of the news stories coded under the topic category “National Blood Supply” follows. The text in Figure 4 was the lead story on page two of the second edition of the *Herald Sun* published on Friday 8 January 1999. The story appears as part of the newspaper’s routine reporting. As mentioned previously, the Melbourne-based *Herald Sun* is a tabloid newspaper, and Australia’s largest selling daily. The story entitled, “Bad Blood Blamed for Deaths” (“Bad Blood”), by journalist Helen Carter is just one of the news stories about the class action by the Tainted Blood Action Group in Australia and New Zealand against the Red Cross, the CSL and state and federal governments as previously discussed.

The newspaper article “Bad Blood” was selected for closer analysis for the following reasons. Firstly, the article covers the main precipitating event for stories about hepatitis C in Australia. Secondly, the story was published in Victoria’s tabloid *Herald Sun* newspaper, Australia’s largest selling daily (“The Herald & Weekly Times Ltd”, 2003; Simper & Doman, 2003, p. 5). The newspaper’s audience extends from “top-end intellectuals” to “battlers” in suburbia (Jackson & Doman, 2003, p. 5; Simper & Doman, 2003, p. 5). The topic, though, had currency throughout Australia as reflected in Kerin and Tobler’s (2002) story on the Tainted Blood Product Action Group’s class action, “Hepatitis Sufferers Sue Over Bad Blood”, published in *The Australian*. Thirdly, journalist Ms Helen Carter as a medical reporter—a specialist field of journalism—is assumed to have more than a rudimentary understanding of medical and scientific topics. Fourthly, the article had a prominent position on page two, rather than appearing in the *Herald Sun*’s regular health and science section. The story has “high traditional news value” (Galvin & Pearson, 1994, p. 118); it was high in consequences and so was handled as general news material. Finally, the article is an uncomplicated example that serves to illustrate common aspects of representations of HCV and of people with hepatitis C in the news that are repeated in other news stories.

As a simple case, the story demonstrates the ready application of Fairclough's (1989; 2001) framework for the linguistic analysis of text.

2

Bad blood blamed for deaths

SEVERAL Australians who contracted hepatitis C through blood transfusions have died from the illness, a lawyer claimed yesterday.

Andrew Grech said fatalities included a Victorian with complications of cirrhosis of the liver, a NSW recipient who had liver transplant complications and several others from NSW.

Mr Grech, from Slater and Gordon, is representing up to 300 people nationally, including up to 150 Victorians, who are suing the Australian Red Cross Society.

He said they had blood transfusions from 1985 to 1990 in Victoria and 1985 to 1991 interstate, then tested hepatitis C positive.

Alex Messina, from Victoria's Department of Human Services, said department funding last August meant the Red Cross had identified donors of the infected blood and traced most of about 550 recipients, mainly Victorians.

Details were not available on how many recipients had been tested or had tested positive.

"The department is offering counselling and advice on being tested for hepatitis C," he said.

Mr Grech said it was thought that in Victoria 1200 to 1500 people had

**By HELEN CARTER,
medical reporter**

received infected blood but 50 to 60 per cent had died due to unconnected reasons. "We are still trying to contact 500 to 700," he said.

Mr Grech said he was bringing individual claims of compensation, including medical treatment, for people who could establish their hepatitis C was caused by the transfusions.

He argues that although there was no screening test for hepatitis C until 1990, the Red Cross failed before then to screen for high-risk donors.

Mr Grech claimed most of up to 200 infected donors had used drugs intravenously, a risk factor for hepatitis C.

He claimed the Red Cross asked donors only if they had used IV drugs after 1980, leaving the door open for those who had used before 1980 to donate. He said Queensland and the US asked if donors had ever used IV drugs.

Mr Grech also alleged the Red Cross failed to do blood tests that would reveal a liver enzyme to indicate liver damage due to hepatitis-caused inflammation. The test was done in the US, Queensland and some parts of Europe from 1986.

He said this question and test would have

helped screen out high-risk donors but he said the Red Cross argued the tests would reduce the donor pool too much.

Mr Grech said receiving hepatitis C-infected blood meant an 85 to 90 per cent chance of contracting it.

Mr Grech expected more victims would come forward and urged anyone who had received a blood transfusion in the time periods to be tested.

But Mr Messina said Victoria's chief health officer, Dr Graham Rouch, saw no justification in distressing tens of thousands of people by unnecessarily asking them to have hepatitis C testing because they had a pre-1990 transfusion.

"Anyone who has received a transfusion and is concerned should discuss it with their doctor," Mr Messina said.

He said 20 years after infection, one in five would be expected to get potentially fatal cirrhosis, which could progress to cancer or require a liver transplant.

A Red Cross spokeswoman said it could not comment because of proceedings before courts.

Mr Grech said the Red Cross had not admitted liability.

A test case in Victoria last year did not go to trial.

Mr Grech said questions were being asked about why it had taken nine years to start tracing.

Figure 4. News story of hepatitis C contaminated blood

Source: *Herald Sun*, January 8, 1999, p. 2

Miles and Huberman (1984, p. 232) caution against making inferences from one weak or non-representative case in qualitative data analysis. Hence, contrasting cases were sought and are discussed at the relevant point. Seventeen of the news stories that covered the major topic “National Blood Supply” were systematically sorted and compared to the attributes of the *Herald Sun* article, “Bad Blood Blamed for Deaths”, to verifying its representativeness (see comparison display in Appendix N). The headlines are pejorative in 15 of these 17 articles. Blood with HCV is considered “worthless”, “unwholesome”, and “the cause of ill health” in nine of the articles. Agency is attributed to the ARCBS in 13 of the articles. Only a small number explicate the relationship between injecting drug use and the contamination of the national blood supply with HCV, but the narrative of most of the articles is such that it is reasonably assumed that people who inject illicit drugs are targeted as carriers of the virus, the putative carriers and guilty. In the majority of articles, too, people with medically-acquired hepatitis C are portrayed as innocent victims. This echoes Sontag’s (1988/2001, p. 115) description of AIDS as a disease contracted by the innocent from “dangerous others”. The news article, “Bad Blood”, is sufficiently representative, and a discussion follows of the language, structure and selection of detail employed in this news story.

Whole-Text Language Organisation Portrays Hepatitis C as a Deadly Disease

Whole-text language organisation concerns the larger-scale structures of a text, many of which will be familiar to readers of newspapers and will influence their reading (Fairclough, 1989, pp. 137–138). In “Bad Blood” the journalist quotes from and paraphrases interviews with lawyer from the firm Slater and Gordon, Mr Andrew Grech, and Mr Alex Messina from the Department of Human Services of Victoria (the DHSV) to tell the story. Grech’s side of the story is given prominence over the opposing view of Messina. The article unaccompanied by photographs or graphics was the lead article on page two; its headline font was double the size of other headlines on the same page.

The striking headline “Bad Blood Blamed for Deaths” is pejorative: it takes as fact that the presence of HCV in blood spoils the blood and devalues it in some material respect. Hepatitis C, readers are told, is bad, dangerous to the point of being deadly, and undesirable.

As is typical with news stories, the article starts with the climax of the story: “fatalities” associated with medically-acquired hepatitis C from blood transfusions. Grech, the lawyer who represents 300 people nationally suing the ARCBS, proclaims these deaths. In the fifth last single sentence paragraph Carter paraphrases Messina, spokesperson for the DHSV:

He said 20 years after infection, one in five would be expected to get potentially fatal cirrhosis, which could progress to cancer or require a liver transplant.

It is of concern that the journalist does not demonstrate enough knowledge about hepatitis C to qualify the information given by Messina about the “natural history” of hepatitis C. “One in five would be expected to get potentially fatal cirrhosis” is an inaccurate statement. In 1999 it was known that a small percentage (approximately 20 per cent) of people infected would clear the virus spontaneously, and that most people with chronic hepatitis C infection would *not* succumb to advanced liver disease. The Government report published by Lowe and Cotton (1999, p. 41) early that same year provides such information that is readily available to journalists:

It is thought that 80 per cent of people who are exposed to the hepatitis C virus become chronically infected...Cirrhosis may develop in up to 20 per cent of people with chronic hepatitis C virus infection: this generally occurs at least 20 years after the time of infection...Some patients will develop liver failure. A proportion of those who develop cirrhosis resulting from chronic hepatitis C virus infection ultimately develop liver cancer.

Readers, though, are likely to rely on Carter’s authority as a medical reporter to produce an accurate interpretation of epidemiological data.

Journalists’ misinterpretation of, and efforts to report, complex epidemiological information in simple terms can render it inaccurate (Galvin & Pearson, 1994, p. 120; Moore, 1989, p. vii). Considering the headline “Bad Blood Blamed for Deaths”, the lead paragraph and the fifth last paragraph discussed above, this article may mislead readers into thinking that hepatitis C infection is always bad and inevitably fatal. Since this story was published in 1999, reporters for the *Herald Sun* have continued to portray hepatitis C as a “death sentence”. The *Herald Sun* story “Blood Payouts Revealed” (Frenkel, 2003a) refers to hepatitis C as a “deadly disease” and an “incurable disease”, and to the blood products in which the virus was found as “deadly transfusions”. So commonplace a feature of journalism is this sort of misinformation that is flagged in the

preface of the book, *Health Risks and the Press: Perspectives on Media Coverage of Risk Assessment and Health*:

The standards of evidence and the rules of publication are very different between the worlds of science and journalism. So different that when journalists cover scientific topics, solid communication does not always take place, and the resulting stories are sometimes misleading. (Moore, 1989, p. vii)

Galvin and Pearson (1994, p. 120) similarly found that medical reporters for Australian newspapers do not “show a sophisticated understanding of the scientific process nor act as skilled interpreters of medical jargon”. Misleading reporting is not restricted to tabloid journalism in Australia. Examples can be found in the coverage by the national public broadcaster, such as “Tainted Blood Reports” (Mazzocchi, 2003), broadcast on ABC radio’s *PM* program. In “Tainted Blood Reports” Mazzocchi prefaces her interview with her informant Josephine, who was allegedly infected with HCV from a blood transfusion, with the statement: “Now more than a decade on she doubts she’ll live to an old age.” Josephine in turn says

I’ve just given up on life quite a bit. I don’t feel like I’m going to live to an old healthy age. I’m told that after 20 years you’re likely to develop liver cancer or your liver is likely to fail.

In this ABC story, we hear Josephine’s fear of developing liver cancer and not living to a normal age. This story inaccurately portrays the usual disease trajectory for many of those infected with HCV, and the journalist does not communicate otherwise to listeners. In practical terms, those working in the field of hepatitis C in Australia need to watch for, and respond to, such instances of misleading reporting.

With regards to whole-text language organisation, the *Herald Sun* article “Bad Blood” is structured as an argument, though only one side of the argument is given. Grech lists the faults in the Australian blood supply that exposed complainants to HCV. His claims are presented in reverse sequential order. Firstly, the deaths from hepatitis C are flagged in the first paragraph: “Several Australians who contracted hepatitis C through blood transfusions have died from the illness.” Next the contamination of the blood supply with the virus is noted in phrases such as: “[Mr Grech] said they had blood transfusions from 1985 to 1990 in Victoria and 1985 to 1991 interstate, and then tested hepatitis C positive.” Then Grech travels back in time to the failure by ARCBS to do blood tests to screen out potentially infected donors and to do blood tests to identify

hepatitis C-related liver damage. As shown in Figure 5, readers can follow the logic of Grech's claims that the ARCBS was responsible for the deaths of the several Australians who contracted hepatitis C through blood transfusions.

Grech gives readers background details such as the blood donor screening in Queensland, the US and some parts of Europe in the 1980s. We are told by Grech that the "Red Cross argued the tests would reduce the donor pool too much". The ARCBS's side of the argument is not reported in this article. However, Messina briefly outlines the steps taken by the DHSV to trace recipients of infected blood and offer testing for hepatitis C and counselling. Messina does not, though, respond to the substance of Grech's claims, and so these claims go uncontested.

Several Australians who contracted hepatitis C through blood transfusions have died from the illness.

[...]

Mr Grech...is representing up to 300 people nationally, including up to 150 Victorians, who are suing the Australian Red Cross Society. He said they had blood transfusions from 1985 to 1990 in Victoria and 1985 to 1991 interstate, and then tested hepatitis C positive.

[...]

It was thought that in Victoria 1200 to 1500 people had received infected blood but 50 to 60 per cent had died due to unconnected reasons.

[...]

He argues that although there was no screening test for hepatitis C until 1990, the Red Cross failed before then to screen for high-risk donors.

Mr Grech claimed most of up to 200 infected donors had used drugs intravenously, a risk factor for hepatitis C.

He claimed the Red Cross asked donors only if they had used IV drugs after 1980, leaving the door open for those who had used before 1980 to donate.

[...]

Mr Grech also alleged the Red Cross failed to do blood tests that would reveal a liver enzyme to indicate liver damage due to hepatitis-caused inflammation.

[...]

He said this question and test would have helped screen out high-risk donors but he said the Red Cross argued the tests would reduce the donor pool too much.

Mr Grech said receiving hepatitis C-infected blood meant an 85 to 90 per cent chance of contracting it.

Mr Grech expected more victims would come forward...

[...]

Mr Grech said the Red Cross had not admitted liability...Mr Grech said questions were being asked about why it had taken nine years to start tracing.

Figure 5. Excerpt from "Bad Blood Blamed for Deaths": Logic of claims

Source: *Herald Sun*, January 8, 1999, p. 2

Other news stories giving attention to the topic “National Blood Supply” report the steps taken by health authorities to protect and “secure” the national blood supply in the wake of transfusions of infected donors’ blood. In one such news story on the ABC radio’s *AM* program, Reynolds (1999) reports that new and more precise blood screening tests offer reassurance to the public. In another, science producer/reporter Mitchell’s (1999) interview of Dr Richard Davey, Chief Medical Officer of the American Red Cross, on ABC radio’s *The Health Report*, gives a detailed explanation of nucleic acid testing of blood for HIV and HCV. By contrast, in *The Australian* Kerin (2000) reports warnings from experts that the Australian public must “accept a higher risk of contracting disease from blood transfusions or risk future chronic shortages”. A few years on, Ryle (2002) quotes Dr Keller, chair of the Blood Donor and Products Committee of the ARCBS, who reassures readers that the risk of contracting disease from the blood supply is extremely small: “We can’t absolutely guarantee the blood supply but the systems we have in place...have made the blood supply very safe today”.

Claimants’ voices are absent from Carter’s article, and from most of the other news items examined. Only three of the 17 articles listed in Appendix N contain interviews with claimants. In such news articles spokesperson for the Tainted Blood Product Action Group, Mr Charles McKenzie, himself hepatitis C positive, and Reverend Bill Crews, a prominent Sydney social activist and commentator speak on behalf of those bringing the class action. In part, this reflects who journalists choose as news sources when seeking comment. McKenzie and Crews are forceful spokespersons. It also reflects the impact of the confidentiality agreements that McKenzie deplores:

The response from the Australian Red Cross...has been to silence certain victims with confidentiality agreements for cash...[I]t means that they can’t share their experiences with their community. (Nolan & Fonseca, 2002)

The claimants are not at a great disadvantage in the article “Bad Blood Blamed for Deaths” because they speak through Grech, their legal representative. However, people who inject drugs are disadvantaged in this text. The voices of injecting drug users, said to be responsible for contaminating the national blood supply, are absent in this news article. Similarly, Körner and Treloar (2003, pp. 49–50) found that staff from needle and syringe programs (NSPs) was the least represented in newspaper coverage of syringe finds on the grounds of a Sydney primary school. Moreover, clients of the needle exchange, that is, IDUs, did not appear in the news reports at all. This absence of

spokespersons for NSPs and IDUs effectively stymied public health messages about injecting (pp. 53 & 54). Being “less quoted” and “less spoken about” (Van Dijk, 1993, p. 260) contributes to the marginalisation of people who inject drugs. The absence of injecting drug users from “Bad Blood” is further explored in relation to the grammatical and semantic features of the article.

Sentences Link Hepatitis C to Blood Transfusion

Twenty of the 23 paragraphs in Carter’s article “Bad Blood” are single sentence paragraphs. The clauses reinforce the causal relationships found in the text, further discussed in relation to its grammatical features. An example is the single sentence of paragraph four: “He said they had blood transfusions from 1985 to 1990 in Victoria and 1985 to 1991 interstate, then tested hepatitis C positive.” In this compound sentence the two clauses are linked by the adverb “then”. There is a temporal relationship between receiving the receipt of blood transfusions and subsequently testing hepatitis C positive. There is also a logical relationship; that the hepatitis C infection was as a result of the blood transfusion. Readers are effectively told that there was no other way that people could have been infected with hepatitis C.

Messina does not respond to Grech’s claims. However, rather than failing to deal with the threat of a contaminated blood supply, the DHSV is shown to have taken action. The Department funded the ARCBS to identify donors of infected blood and trace recipients. The DHSV, and hence the Government, is portrayed as in control and taking action. For example, Messina says: “The department is offering counselling and advice on being tested for hepatitis C.” Apparent inaction, reported in paragraph 17, reflects a process of deliberation by the state’s chief health officer:

But Mr Messina said Victoria’s chief health officer, Dr Graham Rouch, saw no justification in distressing tens of thousands of people by unnecessarily asking them to have hepatitis C testing because they had a pre-1990 transfusion.

Despite such deliberate inaction, though, readers are not informed how many people are affected. Readers are told in the single sentence of paragraph six: “Details were not available on how many recipients had been tested or had tested positive.”

Causality and Blame: IDUs and the Australian Red Cross Blood Service

A range of grammatical and semantic features can be considered in the critical analysis of a text (Fairclough, 1989, pp. 125–127; 2001, p. 242). Such features include the transitivity in clauses (reflecting causation) and the positioning of the writer and the reader by the modes of sentences (that is, whether the text is declarative, interrogative or imperative). Analysis includes asking questions about the modality of the text (that is, features of the text that indicate the authority of the writer and/or informants in relation to one another, and in relation to producing the truth). Such an analysis uncovers the way in which sentences carry meaning, the social relationships reflected in the discourse, and whose voice is represented.

Analysis of “Bad Blood” includes consideration of the balance of sources and perspectives primarily by focusing on causality in the text: “Who is represented as causing what to happen, who is represented as doing what to whom” (Fairclough, 1989, p. 51). Causality in this article is attributed to two agents, the ARCBS and people who inject drugs. Causality is first specified in the headline with “bad blood” blamed for causing deaths. The first paragraph tells readers to *whom* something was done, *what* was done, and the *consequences*. It reads “Several Australians who [to whom] contracted hepatitis C through blood transfusions [what] have died from the illness [consequences]”. These people’s deaths stem from the actions of a responsible agent(s). Blood transfusions are again linked with hepatitis C infection in the third paragraph. Hepatitis C has clear causality (prior to the identification of HCV in 1989 the disease was attributed to a viral agent), and an infectious organism is implied by phrases like “infected blood” and “hepatitis C-infected blood”.

The ARCBS as the national supplier of blood for transfusion is specified as the agent who acted upon blood recipients. Further into the article readers are told what it is that the ARCBS did *not* do (which Grech says it *ought* to have done). The ARCBS, Grech says, failed to screen for high-risk donors by questioning donors about intravenous drug use and by testing donor blood for an enzyme that shows hepatitis-C related liver damage. Grech’s assertion in paragraph nine that he is claiming compensation for people who “could establish their hepatitis C was caused by transfusion” becomes, in effect, a reported fact that the ARCBS is liable. Readers can follow the analysis: if it had been the case that the ARCBS had screened for high-risk donors, then Grech’s clients would not have been infected. By inference the people

Grech represents are “innocent victims”, a categorisation that is also reflected in the text’s vocabulary, which places them in a position of greater moral authority in relation to the ARCBS.

In a previous study Krug (1997, p. 102) describes a television news story about the innocent victims of hepatitis C: two teenaged brothers who acquired hepatitis C from blood transfusions to treat their haemophilia. It is not clear from Krug’s analysis whether or not injecting drug use is mentioned in this particular news story, yet he concludes that “The only people who can be blamed for hepatitis C are injecting drug users...That these boys are not drug users allows them to be victims of fate”. Krug does not explore the attribution of blame further despite noting that the boys’ father is taking legal action for their infection. By contrast, in the story “Bad Blood” lawyer Grech is said to attribute responsibility for ensuring that blood products are free from contaminants to the ARCBS. People who inject drugs are nonetheless said to have contaminated the national blood supply with HCV, causing subsequent hepatitis C-related deaths. Although the perspective of people who inject drugs is not built into the coverage in “Bad Blood”, readers are given a sense that their actions are harmful and are to be controlled. Grech claims that most of the donors infected with HCV had used drugs intravenously. It is implied that the ARCBS in Victoria should have “screened for” or “screened out” people who “had used IV [intravenous] drugs” and were likely to have the virus. People who inject drugs are represented stereotypically as endangering others. It follows that the ARCBS should protect blood recipients from them. Agency in this article, then, is attributed to the ARCBS responsible for screening out people who inject drugs and donate blood.

The modes of sentences in “Bad Blood” are mainly declarative with the journalist communicating information to the reader. The final sentence though—“Mr Grech said questions were being asked about why it had taken nine years to start tracing [infected recipients]”—reads like a grammatical question. The journalist seems to put the question in the minds of readers so that we might ask ourselves and perhaps ask of health authorities, “Why had it taken nine years to start tracing?”

As Grech is the lawyer for 150 Victorians and up to 300 people nationally the issue is represented as being of national concern and of interest to all readers. In Australia blood is considered a community resource for the good of all; collected and distributed by the ARCBS. Blood donation is voluntary in Australia. As researcher Matthew Klugman (2002), from the Centre for the Study of Health and Society at the

University of Melbourne, points out in his story “Blood Gifts” broadcast on ABC radio’s *Perspective* program: “It’s important that blood may only be given, never bought, for it has lent a moral dimension, a specialness, to the culture of Australia’s Blood Services; our blood banks”. Many readers will, at some time, require a blood transfusion or blood products and, it is assumed, would want these products to be safe and free of contaminants.

Vocabulary Casts Moral Judgements About IDUs

“You’ve got this contagious disease. I could hold up banks with my blood. One time in Bali I banged up my finger when this guy closed the door on his vehicle, and squashed my finger. There was this terrifying sight. Here was this toxic stuff all over the place. They’re saying, ‘Don’t worry about it.’ And I’m saying, ‘No, nobody’s got anything to clean it up with.’ I used my t-shirt to try and clean up all this blood everywhere. It’s not like this life giving substance any more. It’s this thing that could poison, could ruin everybody else’s life. You’ve got this stuff that circulates around your body that you’ve always been told keeps you alive but any of my blood could infect somebody else if I’m not careful...I don’t know where the notion of ‘dirty’ comes from. It’s an antisocial disease, an unacceptable disease, so I guess there’s the notion of the unclean and clean from that point of view. ”

– Carol, Interview, April 2003

The vocabulary of the article “Bad Blood” represents people with hepatitis C in a particular way. People with medically-acquired hepatitis C from blood transfusions contaminated with the virus are represented differently to those who acquired the virus through injecting drug practices. Moreover, the journalist’s choice of words creates social relationships in the minds of readers between people with medically-acquired hepatitis C and people with hepatitis C who inject or injected drugs. Hepatitis C “sufferers” who acquire the virus through blood transfusions and other medical interventions, along with those who acquire the virus from needle-stick injuries, are separated out as different from those who acquire the virus during injecting drug use. Binary opposites are used in news stories to attribute blame to those who choose to inject drugs while others with the virus are positioned as victims (Cummings, 2004). The way that social relationships are constructed is discussed next, followed by a closer look at the figurative language in “Bad Blood” and news headlines overall.

In the fifth paragraph of “Bad Blood” readers are told that the ARCBS had identified the donors of infected blood. From then on, these people are referred to as “high-risk donors”, equated with people who “used drugs intravenously”. In the eleventh paragraph Grech reportedly claims that almost all of the infected donors “had used drugs intravenously, a risk factor for hepatitis C.” As noted in the AHC (2001, p. 27) media guide, this phrase implies that injecting drug use causes hepatitis C, rather than transmission of the virus with blood-to-blood contact “when people share any equipment used to inject drugs.”

The language of categorisation is implicated with values such as beliefs that injecting drug users are bad, or at the very least, their activities have negative consequences for others (Taylor, 2001, p. 7). Sontag (1988/2001, p. 134) describes how the categorisation of people with HIV/AIDS as members of a “risk group” “revives the archaic idea of a tainted community that illness has judged”. Not unlike the early portrayals of people with HIV/AIDS described by Jones (1998), “Hepatitis C Sufferers” in other news stories examined are represented as isolated and sometimes anonymous members of the risk group injecting drug users (albeit, in some cases, years ago). Their identity may be protected by the use of an alias and their faces obscured in photographs or television coverage. On the whole, such stories are about the “epidemic” or the risk of infection rather than the sufferer. In practical terms, the categorisation of people as belonging to a “high-risk group” draws attention away from high-risk behaviour(s) involved in the transmission of the virus (AHC, 2001, p. 26). Those who do not associate themselves with the high-risk group may not see themselves as being at risk of contracting the virus as noted by Aroni (cited in Cullen, 2003) in relation to HIV/AIDS. Hepatitis specialist Dr Stuart Roberts, interviewed by Jacinta Tynan (2000) for the ABC’s *7.30 Report* program, cautions that “Hepatitis C is too well stereotyped, in that the only people that have been believed in the community to be affected by this have been those who have used intravenous drugs”.

There is an ideological difference in the preferred terminology recommended by the AHC for use by the media and the vocabulary commonly used by journalists in Australia when writing about hepatitis C. In “Bad Blood” recipients of the infected blood are referred to as victims, a term eschewed by the AHC (2001, p. 26). “Victims” implies that those who were infected with HCV in other ways, specifically, through injecting drug use, are guilty and this categorisation marginalises their actions (AHC, 2001, p. 26; Van Dijk, 1993, p. 275). Moral judgements about illicit drug use are

implicit in “Bad Blood” as in other media stories. In an interview broadcast on ABC radio’s *AM* program, for example, spokesperson for the Tainted Blood Action Group, Charles McKenzie, claims to have received “bad blood” and “tainted blood”. Blood so designated has connotations of ill, or evil, coming as it does from the blood of “[drug] addicts” identified earlier in the same interview by social activist Crews:

Well I’ve found people I love have got it and the way they got it was through a blood transfusion. I know for certain they’ve never been addicts or anything like that. (Grimm, 2002)

As Sontag (1988/2001, p. 136) argues, “A polluting person is always wrong [and] a person judged to be wrong is regarded as...a source of pollution” (p. 136). This also echoes Sontag’s description of AIDS as a disease contracted by the innocent from “dangerous others” (p. 115), and the rhetoric of “innocent” and “guilty” found by Lupton, Chapman and Wong (1993) in press articles about people living with HIV/AIDS.

Injecting drug users constructed as guilty of polluting, or as sources of pollution, receive attention in relation to the topic category “Risk of Infection”. In stories around this topic, journalists report on the perceived risk to the public by means such as: accidental needle stick injuries in public places as in Titeliou’s (2000) news story, “Syringe Pricks Foot at Beach: Tests for Needle Boy” in the *Herald Sun*; contaminated instruments in hospital procedures as reported by Scott (1997) in, “Patients Sought in Hospital Bungle”, in *The Australian*; and non-specific means as in Murphy’s (2001) report, “Hepatitis C Thrives in Jail”, televised on the ABC’s *7.30 Report* program. In the introduction to the latter report the show’s host, journalist Kerry O’Brien, states that upon release, prisoners who inject drugs “take the virus with them” putting the health of their families and others in society at risk.

Fault for contamination of the national blood supply with HCV is attributed to people who inject drugs and carry the virus. The vocabulary in news stories like “Bad Blood” is not beneficially informative. Such coverage confirms Faye’s (2000) assertion that the media contributes to the penalisation of people who have hepatitis C. As noted previously, the Faye’s legal-penal metaphor evokes the Christian notion of disease as punishment described by Sontag (1977/2001, p. 43). It is implicit in “Bad Blood” that readers expect the national blood supply to be pure. Any persons who knowingly allow a contaminant to be mixed with blood is “criminal”, a view held by Reverend Bill Crews, campaigning for people with medically-acquired hepatitis C.

In “Bad Blood” the formal properties of the text cue particular interpretations, drawing upon what Fairclough (1989, p. 24) terms “member’s resources” (MR)

which people have in their heads and draw upon when they produce or interpret texts—including their knowledge of language, representations of the natural and social worlds they inhabit, values, beliefs, assumptions, and so on.

“Common-sense” assumptions implicit in this, and in other news texts, are that injecting drug use is harmful to the individual and to society generally. In the accompanying logic, it is injecting drug use that causes hepatitis C, rather than blood-to-blood contact. Such a common sense “sustains unequal relations of power” (Fairclough, 1989, pp. 84–85) and it follows that people who inject illicit drugs occupy a position inferior to others in society. Moreover, commonsensical assumptions such as “injecting drug use is harmful to the individual and to society” or “injecting drugs causes hepatitis C” can be regarded as “ideological common sense”. The AHC (2001, p. 27) offers an alternative perspective stating in its media guide: “It is blood to blood contact with a person with hepatitis C that enables transmission, not injecting drugs per se”. However, representations of hepatitis C as the penalty for injecting drug use persists in the media coverage in Australia, and any refinement of representations of people who inject drugs illicitly is undercut by the metaphors used in relation to hepatitis C.

Metaphor is a literary device that embellishes language. It is a figure of speech in which an object, person or experience is “spoken of” in terms of another. A metaphor transfers the attributes of one person, object, or experience to another person, object, or experience (Fairclough, 1989, p. 119; Moon, 2001, p. 45). Importantly, metaphor shapes meaning in everyday conversations and in texts such as the newspaper article “Bad Blood”, and where the term “bad blood” is used similarly in other stories such as the aforementioned “Bloody Gifts” (Klugman, 2002). Alongside the overtones of moral contamination, injecting drug use is cast as having the potential to damage the health of the Australian community through the contamination of the national blood supply with HCV. The metaphorical representation of blood containing HCV as bad blood and “infected blood” implies that the virus defiles the blood and, at best, this blood is spoiled and unwholesome. Blood so contaminated is inferior and polluting, the medium for the spread of the disease from person to person. Blood contaminated with HCV might be considered impoverished, as not replenishing the body in the same way as uncontaminated blood does. People receiving bad blood are assumed to fall from a state

of health—a fate reflected in the whole-text language organisation of the article “Bad Blood” in which hepatitis C is inaccurately portrayed as always bad and inevitably fatal. Such usage is in contrast to the usual notion of blood as a fluid that circulates through the body carrying with it nutrients and oxygen to the body’s cells and removing waste products. Notably absent from stories is the value of the blood despite it containing the hepatitis C virus as an extraneous element. As Dr Trevor Mudge for the AMA and its Ethics and Public Health Committee tells Mazzocchi (2002a) in an interview on ABC radio’s *PM* program: “The answer is not to give people blood, and then you’ll have people dying for want of a blood transfusion”.

Another figurative term found in news stories about blood contaminated with HCV is “tainted blood”. The action group for which Mr Charles McKenzie is spokesperson goes by the name “Tainted Blood Product Action Group”. The word “tainted” has overtones of moral contamination, as hepatitis C is associated with illicit injecting drug use. The term “tainted blood” is found in four of the ABC headlines where it is used to denote the 1990 and 1998 national blood supply incidents. “Taint” is synonymous with “contaminate”. In the *Herald Sun* news story “Blood Payouts Revealed” Frenkel (2003a) nominates the hepatitis C virus as the causative agent in the phrase “hepatitis C-tainted stocks”. As with “bad”, the word “taint” also denotes that blood is spoiled, that the quality of the blood is impaired by the hepatitis C virus. Tainted blood loses something of its valuable qualities, and it follows that the health of those infected with hepatitis C is impaired.

The use of the phrases “bad blood” and “tainted blood” is not restricted to the ABC and News Limited publications such as *The Australian* and the *Herald Sun*. A search of Fairfax News publications for “Hepatitis C” for the period January to October 2003 elicited 33 articles, five of which included the expressions “tainted blood” or “bad blood” in the headlines. These headlines appeared in the *Newcastle Herald*, *The Sunday Age* and the *Sydney Morning Herald*.

Yet another figurative device found in other news texts about hepatitis C is the personification of the virus as a secretive and insidious opponent or combatant. The disease has crept up on health authorities: “It seems,” says compère John Highfield on the ABC radio’s *The World Today* program, that hepatitis C “is becoming an epidemic by stealth right across Australia” (Vincent, 2000). *The Weekend Australian* headline designates hepatitis C the “Hidden Epidemic”: unreported or under-reported and “not often spoken about” by those living with the disease (Hickman, 1998).

The vocabulary of “Bad Blood Blamed for Deaths” casts injecting drug users from a moral perspective with words like “bad”, “blamed”, and “victims”. As previously mentioned, Faye (2000) reported participants’ responses to the media portrayal of hepatitis C. Despite not examining media coverage of hepatitis C, Faye concluded that the manner of reporting was not informative and “such HCV coverage was considered to be significantly harmful emotionally, particularly if it was an HCV-positive person’s only source of HCV information” (p. 210). This critique lends weight to Krug’s (1997) finding that media reportage focuses on the moral discourse of intravenous drug use, and Faye’s (2000, p. 210) stance that media coverage of hepatitis C is potentially harmful to those living with the virus.

Conclusion

There is a complex interplay between the whole-text language organisation, grammar, and vocabulary in media texts that represents hepatitis C and people with hepatitis C in particular ways. This has implications for workers in the field of hepatitis C in Australia.

In this chapter, a descriptive content analysis of news items about hepatitis C in the ABC news services, *The Australian* and the *Sun Herald* from January 1996 to December 2003 shows that the tone of news headlines in the majority of stories has negative connotations—that the hepatitis C virus is detrimental to the physical health and social well-being of infected individuals and potentially harmful to others in the community. The issue receiving the most attention during this period is the contamination of the national blood supply by the hepatitis C virus.

The *Herald Sun* article “Bad Blood Blamed for Deaths” is representative of other stories reporting on the issue of the national blood supply. This text was critiqued using Fairclough’s (1989; 2001) framework for linguistic textual analysis to illuminate representations of hepatitis C and people with hepatitis C. The language in this news text separates one group of people from another: those who acquired hepatitis C via injecting drug use and those for whom it was a medically-acquired disease. The rhetoric of innocent victims versus guilty victims has changed little since Krug (1997) described “virus victims”. Such rhetoric echoes descriptions of people living with HIV/AIDS (Lupton, Chapman & Wong, 1993; Sontag, 1988/2001; Treichler, 1987). Many Australian news stories about hepatitis C attribute blame for contaminating the national

blood supply with HCV to those who choose to inject illicit drugs, and reserve the category “Innocent Victim” for people who were infected by means other than injecting drug use. Responsibility for putting contaminated blood into circulation is, in turn, attributed to the ARCBS. News reporting about hepatitis C, though, has been relatively restrained. The disease has not been portrayed as a “plague” in the same fashion as HIV/AIDS (Lupton, Chapman & Wong, 1993; Tulloch & Lupton, 1997, p. 53). However, the terms “bad blood” and “tainted blood” are descriptors of both physical and moral contamination—a threat to everyone in the Australian community—and are commonly used in news coverage of hepatitis C. Workers in the hepatitis C community sector and on government advisory committees may alter the discourse around hepatitis C by critiquing representations in the news media of the disease and people living with hepatitis C, and by challenging people’s beliefs, values, and assumptions.

Journalists may not have the specialist knowledge about hepatitis C to qualify the information they obtain from various sources, as the analysis of “Bad Blood Blamed for Deaths” demonstrates. Media advocacy is one strategy, recommended by Lupton, Chapman and Wong (1993) to health educators in the HIV/AIDS field, which has been taken up to some extent by hepatitis C community sector in Australia. It is important for those working in the hepatitis C field to critique what is reported in order to accurately inform and educate readers. Media organisations offer online databases and archives of articles and transcripts and/or audiovisual recordings of radio and television broadcasts, facilitating a detailed examination of media coverage about hepatitis C. Although it may not be possible to apply all aspects of Fairclough’s (1989; 2001) framework to stories about hepatitis C, the framework is a useful tool for critiquing news stories as they are published and enables the comparison of stories over time. The framework allows, for example, identification of contestable features such as the logic of claims in news stories, thus also having practical application for those working in the media who report on hepatitis C-related issues.

The major topic categories identified in the headlines and lead paragraphs of news stories from the ABC news services, *The Australian* and the *Herald Sun* for the period January 1996 to December 2003 indicate the main suppliers of information about hepatitis C in Australia. News sources and actors—whose voices are represented or the positions from which actors speak—are considered in the next chapter.

CHAPTER NINE

NEWS ACTORS AND THE DOMINANT DISCOURSES IN MEDIA COVERAGE OF HEPATITIS C: A CASE STUDY

If we want to use the media to shift perceptions, we need to acknowledge the way the media works and construct our stories so they say what we want them to say.

– David Crosbie, Chief Executive Officer,
Odyssey House, Victoria, 2003

Introduction

The magnitude of the “hepatitis C epidemic” in Australia in the 1990s, acknowledged by the Minister for Health as a “serious population health problem” (Wooldridge, 2000a, p. iv), gave impetus for development of a national population health strategy to address the disease. The magnitude of the epidemic is also the “news peg” for many of the news stories about the disease, with revelations of the contamination of the national blood supply with the hepatitis C virus in the 1990s forming the major context of stories. The majority of news media stories examined bear negative headlines, portraying hepatitis C as a “deadly” disease. Hepatitis C is associated with people who inject illicit drugs (IDUs) in both public health policy and media texts. Moral judgments are portrayed in media texts, with the escalation of the epidemic attributed to IDUs whose behaviour endangers others. As noted in Chapters Three and Five, the espoused “partnership” between key stakeholders—state/territory and local governments, community organisations, people affected by hepatitis C, and the medical, healthcare, scientific and research communities—is central to the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) (Commonwealth Dept Health & Aged Care, 2000b). Nonetheless, this public health policy text privileges the professional perspective over that of the lay community. The influence of professional

experts is cemented through formal social networks implicated in the *Strategy*'s development, implementation, monitoring, and evaluation. Such influence extends to publication in peer-reviewed journals like the *Medical Journal of Australia (MJA)* from which journalists may source information. Hence, the key types of actors selected in news coverage of hepatitis C and the construction of social relations between actors in a text is of interest to this study.

News stories are texts that are produced—a process that involves selection, interpretation, and representation(s) of events and people—and then interpreted by readers, listeners, or viewers (Fairclough, 1989, pp. 26–27; 50; Saunders, 1993, pp. 63–64). This chapter is concerned with the dominant discourse(s) in news coverage of hepatitis C, focusing on the social relationships between news actors and the subject positions they, and the audience, occupy. The institutional and social processes to which the discourse belongs, and the context of governmental control through institutional and bureaucratic processes are also explored. Media producers may combine voices from the hepatitis C-affected community—hepatitis C-positive people and spokespersons from non-government organisations (NGOs)—with those of medical experts. However, this does not signal a shift in the traditional social relations between medical professionals and patients. As in the *Strategy* (and its foreword), the narrative of news media stories commonly reflects the dominant health paradigm, and the imperative for scientifically-proven high-technology pharmaceutical treatment to combat the hepatitis C virus represented as a threat to individuals and the Australian community.

Major News Actors in Stories on Hepatitis C

Over forty years ago, C. Wright Mills (1959, p. 208) cautioned researchers in the social sciences that the volume of publicity is not necessarily the best indicator of status position. However, the volume of publicity afforded the medical profession in Australia in relation to various health matters is still used as one measure of the status of doctors (Lupton and McLean, 1998). The major news actors in this study were identified in a quantitative content analysis of news items from the Australian Broadcasting Corporation (the ABC) news services, *The Australian* and the *Herald Sun* for the period 1 January 1996 to 31 December 2003. News actors were grouped into categories and the frequencies for each calculated. The major categories of news actors and news sources in stories on hepatitis C for the three news sources examined are presented in Table 5.

Table 5

Major News Actors and News Sources in News Stories on Hepatitis C in the Australian Broadcasting Corporation News Services, The Australian, and the Herald Sun, 1 January 1996 to 31 December, 2003

Ranking	Category of news actor/source	<i>n</i>
1	Government (and opposition), departments and agencies	81
2	Academics and/or researchers	49
3	Hepatitis C-related support / consumer groups	45
4	Medical experts (Australian and overseas)	41
5	Infected (hepatitis C sufferers) & affected individuals	33
6	Publications	28
7	Advisory bodies	26
8	Medical bodies	23
9	Blood services	16
10	Person at risk / victim	14
11	Relative of person at risk / victim	13
12	Hospitals / health care services	10
12	Medical practitioners	10
13	Court / police proceedings	9
14	Dental bodies	7
14	Celebrity	7
15	Local council	5
16	Employee groups	4
17	Legal practitioner	3
17	Person at risk: Person who injects drugs	3
18	Alcohol and drug services	2
18	Nursing bodies	2
	Other	33

The work and opinions of spokespersons for Government agencies and departments, medical experts, academics and/or researchers (particularly medical researchers, epidemiologists, and researchers in field of drugs and alcohol), medical publications—mainly the *Medical Journal of Australia (MJA)*—and Government advisory bodies together carry the most weight. The main suppliers or sources of information about hepatitis C in Australia reflect the “expert voice”. This concurs with studies of the reporting of other health matters as noted above. Galvin and Pearson (1994), for example, found that print journalists reporting on cosmetic surgery in Australia rely almost exclusively and uncritically on the medical profession as their authoritative source. Reviewing health messages in the popular mass media worldwide, Seale (2002, p. 4) similarly notes the news media’s preference for “authoritative sources”.

The three news sources were searched specifically for “Hepatitis C” and news items with accounts of, or interviews with, individuals living with hepatitis C were retrieved. These are the “Hepatitis C Sufferers” identified in headlines, lead paragraphs, and the body of stories. Persons living with hepatitis C—termed the hepatitis C sufferer by the media—and lay support groups representing hepatitis C positive persons receive some attention in ABC and *The Australian* stories, with the inclusion of anecdotes or scene-setting stories (though less than one-third of the total of the combined expert voice). In the tabloid newspaper the *Herald Sun*, though, so-called hepatitis C sufferers and hepatitis C-related support groups are not well established as actors or suppliers of information. Two other categories emerged in the *Herald Sun* stories: the “Person at Risk/Victim” and the “Relative of the Person at Risk/Victim”. These categories of news actors comprise “innocent” individuals who were exposed to a source (possibly) contaminated with the hepatitis C virus, and their families. Such individuals at risk of infection with the hepatitis C virus may become hepatitis C sufferers in the future.

As well as quantitative measures of the status of doctors, though, studies of discourse in media coverage of health matters confirm the status conferred on doctors by media producers who are likely to solicit the judgment or opinion of doctors first and foremost, and frame the news from the medical perspective (Galvin & Pearson, 1994; Lupton, 1992; Lupton, Chapman & Wong, 1993; Lupton & McLean, 1998). As previously mentioned, “discourse” is to do with both language and social practices at a specific point in time or over a period. It relates to the way that topics, people, objects, acts, activities and events and the like are thought and talked about and represented in

our society, the subject positions that people occupy in particular contexts, and the conventions by which people interact in various social contexts (Fairclough, 1989, pp. 22–25; Hall, 1997, p. 44; Hall, 2001, pp. 72–73; Saunders, 1993, pp. 26–27).

The perspective of experts dominates the discourse around hepatitis C in the news media in Australia. This is in accord with Krug’s (1997) findings of media coverage of hepatitis C between 1994 and 1995. Representatives of hepatitis C councils—incorporated community-based, not-for-profit support groups—contribute to this state. Media producers also contribute to this by controlling content, by emphasising hierarchical social relations between news actors, and by setting up particular subject positions for both news actors and the audience, with the latter being “inexpert”.

In 2001, the Australian Hepatitis Council (AHC) produced the first edition of *The Australian Media Guide to Hepatitis C* for the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) (AHC, 2001). The target audience of this guide is journalists and others working in the media (p. 1). The AHC recommends that journalists avoid terms such as “hep C victim” and “hep C sufferer” that imply that persons living with the disease are powerless and lack control of their lives (p. 25). Despite the alternative and preferred terms listed in this guide, the term “hepatitis C sufferer” persists in common usage in the news media. Introducing their case study of newspaper reports of syringe finds near a Sydney school, Körner and Treloar (2003, p. 46) summarise the view widely held by workers in needle and syringe programs: “[T]here has been evidence in Australia that the media have contributed to providing inaccurate information and to promoting stereotypes that cause discrimination against people with hepatitis C.” Moore and Dietze (2005, p. 281) also believe that negative media coverage has an adverse impact upon the provision of services for IDUs, such as the failure to establish supervised injecting facilities in Victoria. Despite the publication of the AHC’s media guide, and the appearance of spokespersons for hepatitis C-related support or consumer groups in news stories—ranked fourth in this study—there has been little change in the usage of terms like “hepatitis C sufferer” by the news media. As discussed in the previous chapter, the media continues to categorise people with hepatitis C, demarcating innocent victims, such as those who have medically-acquired hepatitis C, from the “guilty” who got the virus through injecting drug use. Similarly, postings of support on the website of the Tainted Blood Product Action Group refer to “victims” who are “without fault” and who have been “harmed”

(Tainted Blood Product Action Group, n.d.). Hepatitis C support groups in Australia, however, do not differentiate between categories of people. One such example is the *Strategic Plan 2001–2002* of the Hepatitis C Council of WA (Inc), which uses the term “people affected by hepatitis C” to refer to those infected with the hepatitis C virus and those affected by it including family, friends, and carers (HCCWA, 2001).

In Australia in the early to mid-1990s, hepatitis C support groups formed in the states and territories, albeit with limited funding from government or other sources (AHC, n.d (a)). These groups had community-based management committees and a membership of persons affected by hepatitis C, and most went on to become incorporated. The AHC, incorporated in 1997 and funded by the Commonwealth Department of Health and Ageing, is the national peak body for hepatitis C support groups and councils from the states and territories (AHC, n.d (a)). Dr Michael Wooldridge launched the National Hepatitis C Strategy 1999–2000 to 2003–2004 during his time as Federal Minister for Health and Aged Care (previously Health and Family Services)—a position that he held from the formation of the Coalition Government in 1996 until 2001. Dr Wooldridge’s successor, Senator Kay Patterson responded to claims that hepatitis C antibody positive blood was used to manufacture blood products in 1990 (as discussed in the preceding chapter). Senator Patterson tabled the National Blood Authority Bill in 2002 establishing the National Blood Authority (NBA) to “secure” the supply of blood and blood products in Australia (Commonwealth Department of Health and Ageing, 2003a). She commissioned a review of the national HIV/AIDS and hepatitis C strategies in 2002. Shortly after Senator Patterson’s replacement by Liberal Member of Parliament Tony Abbott in October 2003, the Department of Health and Ageing released the Government’s response to the reviews. A new advisory council headed by Dr Wooldridge (now Professor) was established: the Australian National Council on HIV, AIDS, Hepatitis C (Hepatides) and Sexual Health (ANCHAHS). ANCHAHS is charged with responsibility for “governance arrangements” in relation to transmissible and blood-borne diseases in Australia (Commonwealth Department of Health and Ageing, 2003b).

Throughout this time there has been some coverage by the news media of hepatitis C in which it was portrayed both as a health problem for individuals and as a public health problem for Australians generally. Krug (1997) noted that the media coverage of hepatitis C in Australia during the period of 1994 to 1995 reflected the medicalisation of the disease. Krug identified a number of identities for those with

hepatitis C created by the media at this time: injecting drug users (IDU); baby boomers (who experimented with injecting drug use); those at risk; the “innocent victim”, and the “sufferer” (both IDU and innocent victim) (pp. 99; 102). Krug alluded to, but did not explicate, the power relations at a societal level that shaped this discourse. This study illuminates the practices of media producers that construct particular social relations around hepatitis C positive people and professionals in the field.

Critical discourse analysis is useful for examining the meanings in the media coverage of health issues that informs the development of “health beliefs” by the public (Lupton, 1992, p. 29). Fairclough’s (1989) framework for the descriptive analysis of a text incorporates a set of formal features that are salient in terms of critical discourse analysis. Fairclough’s framework was utilised in this study to examine the discourse in a current affairs story about hepatitis C—the experiential, relational, and expressive values in the vocabulary and grammar of news text. Analysis goes beyond a description of the formal features of the text to consider the social values associated with the text, its relationship to wider social structures, and the power relations therein. In this chapter, the subject positions occupied by hepatitis C positive persons, the positioning of news actors in relation to each other, and the subject position of the audience are explored in Jacinta Tynan’s (2000) story, “Hepatitis C Increasing to Epidemic Proportions”, televised on the ABC’s *7.30 Report* program on February 28 (see transcript in Appendix O).

Case Study of the 7.30 Report's "Hepatitis C Increasing to Epidemic Proportions": The Privileged Medical Perspective

"You know, my whole adult life has been centred around natural healing and natural therapies and, you know, I always believed that that was the best way to go. So, I guess, I was often in denial and I thought that the chemical treatment [combination therapy] just wasn't a good idea. So it was a quest for me to find the most natural treatment. The little information I did have about people's personal stories of treatment, remembering that this goes back some 12 or 13 years, and originally there was very little information and the early treatment seemed to have a very nasty effect on people. The side effects were really heavy and a lot of them did not sustain a cure. Most of them had to undergo that only to be told that the virus had come back. So to me, why put yourself through that, and I couldn't see the significance of the fact that even if you didn't cure the virus you actually gave your liver a bit of, a brief reprieve from having to fight it. No doctor made that clear to me. So basically I'd only heard a few snippets of about people's personal experiences with early treatment and a bit of stuff from the Hep C Council newsletters, which all seemed to say that it was still very unsure of the effects of the treatment later on...All those things made me very reluctant to try, to go on the treatment."

– Anna, Interview, July 2003

Three speaking positions, or "voices", in media representations of hepatitis C can be identified: the expert; the journalist; and the person or institution affected by the disease (Krug, 1997, p. 95). Despite the inclusion of both expert (medical expert) and the person living with hepatitis C in media coverage, the medical meaning is privileged. Representatives of hepatitis C support groups in Australia who maintain the location of hepatitis C sufferers within medical discourse have not heeded Krug's findings. Utilising Fairclough's (1989) procedure for critical discourse analysis, the following case study of "Hepatitis C Increasing to Epidemic Proportions" (Tynan, 2000) shows how the hepatitis C sufferer continues to function in the Australian news media as a preamble to expert medical discourse about the latest treatment for the disease. This critique extends Krug's work to describe the subject position created for members of the audience, and the possible audience interpretations that the text generates. As previously stated, the power relations at a societal level are examined, focusing on Government control over people with hepatitis C. The analysis also brings to light the relationship

between the medical institution and non-government organisations (NGOs) and the pharmaceutical industry in Australia.

The *7.30 Report* is advertised as “the ABC’s national flagship current affairs program” priding itself on “balanced” and “in-depth” reporting (ABC, 2003c). The producers of the *7.30 Report* control the content of its programs and the way in which events or issues are represented. The media producers would also consider the profile and “subject position” of their audience (Fairclough, 1989, p. 50; O’Shaughnessy & Stadler, 2002, pp. 23–4; 67–68). In the *7.30 Report*, as in other media programs, the production process involves the deliberate construction of the story as the following description of the ABC radio program *PM* indicates:

Behind the informative airwaves that makes up Radio Current Affairs, works an essential mix of editorial and technical talent...pieces are edited, mixed and checked, often re-edited, re-mixed, and edited again; scripts are then subedited, printed, copied, and finally distributed to the presenter and on-air team. (ABC, 2003b)

News actors in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) were drawn from the following three categories: “Medical Experts”; “Hepatitis C-Related Support/Consumer Groups”; and “Infected (Hepatitis C Sufferers) and Affected Individuals”. The news actors are hepatitis C sufferer Mr Alan Morgan, hepatitis C specialist Dr Stuart Roberts, and coordinator of the Hepatitis C Council of Victoria, Ms Jill Meade. Journalist, Ms Jacinta Tynan, and journalist, Mr Kerry O’Brien, the show’s compère, also appear in the story. Despite the balance in terms of the categories of news actors represented, the story reports the medical perspective.

“Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) is very much a constructed story fitting within the current affairs genre. The story did not involve live-to-air interviews. Tynan recorded interviews with the three news actors prior to the time of broadcast, which were then edited to create the narrative of the program. The audience does not hear Tynan’s questions and does not see any interaction between her and the interviewees. It is as though the interviewees are speaking directly to the audience, albeit orchestrated by Tynan and other members of the ABC production team (the media producers). The following analysis of this media text considers: the relational values in the textual features; the subject position or social identity of news actors in the text; the subject position of the viewing audience; the institutional and societal processes; and ideological meanings evident in the text.

Maintaining Traditional Social Relations in the “Partnership” between Medical Professionals and Patients

Critical discourse analysis (Fairclough, 1989, pp. 116–117; 125–128; 179–181) reveals that social relations between news actors in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) were established—the status and relative power of each news actor—and a subject position was created indirectly for the viewing audience through the vocabulary, grammatical features and visual images of the text.

The introduction by compère Kerry O’Brien—an experienced and award-winning journalist who is also program editor (ABC, 2003b)—links this text to its situational context. O’Brien tells the audience what they are purported to already know when he states: “When it comes to the deadly blood-borne viruses, HIV, of course, receives most of the attention and funding”. In this opening line, O’Brien effectively tells the viewers what they are assumed to know about blood-borne viruses from previous news reports and other sources. The implicit “presupposition” establishes the baseline knowledge and experience of the world that the program’s producers attribute to their viewing audience (Fairclough, 1989, pp. 152–155).

As discussed in the preceding chapter, the majority of headline and lead paragraphs of the news stories about hepatitis C examined in this study are negative in tone. In this case study, O’Brien sets the tone of the story with a hepatitis C diagnosis tantamount to a death sentence; the “virulent” hepatitis C virus is nominated as one of the “deadly blood-borne viruses”, a “major killer”. He stresses the magnitude of the problem when he says, “with the number of new infections increasing to epidemic proportions, by 11,000 a year”. Heralding the possibility of hope for hepatitis C sufferers from a new drug treatment, O’Brien also establishes a common narrative that fits Seale’s (2002, pp. 29–30; 148) classification of narrative structures in media health coverage. In this story the disease is the villain, hepatitis C sufferer Alan Morgan is a central character or protagonist, and Dr Stuart Roberts and other unnamed research scientists are heroes. Tynan’s (2000) story, however, departs from Seale’s (2002) analogy; the doctor in this text is not a “magician”, and the new medicine is not a “magical solution” but is predictable, scientifically tested and proven through a series of research studies.

The viewing audience is positioned as witness to Morgan's restoration to health in this testimonial for the new drug treatment. Members of the audience are also positioned as potential hepatitis C sufferers. Journalist Tynan says Morgan was diagnosed with hepatitis C "after a routine medical examination". This is oriented to the viewers—members of the audience who like Morgan may not know that they have hepatitis C until it is discovered on a "routine medical examination"—detection of the virus occurring as if by chance.

Turn-taking is one feature of interviews that indicates power relationships between participants and reflects a social hierarchy (Fairclough, 1989, pp. 134–135; Van Dijk, 1993, p. 261). In "Hepatitis C Increasing to Epidemic Proportions" (Tynan, 2000), turn-taking is orchestrated by the program producers rather than negotiated by the news actors themselves. Interviewees are limited to giving answers to questions put to them by the journalist, and their responses edited to fit the program format and length. The journalist and program makers, then, specify the content and control the contribution of the news actors. In a number of voice-overs and a spot address to camera, (seemingly face-to-face with the viewing audience), Tynan also re-words what the interviewees say thereby offering the audience a particular version, and cueing a particular interpretation.

"Modality" in this text is concerned with the authority of the various news actors to tell the viewers the truth, and "relational modality" to do with the actors' authority in relation to others (Fairclough, 1989, pp. 126–127; 129). Morgan, then, is positioned as the giver of information to the viewing audience. He has authority by virtue of his personal experiences—he is hepatitis C positive, a hepatitis C sufferer. Morgan briefly describes the fatigue that afflicts his daily life. In his own words he is sentenced to the unrelenting deterioration of his health. He says: "This isn't something I'm going to get over. This is something that's going to get worse, this is something that's only going to deteriorate further." The audience is not told how Morgan acquired hepatitis C. Through the visual images and the dialogue of this text, though, the audience is given an impression of Morgan. It can be inferred from his list of attributes that he is a "regular Australian male"; he likes to play sport with his friends, he expresses the desire to work and build a career, to provide for himself now and in his retirement, to look after himself, and to take responsibility for his own health.

Dr Stuart Roberts is a speaker with status and authority, established when Tynan introduces him in voice over as: “heading the Australian research team involved in worldwide clinical trials of combination therapies for hepatitis C in patients”. This voice over is accompanied by footage of Dr Roberts, attired in green hospital gown and gloves, taking a box of vials from a refrigerator in a laboratory. He takes the box over to a bench where a female technician (also gowned and gloved), puts one of the vials into a resealable plastic bag. Dr Roberts appears to be overseeing the activity of the technician in this scene (see Figure 6).



Figure 6. Images from “Hepatitis C Increasing to Epidemic Proportions”: Dr Stuart Roberts in laboratory

Source: *7.30 Report*, ABC television, February 28, 2000.



Figure 7. Image from “Hepatitis C Increasing to Epidemic Proportions”: Dr Stuart Roberts, Hepatitis C Specialist

Source: *7.30 Report*, ABC television, February 28, 2000.

In the next scene, Dr Roberts, in suit and tie, is seated in a room that appears to be part of his working environment: including a hand-basin with lever taps and a bench with plastic storage units. On the wall behind him is a coloured chart with images of the liver in different states of disease from hepatitis, bearing the pharmaceutical name

“Roferon[®]-A” (see Figure 7). This footage of Dr Roberts is captioned “Dr Stuart Roberts, Hepatitis C Specialist”. Dr Roberts is portrayed as being in control in both words and images; he is at the top of a medical hierarchy that has links to the rest of the world.

The funding sources of the clinical trials headed by Dr Roberts are not specified in this text. However, the chart in Figure 7 links the doctor to the multinational pharmaceutical manufacturer Roche, maker of the injectable Interferon alfa-2a recombinant which goes by the brand name Roferon[®]-A. The chart is the sort of product promotional material that is provided free to doctors (and hepatitis councils in Australia); it can be used as a teaching aid with patients. This product placement provides for an alternative reading of this text: that Dr Roberts represents the interests of multinational pharmaceutical companies like Hoffman-La Roche Ltd. Roche launched its first genetically engineered (recombinant) drug Roferon[®]-A into the market in 1986, anticipating that the therapeutic use of the drug would expand (F. Hoffman-La Roche Ltd, 2003a) as it ultimately did with its application in the treatment of hepatitis C. The company also acquired the marketing rights to the Polymerase Chain Reaction (PCR) technology that saw the manufacture of diagnostic and blood screening tests for infectious agents such as hepatitis C; diagnostics being part of Roche’s core business (F. Hoffman-La Roche Ltd, 2003b). Similarly, the pharmaceutical firm Schering-Plough Corporation—which has business facilities worldwide—has collaborated with other pharmaceutical and biopharmaceutical companies in the clinical development of combination therapies for hepatitis C and improved delivery systems for pharmaceuticals used in the treatment of hepatitis C (Schering-Plough Corporation, 2003).

Dr Roberts’ appearance in this ABC story reflects the “close collaboration” between doctors and the biopharmaceutical industries that the Australian Medical Association (AMA) advocates as a means of advancing the health of patients in Australia (AMA, 2002, p. 1). A number of such collaborative studies are listed on the Australian Government’s Research Register at the Department of Health and Ageing’s website. Accessible to the public, this Register makes the arrangements between doctors and the pharmaceutical industry seem transparent by documenting the funding sources for most, though not all, projects. However, such disclosure does not guarantee unbiased research. Studies of medical research in other fields, which are sponsored by the pharmaceutical industry, have uncovered bias, particularly publication bias or selective

reporting (Commens, 2001; Lexchin, Bero, Djulbegovic & Clark, 2003; Melander, Ahlqvist-Rastad, Meijer & Beermann, 2003). An examination of the relationship between pharmaceutical industry sponsored clinical trials of hepatitis C treatments and outcomes was not undertaken for this study. The way in which sponsored clinical research in the area of hepatitis C affects medical practice in Australia, however, warrants investigation.

The nature of relationships of power between doctors and the pharmaceutical industry is also prescribed in the guidelines of institutional bodies such as the AMA, the National Health and Medical Research Council (NHMRC), and hospital ethics committees. Benefiting the health of patients is of the essence in such institutional guidelines. However, an editorial in the *MJA* found the openness of clinical practice guidelines for medical practice lacking (Van Der Weyden, 2002, pp. 304–305). Discussing conflicts of interest in the development of clinical guidelines, Van Der Weyden (p. 305) cites a survey by Choudhry, Stelfox & Detsky (2002) that found: “81% of authors per guideline had links to the industry”. Financial conflicts of interest for authors of clinical practice guidelines arising from the relationship between medical practitioners/researchers and the pharmaceutical industry impacts on the medical practice of those doctors following the guidelines (Choudhry, Stelfox and Detsky, 2002).

Developing innovative treatments for patients is central to the alliances that biopharmaceutical companies make with academic and medical institutions, and more recently, NGOs (though it could be argued that the relationship with NGOs is a marketing technique and a strategy for influencing policy-makers). Such partnerships are, for the biopharmaceutical companies, an entrepreneurial strategy to achieve growth, prosperity, and a greater share of the global healthcare market, and influence policy-makers (Burton & Rowell, 2003, pp. 1205 & 1206; Commens, 2001; F. Hoffman-La Roche, 2003a; Herxheimer, 2003, p. 1208; McNeil, Nelson, & Tonkin, 2003, p. 519; Serono, 2003). The relationship between the framing of Dr Roberts alongside a pharmaceutical product poster is discussed further in the final section of this chapter in relation to the institutional and social processes, and ideological meanings in this text.

Dr Roberts uses the pronoun “we” in a number of sentences. Dr Roberts is referring to himself, other medical researchers and doctors in the field, and members of the health care team treating Morgan when he says: “We’ve had a good response in Alan” and “What we know with the treatments now is that the response are that for

every ten people that we treat, four people will have a good long-term outcome, loss of virus from the blood and improvement to normal in their liver function tests”. When Dr Roberts says: “We’ve had a good response in Alan” he is also using a less formal means of address than referring to his patient as “Mr Morgan”. The use of the patient’s first name could reflect the doctor’s “higher” status whereby Dr Roberts feels comfortable and entitled to refer to his patient in an informal manner on national television. However, using an informal address does not necessarily signal dominance (Van Dijk, 1993, p. 261). Such a form of address is congruent with the notion of the “team” or “project” in which both Dr Roberts and Morgan are players (discussed below). It is likely to reflect the style of talk previously established between Dr Roberts and Morgan, and the shift towards informality and “conversation-like discourse” in contemporary medical consultations (Fairclough, 1995a, p. 211; 1995b, p. 51), flowing from sociocultural changes such as “greater individual autonomy and more democracy in relations between professionals and clients, the impact of marketisation and models of consumer choice on the professions” (Fairclough, 1995a, p. 211). However, having complied with the treatment regime, and being “successful”, Morgan is a model patient. The implicit assumption of the relations between doctors and patients remains: the doctor is the “hero” armed with a scientifically proven “cure” for those infected with hepatitis C.

Dr Roberts does not declare Morgan cured; instead he states the physiological response to the treatment six months after treatment stopped: “No traces of detectable virus in his blood”. The audience, which is inexpert, is unlikely to make such a fine distinction. Contestation of the medical profession’s ability to cure hepatitis C comes from the journalist, Tynan, and Meade representing the Hepatitis C Council of Victoria. Towards the end of the story—over images of a laboratory technician filling vials with solution and operating equipment (see Figure 8)—Tynan reminds viewers that sixty percent of patients do not respond to treatment and that the long-term effect of the drugs is not known. The “breakthrough treatment” offers hope, but it is not, says Meade, a cure.

Such contestation by Meade and Tynan is not enough, though, to undercut the imperative embedded in the text’s structure. Citing MacCabe’s (1974) work in relation to the hierarchy of discourse, O’Shaughnessy and Stadler (2002, p. 97) argue that the narrative of a text organises voices “into a particular hierarchy, such that one voice is more important, more truthful than another”. In “Hepatitis C Increasing to Epidemic

Proportions” Dr Roberts and Morgan have considerably more screen time and more dialogue than does Meade. Footage of technicians at work in the laboratory is used as background as the journalist tells viewers of the work of researchers to “refine” drugs, and Dr Roberts informs them of studies to gauge improvements in treatment regimes (see Figure 8). Such images reinforce the status of medical research, something that viewers can believe in. Medical research is literally portrayed as ongoing, behind-the-scenes and continually improving upon its achievements.

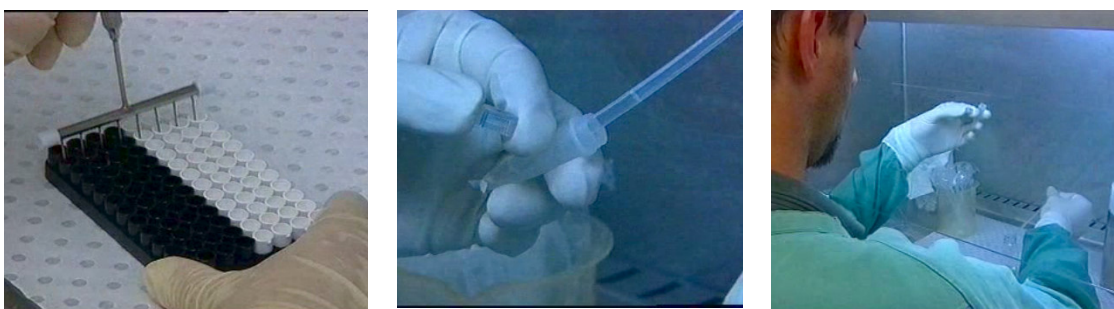


Figure 8. Images from “Hepatitis C Increasing to Epidemic Proportions”: Laboratory technicians at work

Source: *7.30 Report*, ABC television, February 28, 2000.

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Figure 9. Images from “Hepatitis C Increasing to Epidemic Proportions”: Alan Morgan playing tennis

Source: *7.30 Report*, ABC television, February 28, 2000.

However, as with the newspaper reporting of cancer breakthroughs examined by Ooi and Chapman (2003), it is unlikely that the inexperienced viewer watching “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) understands the importance of this clinical trial in terms of its place in ongoing research. Viewers are more likely to interpret this text as reporting a cure for hepatitis C. Viewers are reminded that Morgan has been cured when Tynan states: “But Alan is one who’s benefited from the research, living proof to thousands of other people with hepatitis C that it may not have to be for life”. As Tynan speaks, footage of Morgan playing tennis—through a series of mid-shots, wide-shots and close-ups (see Figure 9)—confirms that he is cured, that he has been restored to an active, healthy life. The benefits of medicine are plain to see.

The pronoun “we” is also used by Dr Roberts when arguing the case for the funding of treatment programs for hepatitis C. When he says: “We know, however, there are a lot of other groups as well who have developed this infection”, he is speaking on behalf of medical professionals working in the area of hepatitis C, but inclusive of the viewing audience who will come to realise the enormity of the “health problem”. It implies that viewers would agree money needs to be spent on hepatitis C treatment once they know how many people—other than injecting drug users—are infected. “Are”—plural of the verb “be”, which indicates that people have this attribute—makes this a definite statement of the truth; it is a fact that people other than those who have injected drugs have hepatitis C. Moreover, it is this “fact” that justifies the spending of money in the area. Logically, if only those who “used intravenous drugs” were infected with the virus, the spending of money may not be so easily justified. Or at least it might be harder to garner the support from the viewing audience, the public, for such spending.

Morgan also uses the pronoun “we” in his statement: “If it changes, well, we maybe [*sic*] go back to the drawing board and start again”. Implicitly, Morgan sees himself as a project, and an active player. Both he and the medical team, he says, will go back to the “drawing board”. This is the notion of a “co-operative” project that currently characterises healthcare (Seale, 2002, pp. 12–13). Seale attributes this style of relationship between doctor and patient to the demise of medical authority. However, Fairclough’s (1989, pp. 71–75) discussion of the trend towards less explicit signs of unequal power relationships points to an alternative reading. By positioning his body as a “project” Morgan contributes to the less direct, yet still effective, maintenance of power by medical professionals. In this regard, Morgan has qualities, notably, self-

reliance and the willingness to “give it a go”, that make him a model patient. Morgan fits the rhetoric of public health at the time. Such rhetoric flows through the current national hepatitis C strategy for Australia that espouses the principle of partnership between people with hepatitis C and treatment service providers (Commonwealth Department of Health and Aged Care, 2000b, pp. 32; 35–36). Morgan fits the model of public health that emphasises the individual as an active health consumer who takes responsibility for his/her own health (Grace, 1991, p. 334; Lupton, 1992, p. 30).

This theme is found in other texts such as “The Hep C Untouchables—One Every Hour” from the *Herald Sun*’s Sunday magazine (Van Den Nieuwenhof, 2001). In this story 35-year-old Carmen Jones (not her real name), a single mother, opted not to have treatment. But in a bid to lead a “near-normal life”, she made lifestyle adjustments such as altering her diet and restricting her alcohol intake. Jones is portrayed as taking control of her life in a manner that is consistent with medical advice at that time:

According to Dr Deakin [a general practitioner who treats about 50 patients with hepatitis C], most of her patients are able to pursue normal lives through careful management of their lifestyle and diet. (p. 23)

Such texts construct hepatitis C as an individual health problem and a medical problem, amenable to medical treatment and/or medical management with which patients must comply.

The construction of “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) by its producers provides cues to the social relationships between the news actors, and between the news actors and the viewing audience. Viewers are reassured that Dr Roberts is telling the truth by virtue of his status and authority in the medical and research field. The journalist, Tynan, does not explicate Dr Roberts’s alliance with the pharmaceutical industry. Dr Roberts receives the backing of Morgan, who the viewers can believe because he is a hepatitis C sufferer. The producers allocate most of the viewing time to Dr Roberts and Morgan; however, the doctor and his patient are not equals in the social hierarchy. Despite the rhetoric of the team and partnership, the social relations between news actors in this media text reflect traditional relations of power between doctors and their patients. It is the medical profession that exercises power, determining the nature of action available to patients with hepatitis C. This is discussed further in the next section in conjunction with the way that the news actors occupy and reproduce the subject positions constructed by the media producers. However, as noted by Fairclough (1995b, pp. 44–45), some caution must be taken when

drawing conclusions. Although representations of hepatitis C in the news often seem to function ideologically, complicity between the medical profession, in the person of Dr Stuart Roberts, and the reporters and producers of the *7.30 Report* “Hepatitis C increasing to epidemic proportions” (Tynan, 2000) to reproduce social relations in which the doctor is dominant over the patient cannot be assumed. At most, the text is one in which both the media producers and Dr Roberts hold a particular point of view about the hepatitis C epidemic in Australia and try to persuade the audience to their point of view. The story tries to garner audience support to influence the Government to do more about funding research and treatment for hepatitis C.

Subject Positions of the “Professional Hero” and the “Hepatitis C Sufferer”

The news actors in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), a current affairs story, appear to occupy comfortably the subject positions set up for them in the interviews. In doing so, these actors reproduce the conventional image of medical doctors as “professional heroes” as Seale (2002, p. 143) so aptly describes them.

Hepatitis C Specialist, Dr Stuart Roberts, appears in his professional role in two “uniforms”. Firstly, he is shown in the garb of the doctor-come-scientist (see Figure 6)—green hospital gown and gloves—supervising the sort of high-technology medical work that often receives “privileged” status in the news media (Lupton, 1992, p. 30; Seale, 2002, pp. 156–157). Secondly, he is shown in a checked brown jacket, white shirt and dark, patterned tie: the dress of the medical consultant (see Figure 7). In this second attire, Dr Roberts responds to questions put by Tynan (positioned off-camera). This creates the effect of him imparting information directly to the audience. Both portrayals cement his social identity as a professional hero.

This text packages together the hepatitis C patient in relation to the hepatitis C medical specialist. It sets up a subject position for hepatitis C sufferer Alan Morgan as that of the patient. In this text the doctor is hero—the healer—who enables the hepatitis C sufferer to play tennis again through the application of high-technology recombinant pharmaceuticals. It is an offer of “hope” says Meade from the Hepatitis C Council of Victoria. For every one person with hepatitis C who is cured, though, many others are not. The audience, however, is not introduced to these people. The media text constructs

a myth: that treatment makes available to everyone who is cured a new life in which the individual can build a career and live a healthy life on into retirement.

Dr Roberts is a dedicated advocate of the principles of the scientific process, the medical model. From this text the audience can learn about the conventional practices in the medical treatment of hepatitis C. Following diagnosis, Morgan started trial drug treatment described by Dr Roberts as follows:

The trial combines the standard treatment for hepatitis C, injections of the chemical stimulant interferon three times a week, with a pill known as ribavirin...He had a full year of treatment and has now completed his six months follow-up. We've had a good response in Alan. There's no trace of detectable virus in his blood and his [liver function] tests have come back to normal.

Medical management of patients undergoing treatment for hepatitis C involves regular monitoring of their response to therapy both during and after treatment. Response to therapy is based on blood tests for virological response to detect the loss of hepatitis C virus RNA (ribonucleic acid) within a specified time frame and for biochemical response to measure the normalisation of the patient's ALT (alanine aminotransferase, a liver enzyme that is elevated when liver cells die) (Cheng, 2003, pp. 20–21). Patients who are not having treatment are nonetheless involved in a similar cycle of monitoring. Faye (2000, pp. 214–217) describes how participants who are not undergoing treatment have regular, six monthly blood tests which both they and their general practitioner or gastroenterologist use to determine the condition of their liver. In the ABC text, Morgan likewise indicates that he has monitored his body's response to treatment over time when he says: "The final result of the test was that there was no trace of a positive hepatitis C result in my blood system". Doctors also monitor for "adverse events" during drug therapy (Cheng, 2003, p. 21) though such events are not mentioned in "Hepatitis C Increasing to Epidemic Proportions". The toxicity of the treatment and its impact on Morgan is not mentioned. This is not surprising as media coverage of medical "breakthroughs" often fails to report on the risks of medications (Ooi & Chapman, 2003, p. 639).

The experiential value of words points to the way in which those producing a text experience, and represent the world (Fairclough, 1989, p. 111). In this case study, the text is framed primarily from a medical perspective, specifically, that of the medical specialist who favours treatment for hepatitis C. Medical terminology dominates the text with words and phrases such as: "virulent hepatitis C virus"; "clinical trials of

combination therapies”; “standard treatment”; “chemical stimulant interferon”; “response rate”; “six-month follow-up”; and “cirrhosis of the liver”. In this text, Dr Roberts informs the audience about the cycle of treatment and the monitoring that accompanies it—a cycle that is reiterated by Tynan:

Jacinta Tynan [journalist]: The trial combines the standard treatment for hepatitis C, injections of the chemical stimulant interferon three times a week, with a pill known as ribavirin.

Dr Stuart Roberts [hepatitis C specialist]: Alan’s had an excellent response. He had a full year of treatment and has now completed his six months follow-up...There’s no trace of detectable virus in his blood and his tests have come back to normal.

[...]

Jacinta Tynan: Researchers are also refining a longer-acting dose of interferon injected just once a week.

The course of treatment appears simple. If the treatment had not effected a cure the audience is told by Morgan that patients can start over: “If it changes, well, we go maybe back to the drawing board and start again and go through the whole cycle again”. In reality, though, Morgan has little control over this decision. Others determine what Morgan can do, what re-treatment options are available to him if the virus is not cleared. Interferon and ribavirin treatment for people with hepatitis C is subsidised by the Commonwealth Government in Australia. Medical practice with respect to patients previously treated who have not responded or who have relapsed is governed by treatment protocols. The Schedule of Pharmaceutical Benefits, which came into effect on 1 November 2003, stipulates the regime for the prescription of highly specialised drugs (section 100 items) that medical practitioners must follow (as did the previous schedule). Schedule criteria for treatment with interferon Alfa-2b, for example, state:

Treatment is to cease if plasma HCV RNA remains detectable by an HCV RNA qualitative assay after 12 weeks of therapy. The course of treatment must be continuous and excludes retreatment of nonresponders or patients who relapse. (Commonwealth Department of Health and Ageing, 2003c)

Such criteria are in turn based on advice from expert bodies such as the National Health and Medical Research Council (NHMRC) (NHMRC, 1997, iii; 33).

“Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) draws upon medical measures of response to drug therapy; measures of normality and abnormality that both doctor and patient monitor. There is the measure of virological response. Dr

Roberts expresses virological response as: “no trace of detectable virus in his blood” and “loss of virus from the blood” while Morgan says: “There was no trace of a positive hepatitis C result in my blood system” and “I’ve been basically told that it’s negative in my system now”. There is also the measure of biochemical response that Dr Roberts talks about: “His [liver function] tests have come back to normal” and “improvement to normal in their liver function tests”.

The tennis match is a journalistic construction that functions as a visual metaphor for Morgan’s cure and return to life (see Figure 9). The story stresses that Morgan faced deteriorating health: “deadly blood borne virus”; “hepatitis C is also a major killer”, “most patients developing chronic liver infections”; “the future is usually grim” for hepatitis C sufferers; and “one-quarter develop cirrhosis of the liver, and many liver cancer or failure”. The new treatment is depicted as offering the chance of regaining a “normal” life—being able to do daily activities such as getting up in the morning, climbing a flight of stairs, and playing a game of tennis. Tennis is a metaphor for Morgan’s life being “turned around”. The treatment offers the chance of a new life, a rebirth or as Morgan says the opportunity to “create a life again”. The audience (interpreting the text) is expected to make the connection between the drug therapy that cures Morgan and enables him to play tennis again. Early in the text Morgan and Tynan emphasise fatigue, a symptom of the disease:

Alan Morgan [hepatitis C sufferer]: The most difficult thing is, I suppose, fatigue. It’s nauseatingly difficult to just even get up in the morning. Day by day, it gets harder and harder even to climb a flight of stairs.

[...]

Jacinta Tynan [journalist]: It wasn’t so long ago that a game of tennis was out of the question for Alan Morgan.

The absence of symptoms of the disease is linked to core components of Morgan’s evaluation of drug therapy: it enables him make plans for his future; to plan to work; and to provide for himself. The audience can infer that Morgan returns to work just as he returned to playing tennis. Morgan’s evaluation of treatment is posited upon a particular point of view about adult life in Australian society. Such an ideological representation (Fairclough, 1989, p. 115) is also implicit in the way that this text constructs the audience (as is discussed later in relation to the subject position of the audience).

Although Morgan, the patient, views himself as part of the team, he nonetheless occupies a subordinate position in relation to his doctors who implement the medical management plan. Morgan is the “object” of medical intervention; he is “acted upon” (Saunders, 1993, pp. 1–4). What is done in terms of treatment and monitoring is done according to established medical practice. Agency in this text resides with Dr Roberts. Dr Roberts cures Morgan with high-technology drug therapy. The doctor controls what is done. The patient is required to comply with drug therapy according to a set treatment protocol derived from the conventions and application of the scientific method. The benefits of medical science are represented as uncomplicated and transparent.

Patients must also comply with the timetables of the health care institution. As expected, health professionals enact power by controlling contextual aspects of interaction such as time, place, and setting (Van Dijk, 1993, p. 259–260). In an interview conducted for the newsletter of the HCWA, the clinical nurse consultant, and the research nurse for the Hepatology and Liver Transplant Services at Sir Charles Gairdner Hospital stress the constraints on providing individually tailored health care in the outpatients’ setting (Pugh, 2002). The following comment sums up the situation:

Ms Barbara Chester [clinical nurse consultant]: We’re a bit hamstrung about trying to work a hospital schedule around the needs of people...The pressure on the outpatients’ department restricts us because we are only allocated one morning clinic a week. Often people will say that they can come in Wednesday or Thursday, and we have to say that’s not really an option. (pp. 12–13)

Such operations of treatment centres are reported as posing a barrier to active or current hepatitis C-positive IDUs who want to access treatment (Jewell, 2003, p. 3; Madden, 2004).

The concept of the team is found in the rhetoric of this same interview:

Ms Barbara Chester [clinical nurse consultant]: We very much try to keep the patient as a dominant component in the loop, and...we’re mindful that we can’t work as a team unless they see themselves as part of that team. So when you’re working hard and setting all these plans up and people don’t keep appointments, and change things without checking with you, we’ve had to revisit with them that they’re an essential part of the team – and to be successful here we’ve all got to be doing our bit. (Pugh, 2002, p. 14)

In this interview, as in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), the patient occupies a subordinate position in the health care team. The patient is

expected to follow the plan of action orchestrated by the experts. The team is not a single entity; rather, it reflects a number of units. In practice, the patient is not a member of the team that determines treatment options:

Barbara Chester [clinical nurse consultant]: There are just so many treatment arms—they [the doctors] will say to Jo [research nurse] “How many have we got on this drug company’s program because I think this patient might qualify for that treatment?” She might say, “At this point in time we’ve used those spaces up but there’s possibly another six place that they’re going to give us...” So a lot of that behind the scenes work is going on, as a team together. That is not something that is explained to everyone in the clinic, there is just not the time. (Pugh, 2002, p. 16)

The level of participation by hepatitis C patients in the health care team warrants further study, particularly in light of Grace’s (1991) findings on health promotion discourse discussed later in relation to institutional and societal processes and ideologies.

At another level, Dr Roberts in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000)—who prescribes and monitors Morgan’s treatment for hepatitis C—acts within parameters set by particular institutional bodies previously noted. In *The Birth of the Clinic*, Foucault (1973, p. 27) traces the system of double checks by political authorities and privileged medical bodies over medical practitioners in Europe at the start of the nineteenth century. A hierarchy of power—organised and institutionalised (Van Dijk, 1993, p. 255)—reminiscent of that described by Foucault exists in Australia today. The monitoring of response to hepatitis C therapy by doctors in Australia, including medical specialists, is stipulated in clinical protocols or guidelines specifying the action to be taken by medical practitioners in particular circumstances. The national health program in Australia includes national surveillance for viral hepatitis, the highly specialised drugs scheme and the Therapeutic Goods Administration that regulates medicines, blood and medical devices such as the diagnostic tests used in serological testing for hepatitis C (Commonwealth Dept of Health & Aged Care, 2000b, p. 56). Australia has implemented a standardised approach to gauging patient response to antiviral therapy proposed and adopted by expert groups such as the US National Institutes of Health Consensus Development Conference and the European Association for the Study of the Liver Consensus Panel (Commonwealth Dept of Health & Aged Care, 2000a, p. 8). On a practical level, this standardisation links Australian medical practice in this field with international medicine and facilitates international trials of drug treatment. Expert medical groups, such as those mentioned above, exercise power by determining which course of action (medical practice) is

appropriate for a given situation. In this case, both Dr Robert's (the doctor's) and Morgan's (the patient's) social positions are pre-determined by expert medical bodies and ratified by the Australian federal government via NHMRC protocols for medical practitioners (Commonwealth Dept of Health & Aged Care, 2000b, p. 31).

Timetables that establish rhythms and regular activities have long permeated institutions such as schools, hospitals, armies, and factories (Foucault, 1977, pp. 149–151). The clinical protocols that govern the medical monitoring of the patient's response to therapy for hepatitis C during and after treatment, discussed above, have built-in timetables that control the activities of both doctor and patient. Treatment regimes may change over time as doctors like Dr Roberts engage in pharmacological research studies (trials), but both doctors and patients continue to act within set practices.

Although agency can be identified in this text, causality is sidestepped. The audience is not told how Morgan was infected with hepatitis C. This text lacks the overt moral discourse that Krug (1997, p. 94) found in texts in which hepatitis C is portrayed as a "visitation upon those who may have injected drugs". In this ABC text the audience is not expected to concern itself with causality. As previously mentioned, the association of hepatitis C with injecting drug use is not expected to engender support from the audience. Instead, the "need" to fund hepatitis C research and treatment is based on facts and statistics about the size of the public health problem. Tynan, videotaped in a medical laboratory, speaks directly to camera. The camera slowly moves in so that she appears to become bigger, adding emphasis:

Jacinta Tynan: The treatment is the best news yet for hepatitis C patients, for whom the future is usually grim. 85 per cent of carriers will develop a chronic liver infection, one-quarter develop cirrhosis of the liver and many, liver cancer or failure. It is now regarded as the biggest threat to public health in Australia. (Tynan, 2000)

Meade concurs when she states the number of people infected—approximately 200,000—and the annual rate of new infections. Hepatitis C is, she says, "at epidemic proportions." The viewing audience is expected to trust Meade because she is spokesperson for a NGO and represents the "consumer". The use of statistics is a common discursive strategy employed by the news media to create a sense of danger or crisis in the audience (Lupton, 1992, p. 31). The magnitude of the hepatitis C epidemic in Australia was identified in the previous chapter as a major news peg in the coverage of hepatitis C by the ABC, *The Australian* and the *Herald Sun*. In "Hepatitis C

Increasing to Epidemic Proportions”, quantification is used to garner audience support for government funding of hepatitis C medical research and treatment.

Despite the apparent balance of sources with the inclusion of a hepatitis C sufferer and a spokesperson for the Hepatitis C Council of Victoria—an incorporated organisation which started out as a support group in 1992 (Hepatitis C Council of Victoria, 2002c)—it is clear that medical discourse is the dominant discourse in this text. The doctor, specialist Dr Roberts, comfortably occupies the position of professional hero set up for him by the media producers. The text is framed from the medical perspective via the use of medical terminology, the portrayal of medical practices associated with the anti-viral treatment for hepatitis C, the attribution of agency and the visual metaphor of the cure. In constructing this perspective, the media producers also construct a subject position for the audience that reflects a particular view of Australian society.

Speaking to a Middle-Class Audience

The 7.30 *Report* story, “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), is structured in such a fashion that the medical discourse is dominant. The imperative in the structure of the text is the medical breakthrough in curing hepatitis C. This is achieved through the narrative form of the current affairs genre and by the construction of a subject position for the audience. The audience to whom this text is addressed is stereotypically middle-class.

The concept of the middle-class in Australia is used in a diverse range of texts without it being well defined. Discussing the validity and authenticity of middle-class Australian hip hop bands “Good Buddha” and “tzu” Connor (2003), for example, loosely associates “middle-class” with privilege and socio-economic position. Particular patterns of lifestyle and behaviour are associated with the middle-class. The concept of “class” informs the perspective of artists in Australia. Filmmaker David Caesar and artist Ben Quilty, for example, consider specific suburbs in Australia working-class and others middle-class. In interviews published in *The Weekend Australian Magazine*, Caesar and Quilty speak about the adoption of working-class symbols, such as the black beanie, Ugg boots, the Holden Torana and Staffordshire terriers as fashion statements by the middle-class (Lacey, 2003, pp. 30–31).

Numerous commentators in newspapers and journals of opinion (for example, Hamilton, 2002a; Hamilton, 2002b; Henderson, 2003; Megalogenis, 2000; Megalogenis, 2003; Rintoul, 2000; Saunders, 2003) debate the extent to which the impact of globalisation, the deregulation of the Australian economy and structural changes in industry have eroded the socio-economic position of the middle-class. Tracing Australian Prime Minister John Howard's rhetoric, Brett (2003) outlines the changes in the constituencies of the Liberal and Labor parties in relation to the middle-class. Nonetheless, household income, educational attainment, and occupational group are major determinants of who is considered middle-class in Australia. Writing for *The Weekend Australian* about the role the middle-class will have in determining the outcome of the 2004 federal election, author George Megalogenis (2003, p. 18) regards middle-income earners with a family income between \$50,000 and \$60,000, in 2000–2001, as middle-class. According to Germov (2002), the concept of the middle-class developed by sociologist Max Weber consists of “those occupational groups with qualifications and skills that provided them with market advantages (higher wages, prestige, and better working conditions) over those in manual occupations”. Pusey (2003, pp. 54–55) similarly stresses the importance of educational attainment in determining class in his work on the experiences of middle Australia. The middle-class Australians in professional, managerial and technical occupations interviewed by Pusey were educated to tertiary level, and this was believed to give them status and advantage. Taking a neo-Marxist view of society, Scambler and Higgs (1999) provide a useful description of classes in relation to one another. Individuals can be considered middle-class if they belong to occupational groups that engage in strategic decision-making in the workplace, and exercise control and surveillance over other employees or workers.

Today middle-class Australians tend to have a high level of debt to fund their ever-increasing consumption of luxury goods and services (Hamilton, 2002a; Rintoul, 2000). In Australia, the middle-class also pay a high level of personal income tax to fund government social welfare programs of which they are beneficiaries at various points in their lifetimes increasingly via direct government assistance to purchase services from the private sector (Hamilton, 2002b; Kenworthy, 1999; Megalogenis, 2003; Saunders, 2003, p. 6). Despite sharing in government welfare benefits and services, it is generally considered that middle-class Australians are able to choose and finance their own education (including higher education), private health care (albeit with government rebates), home ownership and retirement (through savings such as

superannuation and/or investments) (Henderson, 2003; Megalogenis, 2002; Saunders, 2003).

An investigation of audience response to the “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), and other texts, is beyond the scope of this study. However, an analysis of the “subject position” of the audience implicit in this text was undertaken. This involved consideration of what is in the text and drawing upon my own experiences, knowledge, and the assumptions that the text cued. Such interpretation mirrors the work of the viewing audience would have done and is a recognised analytic tool of social scientists (Fairclough, 1989, pp. 141 & 145; Mills, 1959, p. 196; Saunders, 1993, p. 13; Van Dijk, 1993, p. 258). The *7.30 Report* text implicitly attributes properties to the Australian people (shown in Figure 10).

In this story at least a fraction of the viewing audience is positioned as being yet to find out if they have hepatitis C. Still the text is constructed as of relevance to them. Viewers, and the public generally, are expected to desire the same sorts of things out of life that Morgan lists as of importance to him: looking to the future; creating a life for themselves; building a career; and planning for their retirement. It is implied that viewers take for granted performing the routine daily activities that Morgan finds difficult. These aspirations can be applied to the viewers. The construction of Australians (the viewers) can be summarised as: independent in their daily activities of living; sociable but self-reliant; providing for themselves; taking responsibility for their own health; active in their old age; willing to have a go; and trusting in science and experts to cure disease.

Besides having this “list” of properties attributed to it, the audience is treated as though its members are well-educated, able to think critically, and receptive to a particular style of communication. The audience is acquainted with the facts and statistics about the size of the public health problem that hepatitis C poses to the Australian public (discussed in the earlier section on the subject position of news actors, and in relation to the influence of advertising discourse in the section that follows). Characterising the way in which tertiary-educated professionals are set apart from less educated Australians, Betts (n.d.) is quoted by Brett (2003, p. 23) as claiming that they are more likely to “justify positions through argument and evidence rather than by appeals to authority”. The media producers of “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) carefully attempt to engage the trust of the viewing audience by outlining the argument and evidence from a number of sources, each of

whose authority to tell the truth is arrived at differently as discussed in the earlier section about relational values. What the media producers construct, therefore, is a view of middle-class Australia comprising independent and self-reliant individuals who choose to be healthy and who support modern medicine based as it is on evidence and technical expert knowledge.

Alan Morgan [hepatitis C sufferer]: The most difficult thing is, I suppose, the fatigue. It's nauseatingly difficult to just even get up in the morning. Day by day, it gets harder and harder even to climb a flight of stairs...

(Image of Alan Morgan, wearing tennis whites, seated out of doors. Cuts to footage of Alan playing tennis on grass court.)

Jacinta Tynan [reporter]: It wasn't too long ago that a game of tennis was out of the question for Alan Morgan. He was diagnosed with the hepatitis C virus seven years ago after a routine medical examination.

(Footage of Alan Morgan playing tennis.)

[...]

Alan Morgan: It's given me the opportunity, I suppose, to look forward into the future and start to create a life again and start to build a career and start to look forward to, actually, a retirement...a healthy retirement.

(Image of Alan Morgan, wearing tennis whites, seated out of doors.)

[...]

Jacinta Tynan: But Alan is one who's benefited from the research, living proof to thousands of other people with hepatitis C that it may not have to be for life.

(Footage of Alan Morgan playing tennis: wide shot of Alan and tennis partner followed by close-up of Alan playing.)

Alan Morgan: If it changes, well, we go maybe back to the drawing board and start again and go through the whole cycle again, but I'm convinced that it's gone and I doubt very, very much that it would come back.

(Footage of Alan Morgan, wearing tennis whites, seated out of doors. Cuts to Alan walking up to the tennis net towards his tennis partner; he is smiling.)

Kerry O'Brien [compère]: Good reason for optimism, it seems.

(Kerry O'Brien seated in studio, speaking to the audience.)

Figure 10. Excerpt from “Hepatitis C Increasing to Epidemic Proportions”: Properties of “ordinary” Australians

Source: *7.30 Report*, ABC television, February 28, 2000.

Although causality is not considered in “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), other news stories report on the “shame” attached to contracting hepatitis C via injecting drug use. In the *Herald Sun* story, “The Hep C Untouchables”, for instance, readers are told that in her youth Carmen Jones “sabotaged” her own health by injecting drugs (Van Den Nieuwenhof, 2001, p. 18). Jones is presented as someone whose past has caught up with her: “Long after she had

cleaned up her act and ceased taking drugs...put her wild past behind her...her careless transgressions came back to haunt her" (p. 19). Similarly, in "Hepatitis C Thrives in Jail" (Murphy, 2001), broadcast on ABC television's *7.30 Report*, Lisa Waller is described as having a "brief flirtation with drugs years ago [that] has returned to haunt her". News actors such as Jones and Waller move beyond the stereotypical media portrayals of "drug addicts" that Faye's (2000) informants spoke of, and beyond the portrayals of "otherness" identified by Krug (1997). Waller and Jones tell the reading or viewing audience that people who inject or injected drugs could be our mothers, fathers, co-workers, or employers.

Injecting drug use in such stories is portrayed as an indiscretion, a temporary aberration or digression that may occur in the life of otherwise "active and solid citizens". No longer injecting drugs, Jones works as a social worker, is raising her daughter as a single mother, is buying her own home in a fashionable Melbourne suburb, has a financial portfolio and enjoys going out with her girlfriends after work. Jones is held responsible for becoming infected with hepatitis C, and her subsequent health problems. Finding out that she had hepatitis C threatened to disrupt Jones's successful adult life, as did the symptoms of the disease. The notion of the "reformed drug user" in this text implies that Jones underwent a change in the way that she used and marked her body. Following her diagnosis with hepatitis C, she effected yet another change in her lifestyle to ameliorate the physical effects of the virus. She took responsibility for her health once again. The story hints at future psychological growth and change as Jones deals with the social stigma attached to the disease, a stigma that is her personal "burden".

The analysis of the portrayals of Jones and Waller imply something about the audience of the "Hepatitis C Increasing to Epidemic Proportions" (Tynan, 2000) in this case study. The reformed drug user is accommodated by the news media within representations of middle-class Australian life that includes a period of experimentation or "dabbling". Van Den Nieuwenhof (2001, p. 21) reporting for the *Herald Sun* characterises reformed drugs users as

men and women who are in responsible jobs, have young families and mortgages...Says one doctor: "I commonly see patients in their late 40s and early 50s who are now well established in life and prosperous, working in the private sector with family responsibilities and in every way they are conventional citizens".

The ABC story “Hepatitis C Thrives in Jail” (Murphy, 2001) makes the same point. In this text Waller tells viewers:

I went on to further study, to build a career, you know, to achieve all of those things I think people want. I’ve travelled. I’ve got a really happy, really loving relationship. I’ve got a great job.

The normality of Jones and Waller’s lives following their successful “reformation” echoes that which Morgan aspires to after being cured of hepatitis C.

Such men and women as Jones and Waller, described above, provide a point of identification for the audience of the *7.30 Report* text “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) of this case study. They and others like them are the audience that the *7.30 Report* addresses. The audience includes those whose patterns of lifestyle and behaviour accommodate injecting drug use as a transient and discrete part of their lives. Such viewers are not the injecting drug users Dr Roberts says are stereotypically associated with hepatitis C. In a society that is moving away from the direct provision of welfare by government towards what Saunders (2003) terms a “privatised mode of consumption”, members of this audience are expected to be self-reliant, assuming responsibility for almost all aspects of their lives and making provision for themselves.

By contrast, in the preface to, *Dealing with Risk: A Multidisciplinary Study of Injecting Drug Use, Hepatitis C and Other Blood-Borne Viruses in Australia* (Dealing with Risk), Professor Margaret Hamilton (2003, p. x)—executive member of the Australian National Council on Drugs—writes: “Unlike me, the injecting drug users studied are economically and socially marginalised”. The qualitative cases studies in *Dealing with Risk* portray people who inject drugs and are hepatitis C positive as living in poverty, living a “precarious existence” and in “dire circumstances” (Southgate, et al., 2003, p. 88). The normative construction of Australian society of the *7.30 Report* “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) and of texts like the Herald Sun’s “The Hep C Untouchables—One Every Hour” (Van Den Nieuwenhof, 2001)—discussed briefly—seems well outside the reach of those who participated in the research reported in *Dealing with Risk*. Moreover, current or past injecting drug users who are not “responsibly” supporting or contributing to the economic support of a household are not addressed as part of the viewing audience of the text of “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000). The exclusion of particular voices in communicative events contributes to the marginalisation of specific groups of people

(Van Dijk, 1993, p. 260). The middle-class profile of the viewing audience of this 7.30 Report story excludes many injecting drug users who are hepatitis C positive. Not speaking to a particular audience may also constitute a form of “communicative discrimination”—a term borrowed from Van Dijk.

The relational value of the 7.30 *Report* “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) represents everyone infected with the hepatitis C virus as being the same. Grouping all hepatitis C sufferers together risks putting them in the same circumstances. What this ABC text claims about the generic hepatitis C sufferer and the audience may not hold for all individuals living with the virus, particularly those who are currently injecting drug users. The text in this case study, however, does not address the circumstances of people’s lives beyond the impact of symptoms of the disease. As noted in the previous discussion of the subject position of actors in this ABC text, the tennis match—itself a middle-class sporting and social activity—is a visual metaphor for Morgan’s cure and return to life. The audience can infer that Morgan returns to work just as he returned to playing tennis, and that such circumstances are available to others infected with hepatitis C. It is an unproblematic and idealistic portrayal.

This study has only touched upon the “new life” that the news media says awaits those who undergo treatment for hepatitis C. I can only speculate that such a life may not accord with the aspirations and expectations of many Australians living with the virus, particularly those who are currently injecting drugs and living in poverty. More research into this disparity is required.

Institutional and Societal Processes: “Pseudo-Participation” of Health Consumers in the Marketing of Medical Treatment

*“I’ve thought about going on treatment but I can’t do that to myself. I couldn’t poison myself with a treatment which, to me, is relatively unproven, with a really low success rate. Because I’m a 1B, which doesn’t respond so well to treatment, and that from what I can understand the virus doesn’t necessarily sustain a response. You know, the research figures are based on six-months after treatment finishes not on 12-months, 18-months down the track. I don’t think that’s an option at all. I don’t see treatment as an option...I couldn’t put myself through something that I don’t believe in. I’m just anti-drugs, medical drugs. You still have to have one of those bloody awful biopsies, liver biopsy, you can’t get into any program without that. I really don’t like the idea of one of those...I just have this distrust of the medical profession and **those** big drug companies...I’m constantly trying to find ways to get rid of it, slow it down, or alleviate the symptoms, so that it’s there but it’s not a big deal. And that’s the story that sort of comes out with a lot of people at support groups too. They’ve done all that sort of stuff, they’ve tried the Chinese herbs, they’ve tried this, that, and the other thing, and in the end nothing’s worked and they’ve thought, ‘Well, I’ll just have to give Interferon a go.’ And maybe that’s what I’m doing. I haven’t quite eliminated all the other things yet and I’ll get so desperate, so desperate.”*

– Carol, Interview, April 2003

The 7.30 Report story “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) broadcast on ABC television offers a particular a view of Australian society through its portrayal of the social relationships between doctor and patient, and the status and power of each. The discourse in this text belongs to particular institutional and societal processes, and is ideologically determined and ideologically determinative (Fairclough, 1989, p. 192; Saunders, 1993, p. 39). Many perspectives of the way the world is are “taken-for-granted” or considered “natural”. Such assumptions inform the way in which people view themselves, and their position in relation to others, and conventionally behave in relation to others in various contexts. Hence, the analysis of texts involves consideration of the power relations within social relationships, and identifying the status of various actors (Fairclough, 1989, p. 2; O’Shaughnessy & Stadler, 2002, p. 191; O’Sullivan, Harley, Saunders, Montgomery & Fiske, 1994, p. 140; Saunders, 1993, pp. 49–50; Wetherell, 2001, p. 286).

Grace (1991) traced the parallel of health promotion discourse with that of marketing in New Zealand in the 1970s and 1980s. Based on a set of qualitative interviews with individuals working in health promotion, Grace found that the construction of the individual as a “health consumer” by health promoters created a situation of “pseudo-participation” by the consumers. In Grace’s model of consumer capitalism, health and public health professionals are in a position of control, determining population health “needs” and selling “health”. The consumer is positioned as an individual customer with freedom of choice (pp. 334–335).

Medical specialties in Australia struggle for a share of government funding and support. In “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) journalist Kerry O’Brien introduces the notion that funds for public health are in short supply when he tells the audience: “When it comes to the deadly blood borne viruses, HIV, of course, receives much of the attention and funding”. There is an evangelical quality to the portrayal of Dr Roberts as he tries to persuade the audience (and the Government) to support his call for funding for hepatitis C medical research and treatment programs. His participation in this story has a strategic purpose. It is an example of the way in which the medical profession uses the broadcasting medium as a vehicle for swaying public opinion about an issue, namely, funding for hepatitis C research and treatment. Dr Roberts implies that funding is imperative, a matter of need, when he says:

We know, however, there are a lot of other groups as well who have developed this infection and that the large numbers of Australians who have evidence of hepatitis C can only make people realise that it is a major health problem and that more dollars need to be spent in this area.

In the context of scarce resources that are apportioned to different parts of the public health sector on the basis of need, it is often professionals who use the media to tell the public what the community’s health needs are (Grace, 1991, pp. 337; 340–341). Professionals can be expected to try to persuade the viewing public to their way of thinking (Van Dijk, 1993, p. 254). Dr Roberts essentially appeals to taxpayers in the audience to fund hepatitis C research and treatment programs because they may need treatment themselves. Although patients generally access such treatment programs through the public health sector in Australia as government-funded treatment, this could be regarded in Saunders’ (2003) terms as a transient dependence on welfare, part of the “churning” of individual status and income in an otherwise market-oriented society.

Although a current affairs text, “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) has a research and medical marketing imperative. Multi-centre biomedical research is considered an important means of generating knowledge, and integral to the maintenance of the status of the medical profession in Australia (AMA, 2000, pp. 1–2). The AMA acknowledges and encourages the collaboration between doctors and the pharmaceutical industry in needed, ethical and scientifically valid medical research that does not involve a conflict of interests for its members (AMA, 2002, pp. 1–3). However, product endorsement is fraught with ethical implications for the medical profession. In a position statement, the AMA specifies four main categories of products and services that could be considered for endorsement by its members. The commercial product Roferon[®]-A, which appears clearly on the poster behind Dr Roberts in the story (see Figure 7), falls into the first category listed by the AMA: products used by patients to maintain health (AMA, 1989, p. 1). Product placement is a common marketing and advertising strategy:

Product placement is an alternative to the traditional method of advertising. It is an effective and well established method of developing brand recognition by getting the products featured before the public on prime time television and in feature films...With this form of advertising it is easy to build awareness of a new product or to single out a product in a highly competitive market. (Hollywood International Placements, Inc, 2003)

The placement of the Roche Roferon[®]-A poster as a prop, prominently in frame with Dr Roberts, can be construed as endorsement of this product. It shows viewers that Roche is a major, trustworthy manufacturer of pharmaceutical products for treating hepatitis C.

“Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) bears the influence of advertising discourse in other ways, too. The audience is expected to want to know about new treatments for hepatitis C because statistics show that many Australians are confirmed as being infected with the virus, and many more will find out that they are infected on routine medical-check ups. Informing the public about the science behind innovations in health and medical research is seen by the AMA as integral to the process of maintaining the public’s trust in the medical profession (AMA, 2000, p. 3). The text uses the “profile”, a common type of feature article in advertising (Bivins, 1995, pp. 151–152; 155 & 156). It profiles combination antiviral therapy for hepatitis C drawing attention to the promise of an improved cure rate; listing facts about the number of people infected; the number of new cases; the type of treatment and

monitoring; and calling attention to hepatitis C sufferer Alan Morgan who has benefited from the new treatment. In doing so, the text also calls attention to the medical specialist who heads the Australian research team and creates publicity—whether intentional or unintentional—for one of the pharmaceutical companies that manufacture such drugs.

“Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) also uses Meade from the Hepatitis C Council of Victoria—a NGO—to take the message to the audience (and potential consumers of anti-viral drugs). The media producers have used multiple sources—Dr Roberts (expert), Morgan (hepatitis C sufferer), and Meade (advocate)—to engage the trust of the viewing audience. The construction of this ABC text parallels the marketing strategy espoused by Edelman, the public relations (PR) company for Roche. Based on surveys of “thought leaders” in Europe, Australia, and the United States, Edelman (2001) developed its appreciation of the role of NGOs that informs its model of communication. Richard Edelman, the company’s president and chief executive officer, dubbed NGOs “The Fifth Estate” in recognition of their significant influence and credibility with consumers. Experts like Dr Roberts represent one interest group, along with NGOs and consumers in Edelman’s model of communication termed the “sphere of cross influence” (Edelman, n.d., pp. 8 & 10; Edleman, 2000). Edelman believes that this model—which replaces the hierarchical, top-down pyramid of authority—enables assumptions to be challenged. Nonetheless, when applied to the construction of news media texts, this model of communication flow still sees one perspective privileged over another as outlined in this case study, in keeping with Grace’s (1991) concept of pseudo-participation by consumers.

Pharmaceutical companies like Roche employ PR companies to promote their products. Like the news media, PR companies publish positive comments on pharmaceutical products from experts, a “third party technique” that trades on the status of the expert (Breen, 2004, p. 409; Burton & Rowell, 2003, p. 1205; Mansfield, 2003, p. 645). In October 2003, Edelman Health distributed a media release on behalf of Roche about the listing of Pegasys RBV™ (peginterferon alfa-2a plus ribavirin) on the Pharmaceutical Benefits Scheme in Australia. In this media release, Dr Stuart Roberts, Deputy Director, Department of Gastroenterology at The Alfred Hospital in Melbourne—who features in this case study—attests to the treatment benefits of this pharmaceutical product in the treatment of hepatitis C. President of the AHC, Mr Stuart Loveday, is also quoted as saying:

The availability of the new combination treatment is extremely welcome and should significantly help curb the long-term effects of this serious public health issue. (Edelman Health, 2003)

This media release mirrors the structure of the *7.30 Report* text in its choice of news actors: interviews with Australian medical experts; published medical research from the reputable *New England Journal of Medicine*; a chronic hepatitis C patient who has been treated and now lives “a full and healthy life”; and a spokesperson for the peak body of the Australian hepatitis C councils. It is a stock strategy of offering experts and “real” people, the latter representing the human face of the disease.

As Fairclough (1989, pp. 33–34) would suggest, the alliance between the biopharmaceutical companies and the medical profession and NGOs working in the field of hepatitis C stands to benefit shareholders in such companies through increased company growth and profits. Through seemingly “good citizenship” these same companies maintain a link to the Australian public. For instance, the Hepatitis C Council of Victoria lists Roche as one of the major sponsors of Awareness Week 2002 (Hepatitis C Council of Victoria, 2002a), and its South Australian counterpart listed three pharmaceutical companies—Schering Plough, Roche and GlaxoSmithKline—as major sponsors of its Hepatitis C Awareness Week 2002 (Hepatitis C Council of South Australia, 2002, p. 10).

Helping clients establish trust in their brands is central to the work of the PR firm of Edelman, which represents Roche in Australia. In accordance with its “relationship imperative”, Edelman targets NGOs and doctors amongst the multiple stakeholder groups in its approach to building a market for its clients’ products and influencing its audience (Edelman, n.d.). This was brought home to me when—having identified NGOs with an interest in treatments for hepatitis C—Edelman emailed its media release addressed to me as the editor of the newsletter for members of the HCWA, a NGO (Edelman Health, personal communication, October, 2003). This approach is a recent development, with the 2003 email constituting the second active posting of material by Edelman’s, on behalf of Roche, to the editor of the HCWA’s newsletter. The first round of electronic postings by Edelman to me as editor occurred in July 2003. In this instance Edelman’s account manager sent a media release and abstracts of studies of viral response to combination treatment with Roche’s pegylated interferon plus ribavirin presented at the European Association for the Study of the Liver. Professor Graham Cooksley, a hepatologist at the Royal Brisbane Hospital, was

available for interview regarding these studies (A. Wakefield, personal communication, July 21, 2003). Up until this time, I was unaware of the PR company Edelman. This unsolicited product information spurred me to visit the company's website and find out about it. Edelman extends the marketing technique outlined by journalists Burton and Rowell (2003, p. 1206) in which PR companies recruit and train

“key opinion leaders” to speak on behalf of the sponsoring pharmaceutical company. Their role at conferences, for example, can span everything from presenting papers to fielding questions in open conference sessions.

The inclusion of HCWA as a stakeholder in Edelman's marketing strategy assumes that the HCWA and other organisations representing people living with hepatitis C in Australia provide an indirect route to the consumer. The practice of building relationships with self-help groups and support organisations by pharmaceutical companies in order to advance market expansion and influence policy-makers has come under scrutiny in the United Kingdom (Burton & Rowell, 2003; Herxheimer, 2003). This has seen the Long Term Medical Conditions Alliance develop guidelines for self-help and patient support organisations collaborating with pharmaceutical companies in the United Kingdom (Herxheimer, 2003, pp. 1208–1210). A comparable umbrella body in Western Australia (WA), the Health Consumers' Council, however, has not published a policy or guidelines in this area. Although individual NGOs such as the Hepatitis C Councils of Victoria and South Australia, previously mentioned, acknowledge their major sponsors for particular events, further research is required to ascertain the standards of disclosure for sponsorship and funding applied in the NGO sector as a whole.

The overall structure of “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) resembles an information advertisement, borrowing from the discourse of marketing. In effect, the profile in this text constructs a narrative about the health benefits of complying with traditional western medicine as discussed in relation to the subject position of the audience. It is a story of renewed health, a cure for a debilitating and so-called deadly disease. This is brought about by advances in research-based medical practice and the development of a treatment that attracts investment from the pharmaceutical industry. The text offers the audience two dominant sets of images, the high-technology medical research and treatment and the hepatitis C sufferer playing tennis, which together construct the narrative. The images of Morgan playing tennis

imply and normalise a middle-class life: friends and family; a career; the individual earning his/her own livelihood; and planning and living a healthy retirement. A cure for hepatitis C offers the promise of a transformation of the sufferer's material condition. The text contains the common-sense assumption that all people with hepatitis C will want to be treated.

The images of Dr Roberts as the professional doctor in the garb of the research scientist and that of the consultant, and those of various technicians at work in laboratories, instil confidence and trust in the audience. The text does not tell the audience exactly what the technicians are doing. Rather it shows images or signifiers (O'Shaughnessy & Stadler, 2002, pp. 80–84) of technicians dressed in protective clothing and working in protective cabinets, manipulating solutions, pipettes, vials and a range of computerised machines. These images carry connotations of scientific inquiry, advances in medicine, innovative clinical research, expertise, and authority. The images also convey a sense of the level of resources that need to be allocated to achieve advances in the treatment of hepatitis C.

Considering this discourse as part of societal processes (see Fairclough, 1989, pp. 194–196) it is evident that the relationship of medical practitioners to their patients, and to the public generally remains a matter of control and authority. There have been changes to medical authority and a loss of confidence in institutions in Australia as in the US, the UK and Europe (Lombardo, 2000; Seale, 2002). There has been growth of the consumers' voice in health care evidenced by state-based organisations such as the Health Consumers' Council in WA and national organisations like the Consumers' Health Forum of Australia. The representation of consumers on government, industry, professional, and NGO committees reflects adherence to an ideology of consumer participation. It assumes that consumers are on an equal footing with medical experts by virtue of their experience(s) rather than knowledge or technical expertise in medicine and/or research. But as this case study shows, the relational modality between medical expert and patient may still indicate unequal power relations, though less explicitly expressed.

Looking at the position of hepatitis councils in Australia, there is some acknowledgment of their influence in the health sphere. Recognising the rise of the consumer group—the NGO—has been critical to institutions such as medicine, government, news media, and marketing. Consumer advocacy in the field of hepatitis C is contained within the parameters of health and public health set down by experts in

Australia. NGOs are also the focus of the current model of communication and the marketing strategies put into effect by PR companies on the behalf of the pharmaceutical industry. Further research is required to determine the extent to which concessions to the strength of NGOs in the field of hepatitis C have made gains for people living with the virus.

Krug (1997) found that although representatives of community groups appear in media stories about hepatitis C, their “testimony” on behalf of those affected by the disease is always “backed up” by medical experts. This analysis of the *7.30 Report’s* “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000) demonstrates that news actors drawn from hepatitis C support groups may be utilised by media producers to back up or endorse the testimony of medical experts. This mirrors the current marketing strategies of PR companies like Edelman which have moved away from the “old” pyramidal model of information dissemination to a “circle of cross influence” (Edelman, 2000), involving NGOs which have credibility and the trust of consumers.

Conclusion

Media stories about hepatitis C reflect the medicalisation of the disease—it is subject to medical control and technologies (including treatments). Medical experts, academics and researchers in the field of hepatitis C and spokespersons for government advisory bodies define the disease and construct the messages about hepatitis C in Australia. The *7.30 Report* “Hepatitis C Increasing to Epidemic Proportions” (Tynan, 2000), discussed in this case study, hangs on the news peg of a breakthrough in medical treatment for hepatitis C. Hepatitis C is constructed as a disease: the virus is contagious and the disease is life threatening. The prevalence and virulence of the hepatitis C virus is compared to that of HIV and found to be greater. Hepatitis C is portrayed as an infectious disease that, through neglect by public health planners as much as its inherently robust viral characteristics and infectious nature, is set to cost many Australians who live with the virus and the community generally.

This case study elucidates the discursive strategies that maintain the position of power attributed to doctors in Australia. The genre and conventions of the current affairs story largely predetermine the shape of the story. The media producers orchestrate the subject positions and social hierarchy of news actors to construct a story in which the medical perspective is dominant, and traditional relations of power

between doctors and their patients are maintained. The representative of the NGO and the patient contribute to this dominance along with the doctor.

High-technology pharmaceutical treatment for hepatitis C is portrayed as the norm and desirable as it is associated with sufferers regaining their health, ability to work, and improved prospects for the future. The notion that all people infected with the hepatitis C virus will desire and seek treatment is taken-for-granted. The alliance between the biopharmaceutical industry and medicine and NGOs is left unquestioned. The text is oriented to a middle-class viewing audience—*not* socio-economically marginalised IDUs—who are in a position to appreciate the testimonial to biomedical and biopharmaceutical research and development.

CHAPTER TEN

CONCLUSION

This study has addressed a gap in research on the sociocultural context of living with hepatitis C in Australia through an analysis of representations of hepatitis C in current public health policy and selected news media texts produced by the institutions of public health and the media. The texts examined were the first national hepatitis C strategy, the *National Hepatitis C Strategy 1999–2000 to 2003–2004* (the *Strategy*) produced by the then Commonwealth Department of Health and Aged Care (2000b), and news stories about hepatitis C published by three media institutions—the Australian Broadcasting Corporation (ABC) news services, *The Australian* and the *Herald Sun*—from 1996 to 2003. The *Strategy* represents the official discourse of hepatitis C in Australia, and is the building block for subsequent population health strategies. The *Strategy* formalises the language for talking about the virus and people affected by hepatitis C. It also sets the form for interactions between governments, medical, scientific and health care professionals, and between these professional communities and people living with hepatitis C.

The analysis of the *Strategy* and the news texts examined confirm previous studies by Krug (1995), Hepworth and Krug (1997), and Krug and Hepworth (1999), that the institutions of public health and the media in Australia legitimate the dominance of biomedical discourses, which frame hepatitis C as an infectious disease. These institutions do so by including something of the objectives, interests and concerns of the hepatitis C-affected community. The collection for this study of a small number of interviews of persons living with chronic hepatitis C infection sheds light on other perspectives of hepatitis C that do not fit the dominant biomedical perspective evident in the *Strategy* and news media texts. The purpose of this study was to examine the discourses of hepatitis C evident in the aforementioned texts. The scope of the study was managed by focusing on those aspects of the texts related to the participation of the hepatitis C-affected community in policy development and the production of news texts.

This chapter presents the conclusions of this study, some directions for further research, implications, and recommendations of this study—particularly for hepatitis C non-government organisations (NGOs). The summary of findings focuses on the five research questions that guided this study:

- How are hepatitis C and people living with hepatitis C represented and constructed in Australian public health policy and the Australian news media?
- What is the dominant narrative in texts?
- What message(s) about hepatitis C are communicated in texts?
- Whose interests are involved in constructing these messages?
- What normative ideas about hepatitis C are expressed?

In this study, hepatitis C is not taken to be solely a bloodborne virus transmitted through blood-to-blood contact that may lead to progressive liver disease. Hepatitis C is also considered a socially constructed concept, to which the producers of public health policy and news media texts attach sets of beliefs and values that can be contested and altered. Experiences and understandings of hepatitis C differ from one group of stakeholders to another. The focus of this study is on the meanings of hepatitis C represented in the first national hepatitis C strategy in Australia, and in selected news media coverage of the “hepatitis C epidemic”.

The *Strategy* and the news texts about hepatitis C that were analysed for this study were deliberately constructed. As Fairclough’s (1995b, p. 18) work informs us, choices were made as to how to represent the hepatitis C epidemic, those living with hepatitis C, and those at risk of hepatitis C infection. The producers of these texts made choices about genre, and how to address their respective audiences. Importantly, they also made choices about what to omit, and whose voice(s) to omit, from a given text. Critical discourse analysis opens the way for hepatitis C-NGOs to recognise the constructed nature of public health policy and news texts. Such texts establish the authority of scientific and biomedical discourses about hepatitis C, in which professionals speak for and about hepatitis C-positive people.

In the foreword to the *Strategy*—the *Foreword* (Wooldridge, 2000a)—discussed in Chapter Three, the hepatitis C epidemic and the affected community are represented as a problem, with injecting drug use in Australia at the core of the hepatitis C epidemic. Hepatitis C is described as a *danger* to the Australian community, for those infected with the virus and those at risk of infection (as detailed in the analysis of media representations in Chapter Eight). The *Strategy*, too, emphasises that hepatitis C as an infectious disease poses real dangers (see Chapter Seven). The then Minister for Health and Aged Care, Dr Michael Wooldridge, also refers to the hepatitis C epidemic as an economic burden. He depicts it as a *challenge* to the professional reading audience from the scientific and medical communities and public health—an invitation to test their intellectual abilities. As discussed in Chapter Six, the hepatitis C epidemic is also cast as intractable in the *Strategy*, given the resource-poor circumstances of the public health care sector (particularly outside metropolitan areas), and the discriminatory behaviour of health care workers towards injecting drug users (IDUs). Reflecting the genre of the political speech, the *Foreword* is a carefully constructed text that calls for action by sectors of the Australian community. The Minister is careful to persuade lay readers that a problem exists, briefly outlines the solution, and argues his case. Addressing his primary audience of professionals, the Minister also establishes his authority and issues commands. The *Foreword* indicates that the Minister looks to the scientific and medical communities to deal with the hepatitis C epidemic. In doing so, though, professionals are expected to engage with the hepatitis C affected community in a partnership. However, in the *Foreword* as in the *Strategy*, people living with hepatitis C are constituted as objects and bearers of the virus and the disease. The hepatitis C epidemic is framed as amenable to scientific, biomedical, and managerial interventions.

As discussed in Chapters Three and Five, the rhetoric of “partnership” that pervades the *Strategy* (and its foreword), belies the controlling and constraining nature of the rational, problem-solving approach taken to policy-making. The *Strategy* reflects a process of policy-making that publicly considers and includes stakeholders affected by the policy. However, the institutional sites from which the discourse derives is predominantly those of the biomedical sciences (including epidemiology and public health). This was considered in relation to Lowe and Cotton’s (1999) review of Australia’s response to hepatitis C, which was closely followed by the *Strategy*. Community consultation is but a step in the process of identifying areas for action by the professional community. The selection of advisors and contributors framed the

review process undertaken by Lowe and Cotton, the content of their report, and the subsequent *Strategy*, from the perspective of the “expert”, in particular, professionals from public or population health (particularly, diseases control and population health planning), medicine (including medical research), and academia. Biomedical, bureaucratic, and academic representatives far outnumbered groups and individuals representing those living with hepatitis C in the development of the *Strategy*. Hence, the consensus reached by participants in determining a solution to the problem of the hepatitis C epidemic can be described as selective. However, any discrepancies among the points of view that make up the consensus in the development of the *Strategy* are absent from the text. Instead, the notions of “community” and “partnership” suggest common goals and exclude different discourses (whether from the heterogeneous hepatitis C-affected community or the biomedical community).

Moreover, information and knowledge derived from the experiences of those living with hepatitis C was ratified by experts. Professional, expert knowledge about hepatitis C is privileged over that of hepatitis C-positive persons. Evidence-based policy that relies heavily on, and values, scientific evidence and expert evidentiary sources (favouring biomedical data, particularly epidemiological and clinical data) is preferred. Not surprisingly, the bulk of Government spending on hepatitis C research follows suit (as outlined in Chapter Seven).

In Australia NGOs authorised to speak for the hepatitis C-affected community have been co-opted into the process of expert management of those living with hepatitis C. Such community groups represent the affected community on bureaucratic committees such as the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH) (often via their peak body). However, the descriptive representation (see Pitkin, 1967 cited in Contandopolous, 2004, p. 322) of these hepatitis C-related governance and advisory structures is limited, favouring the perspective of the medical, scientific, and public health managerial communities. Community representatives are on the periphery of networks—social and bureaucratic networks at the upper level—that influence hepatitis C policy-making, and the monitoring and evaluation of the implementation of such policy. This situation is further complicated by unexplored questions about the composition and representativeness of the NGOs that speak, and act, for those living with hepatitis C. In either case, the bureaucratic networks established to respond to the hepatitis C epidemic in Australia, which are dominated by expert and managerial voices as outlined in Chapter Three, are

likely to make hepatitis C-related policy-making resist any deviation from the existing consensus (see Hanney et al, 2003, p. 8).

As discussed in Chapter Four, the *Strategy* is a blueprint to guide professionals dealing with the hepatitis C epidemic and the hepatitis C affected community. It is an expository text that is highly prescriptive. The problem(s)–solution(s)–argument(s)–authority put forward in the *Foreword* is visually represented in the *Strategy*. The formality, convention of design, and whole-text language organisation of the text reinforce this purpose. Such aspects of the text contribute to the representation of the Government as efficient, effective, accountable, and transparent in its actions. The *Strategy*, though, can also be used as a guide by NGOs. In this regard, NGOs contracted to deliver hepatitis C-related public health services are expected to conform to the professional practices of public health—particularly evidence-based practice and performance measurement associated with the strategic-oriented model utilised by the public sector (see also Chapter Five). As outlined in Chapter Six, privileging what can be seen and measured as legitimate—over what is spoken, heard, and felt or intuitive—may restrict the enterprise of NGOs representing people living with hepatitis C, and overlook the lived experiences of individuals. This study collected a small sample of stories of individuals living with chronic hepatitis C, drawing my attention to the absence or neglect of, for example, alternative narratives in public health discourse and news media discourse on hepatitis C.

This study is in accord with previous research by Krug (1997) and Krug and Hepworth (1999) that the interests served by public health and news media texts are primarily those of the scientific and medical communities, rather than the hepatitis C-affected community—particularly hepatitis C-positive IDUs—about whom the *Strategy* speaks. As a text in which the virus is spoken about, and people with hepatitis C are spoken for and about, the *Strategy* reflects the exclusion of lay people from hepatitis C public health discourse, and the dominance of the professional perspective. In Chapter Four this was shown in regard to the conventions of public health policy writing. In Chapter Five it was shown in relation to Shiell's (1998) economic analysis commissioned by the Department to inform the development of the *Strategy*, one of its "source communicative events" (Fairclough, 1995b, p. 37; 2001, pp. 254–255). In Chapter Seven it was shown that the organising structures of the text reflect a medical perspective, with its predilection for war metaphors. More generally, the producers of the *Strategy*, as in its foreword, chose not to include the voices of those living with

hepatitis C. The third-person narrative constructs an authoritative perspective framed primarily by scientific research from the biological and clinical sciences, and epidemiology, rather than from the experiences of those living with hepatitis C, with the latter appearing lower in status than the former. This is especially telling when surveillance to know the hepatitis C epidemic, and people at risk, is spoken about in the *Strategy* as detailed in Chapter Seven.

As with the *Strategy*, the production of news media texts examined reflect a relatively stable set of discursive practices. Salient aspects of the news-making practices and the generic form of programs such as the ABC's *7.30 Report* are sufficiently stable that they contribute to the reproduction of traditional power relations between experts and the lay community. Producers of news texts control the topic, orchestrate the contribution of news actors, and use formulaic elements to represent the narrative (see Fairclough, 1995b, p. 23). These are highly structured techniques that cue possible interpretations by audiences (readers, viewers, and listeners). As seen in the critique of the *7.30 Report*, "Hepatitis C increasing to epidemic proportions" (Tynan, 2000), in Chapter Nine, news texts also speak to the audience as potential consumers of hepatitis C-related health care services, and pharmaceutical products.

As detailed in Chapter Nine, journalists rely on a limited and predictable set of sources in their coverage of hepatitis C in Australia, in particular, medical experts, academics and/or researchers, and government spokespersons. Spokespersons from NGOs representing the affected community and laypersons—presented as typical cases or examples of the person living with hepatitis C—are used as sources to a lesser extent. As noted in Chapter Eight, spokespersons from IDU peer-based groups are rarely called upon to give their opinion about hepatitis C-related issues, and rarely referred to in news media coverage of hepatitis C-related issues. It may be that the larger classification of "community groups" is presumed to subsume IDUs, or IDUs are ignored or excluded by producers.

In the case of the *7.30 Report's*, "Hepatitis C Increasing to Epidemic Proportions" (Tynan, 2000), televised on the ABC, a predictable set of social identities is constructed. This text features a medical expert, a layperson, a spokesperson for an NGO, and journalists. The construction of social relations between these news actors establishes the privileged status and relative power of the medical expert. Traditional hierarchical social relations in the partnership between medical professionals and patients are maintained via the turn-taking of interviewees orchestrated by the program

producers, and the selection of interviewees who viewers are expected to perceive as authoritative, and who exhibit their authority in relation to others in language, dress and action. While this program includes different voices, these voices are ordered in such a way as to privilege the medical perspective. It was shown in Chapter Nine, for instance, that media producers utilise news actors from hepatitis C NGOs to endorse the testimony of medical experts, mirroring the marketing strategy of the PR companies operating on behalf of major pharmaceutical companies.

Alongside the information communicated, the verbal and visual language of the text represents the treatment and management of persons infected with hepatitis C from the medical specialist's point of view (drawing upon classification schemes of biomedical discourse). As in the *Foreword* and the *Strategy*, the patient is the object of medical intervention, expected to follow a plan of treatment and medical management orchestrated by experts from within hierarchical institutional bodies. The text invites the audience to take the job of managing and treating hepatitis C to be the natural work of scientists and doctors, working with compliant patients.

This study found that hepatitis C public health policy texts and news media texts about hepatitis C favour certain narratives and neglect other narratives, and express normative ideas about hepatitis C. There was consistency in the narratives presented by the *Strategy* and the examined news texts. Hepatitis C is constructed as a problem that requires detection, diagnosis, monitoring, treatment, management, and risk prevention managed by the public health care sector (which co-opts the non-government sector to provide specific services). The dominant narrative in the *Strategy* and news stories is one that assures us that we can look to, and trust in, science to solve the problem of the hepatitis C epidemic, tempered by practical-operational considerations (as discussed in Chapter Five).

The narrative event line (Fairclough, 1995b, p. 91) of both types of texts is strikingly similar. It favours middle-class individualism and the "medicalisation of self" previously identified by Krug (1995), with the hepatitis C virus represented as a danger to the infected individual and the Australian community. In this narrative event line the hepatitis C-positive person is depicted as:

- Knowingly or unknowingly infected (via injecting drug use or another event such as receiving a blood product contaminated with the hepatitis C virus);
- Experiencing illness (that can go unrecognised for some time);
- Tested and diagnosed (often inadvertently), and notified to the health department;
- Treated;
- Monitored; and
- Regaining health and returning to active life participation (including returning to work).

The narrative event line also accommodates persons who are hepatitis C positive but not experiencing illness, and those who are inadvertently diagnosed. Such a narrative, though, does not dwell on those who decide *not* to have treatment. The narrative event line reflects the normalising focus of the dominant health paradigm and Australia's individualistic culture (discussed in Chapters Three, Seven and Nine), in which hepatitis C is portrayed as an individual health problem that is increasingly amenable to treatment (that is, scientifically tested and proven high-technology pharmaceuticals and diagnostics). Individuals living with hepatitis C—including those who experience wellbeing and IDUs—are expected to accept responsibility for their own conduct and health; be independent and self-reliant; exercise self-control and self-care; and undertake self-surveillance.

The brief consideration of personal narratives in this study alerted me to alternative narratives that can be read as counter to the medicalised perspective of hepatitis C. In Leanne's case, hepatitis C-positive persons can be constructed from an eco-feminist perspective. Such a perspective encourages those living with the hepatitis C virus to subject the dominant discourses of hepatitis C to critical examination. Leanne's narrative indicates that some people are capable of living with the virus in a reasonable state of health without undergoing antiviral treatment to be rid of the virus. Moreover, Leanne intentionally constructed and narrated her experiences to incorporate the disruption by chronic hepatitis C infection. As such, Leanne offers a challenge to the dominant health paradigm—the latter with its economic imperative for treatment to

contain the disease—which parallels the approach of “resilience” promoted by Galbally (1996) discussed in Chapters Five and Six.

The vocabulary of news media representations, discussed in Chapter Eight, commonly casts moral judgments about IDUs as “guilty” of polluting or tainting the national blood supply (or sources of such contamination), and those who acquired the virus from infected blood as “victims”. However, there was evidence of the construction of the hepatitis C-positive individual in the *Strategy*, and in selected news texts, which accommodates the reformed and transformed IDU. In keeping with its inclusive brief, the *Strategy* also accommodates injecting drug use while not condoning it. It positions IDUs within the highly regulatory discourse of “Responsible IDUs”. Such discourses construct the social identity of the responsible IDU predominantly through the moral imperative to control risky behaviour. In so doing binary opposites are created such as the “Responsible IDU/Irresponsible IDU”, and practices such as “Safe Injecting/Unsafe Injecting”. Knowledge produced by experts through research in the biomedical sciences and, to a lesser extent, the social sciences, is used to construct ways of behaving for the hepatitis C positive person, and particularly, the hepatitis C-positive IDU. The hepatitis C-positive person is represented in such a way as to fit with the requirements of governments, public health, medicine, and the pharmaceutical industry, all of which have an investment in the construction, regulation, and control of subjects (see, for example, discussion of the “pseudo-participation” (Grace, 1991) of health consumers in the marketing of medical treatment in Chapter Nine). With their unique access to IDUs, peer-based IDU groups are co-opted as service providers to help produce disciplined, responsible IDUs, thereby controlling people’s behaviour and containing the disease (as discussed in Chapter Six). It is argued that “participation” is more a strategy to get hepatitis C-positive people to undertake treatment rather than indicative of a shift in power relations in their favour. Moreover, while national public health policy advocates an inclusive approach to disease prevention and control, a communicable diseases framework based on a medicalised perspective of public health, overshadows issues of social justice and equity.

Directions for Further Research

Four main areas for further research emerged during this study. Further analysis of the composition and representativeness of key stakeholder groups, and the level of participation in decision-making and hepatitis C-related public health policy-formation processes by people living with hepatitis C is warranted. The impact of governance by public health institutions on the operations of hepatitis C-NGOs is another area that provides scope for study (for example, “critical ethnographic” research (Fairclough, 1995a, p. 10)). This study also points to the need for further research in relation to the wellness/illness experiences of people living with hepatitis C, encompassing interrelationships with body, self, space, time, and others. Finally, the biopharmaceutical industry’s relationship with the medical community, and hepatitis C-related NGOs, requires further study.

Issues identified in these discrete areas for further study include the following:

- The nature of the hepatitis C-affected community, and the extent to which the hepatitis C-affected community can be regarded as a collective subject and a “competent community” (Coveney, 1998). Exploration of the differences within this heterogeneous community is warranted;
- The formal, descriptive and symbolic representation of governance and advisory structures intended to respond to the hepatitis C epidemic;
- The characteristics of NGOs and peak bodies representing the hepatitis C-affected community in governance structures and partnerships;
- How NGOs in Australia, such as hepatitis C councils, undertake symbolic and political work to objectify their status as legitimate representatives of all people living with hepatitis C;
- How the *Strategy* (and the second hepatitis C strategy)—as a document—affects the organisational decisions and actions of hepatitis C-related NGOs;

- The impact of funding arrangements for contracting NGOs to deliver public health services—within a public sector that utilises a strategically-oriented model for performance measurement—on the work of the respective NGOs. In particular, the impact of funding arrangements on NGOs’ advocacy on behalf of the hepatitis C-affected community (including those who express difference to, or disagreement with, the funding bodies).
- The impact of the anticipation of illness—in the space, or temporal gap, between diagnosis and future illness—for those who are diagnosed with hepatitis C but otherwise well.
- The impact of space and place in the delivery of health services to hepatitis C-positive individuals, particularly, IDUs;
- The level, and characteristics, of participation by hepatitis C patients in the health care team;
- The impact that the sponsorship of clinical research—such as hepatitis C treatment trials—by the biopharmaceutical industry has on medical practice; and
- The relationship between NGOs and pharmaceutical companies marketing hepatitis C treatments, and the standards of disclosure for the sponsorship and funding of the hepatitis C-NGO sector by the biopharmaceutical industry in Australia.

Implications

This study’s findings have implications for the development of hepatitis C public health policy and the production of news media stories about hepatitis C in Australia, particularly for NGOs representing the hepatitis C-affected community. The *Strategy* does not, for example, encourage readers to attend to the way in which persons living with hepatitis C understand themselves. However, it does provide a sense of how they are placed within relationship to others.

Terms like “partnership” and “community participation” have become everyday terms in institutional rhetoric that disguise the diversity within and between groups addressed by the *Strategy*. Members of the partnership are expected to have common

aims or views but there is no guarantee of changes in practice flowing from such rhetoric. The Department specifies “consultation” and “joint decision-making” as mechanisms for developing partnerships and involving affected communities but, as the Australian Hepatitis Council (AHC) (2002) recognised, it does not delegate its authority or hand over control to affected communities. At the outset, I presupposed that power relations are evident in public health policy and news media texts. Indeed, the discourse of “partnership” does not represent a real dispersal of power to the hepatitis C-affected community. Instead, the management and governance of those living with hepatitis C by the biomedical community is enshrined in the *Strategy*.

In public health policy development that culminates in texts such as the *Strategy*, the production and consumption of texts is not clearly demarcated one from the other. The production of hepatitis C policy health policy involves consumers in the consultation process, and NGO representatives on those committees that oversee the production, implementation, and evaluation of resultant strategies. Such consultation provides an avenue for the exploration of alternative models for responding to the needs of those living with hepatitis C to that of the communicable diseases framework preferred by the majority of stakeholders consulted in Lowe and Cotton’s (1999) review of Australia’s response to hepatitis C. It is recommended that NGOs seek models that put social action dealing with hepatitis C-related discrimination at the forefront of public health policy, and relegate concern for biomedical research and treatment to a secondary position. It is also recommended that NGOs explore alternative configurations of the network of bureaucratic committees and advisory groups via which community groups interact with the Government. Proportional representation, for example, would see greater representation of peer-based IDUs groups, with IDUs speaking for themselves, identifying issues and concerns around hepatitis C, thereby framing problems and solutions from their perspective. This could see, too, a move away from the dependence on biomedical research as the main source of evidence utilised in policy-making.

Central to the *Strategy* is the claim of “partnership” and “community participation” in the development of public health policy. However, as shown in Chapters Six and Seven, the apparent hepatitis C community-centredness of public health policy serves to mask its highly regulatory discursive work to ensure that hepatitis C-positive IDUs become responsible IDUs in ways that are compatible with government-sanctioned public health services such as needle and syringe programs.

This study has shown the way in which public health discourse works to protect the broad interests of non-IDUs in Australian society, and regulate the lives of IDUs from within the institution of public health. Rather than indicating a shift in power relations in favour of hepatitis C-positive IDUs, “participation” is employed as a strategy to get hepatitis C-positive people to undertake treatment in order to contain the disease (as detailed in Chapter Six). NGOs could give closer and more systematic attention to the representations of IDUs in public health policy documents. Peak bodies such as the AHC and the Australian Injecting & Illicit Drug Users League’s (AIVL) could also devise a ratio, and specify stakeholder groups, to address the gross imbalance of medical and bureaucratic representatives to lay representatives—the latter of which are fractured into small groups—on bureaucratic committees that inform hepatitis C public health policy-making to achieve proportional representation (particularly of IDUs). In this way those living with hepatitis C would be able to speak for themselves, and identify their issues and concerns.

The construction of public health policy texts has consequences in terms of the perceived legitimacy and status of knowledge derived from lived experiences. In choosing to be guided by the decisions and advice from “experts” in the field, the Government has a responsibility to ensure that the criteria for those expert decisions are compatible with its stated goal of including the community. This is especially important as it relates to social justice and equity for hepatitis C-positive IDUs. However, the *Strategy* cannot be said to be inclusive of the interests of *all* persons living with hepatitis C. On the contrary, it is exclusive, in the sense that it does not recognise and value a broad variety of ways of understanding living with hepatitis C, nor of understanding drug use. Nor does it encourage its readers to do so, and it is, therefore, potentially normative in its effects. The stories of people infected with hepatitis C are sidelined in this text because they do not fit. Professionals (experts) controlled the contribution by lay people to the production of knowledge about hepatitis C used in the development of the *Strategy*, and its subsequent distribution. As Fairclough (1995a, p. 210) notes, “intertextual analysis...suggests a view of text as choice at a different level of analysis, involving selection amongst options within what one might call the intertextual potential of an order of discourse (i.e. available repertoires of genres, discourses and narratives).” NGOs can push for the Government and its departments (such as population health) to choose different genres, different discourses and/or different narrative(s) that legitimise the experiences of persons living with hepatitis C.

NGOs can continue to bring to debates in the process of policy development research findings from outside of the dominant biomedical perspective.

This study provides impetus for the AHC to augment the criteria by which it judges media texts, and to develop criteria for judging public health policy texts. NGOs should be cognisant of the routine ways in which news media producers construct a news story, and the various “communicative events” (Fairclough, 1995b, pp. 48–49) or “chains of discourses” (Fairclough, 2001, pp. 254–255) that go towards this process. Hepatitis C public health policy documents, press releases from government departments and advisory bodies, and political speeches should not be taken at face value. The AHC should encourage its member organisations to engage with texts in ways that enable them to recognise and resist the processes by which producers of texts construct meanings, which may leave the hepatitis C-affected community open to strategic management by the producers of texts (for example, community representatives used to endorse the testimony of medical experts as discussed in Chapter Nine). NGOs representing people living with hepatitis C could develop a range of skills and strategies—such as critical discourse analysis—for undertaking a critique of government policy and media representations, and use those strategies to counter textual manipulation. Hence, hepatitis C-NGOs should be concerned with how they read public health policy documents and media stories. Fairclough’s (1989) framework for critical discourse analysis provides one such set of strategies for reading texts differently and critically, to arrive at an interpretation. The analysis of the *Strategy* in this study, for instance, provides information for the revision decisions in the process of reviewing public health policy documents. When publicising public health policies to members, the AHC and other NGOs could also develop alternative texts aimed at improving the understandings of lay readers, rather than solely re-printing the summaries provided by the producers of texts.

As I completed this study a conversation with a worker from a peer-based IDU group during a social occasion a couple of years ago came to mind. Phil [name changed] asked me how this study was going, and listened intently as I outlined the gist of my findings. He then told me something about his participation representing IDUs on a state committee concerned with hepatitis C. He said that for many months he had turned up to regular meetings of the committee, which was heavily dominated by doctors and bureaucrats. He said that he felt out of place amongst the other committee members. He also expressed his disconcertment regarding the apparent lip-service paid to involving

IDUs as stakeholders. “Most of the time I don’t know what they’re talking about or why I’m there,” he said, “I could probably follow if I tried really hard but no-one bothers to explain things.” So, he said, he usually chooses not to say anything. The silencing of Phil portrayed in this anecdote brings home to me the context and “reality” in which this thesis is situated, and to which it provides a rejoinder. It is the context of social institutions (such as the media and public health), and the reality of participation by representatives of the hepatitis C-affected community in social networks wherein participation is largely determined by social position and may not greatly transform the traditional power relations between experts and the lay community.

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Appendix A

Text of “Letter to NGOs”

Judith Pugh



Ms Susan Carruthers, Chairperson Management Committee
Hepatitis Council of WA (Inc)
PO Box 8060
Perth Business Centre WA 6849

Dear Ms Carruthers

Re Research flyer as insert to *the C files*

I am seeking your permission to include the attached ‘Seeking expressions of interest’ flyer for my research in the February/March issue of *the C files*.

Please find attached a copy of the abstract of my proposed research, the statement of disclosure for participants and the consent form for your information.

My proposal was peer reviewed. External reviewers Professor Sandy Gifford, Deakin University, and Professor Vera Irurita, Curtin University of Technology, recommended that this research be undertaken.

My research proposal has been approved by the Committee for the Conduct of Ethical Research at Edith Cowan University.

Many thanks for your consideration.

Yours sincerely

Judith Pugh
3rd February 2003

Appendix B

Text of “Expression of Interest” Flyer

The Cultural Construction of Hepatitis C in Australia: Metaphors, Discourse, and Personal Narratives

By Judith Pugh, Postgraduate student, Edith Cowan University

Seeking expressions of interest

I am looking for volunteers to tell their experiences of living with the hepatitis C virus. I am currently studying the cultural construction of hepatitis C in Australia for my PhD studies at Edith Cowan University. I will be looking at conceptualisations of hepatitis C in biomedical writings, public health documents, the media and personal stories.

The public health response to hepatitis C in Australia has been based on medical and scientific models of disease. The biographical, the personal and storied knowledge of hepatitis C takes a back seat.

I want to record people’s stories of living with chronic hepatitis C. Stories are a way that we display our sense of who we are, and present ourselves within our social and cultural world. Research suggests that people living with hepatitis C want to hear or read stories that may help them restore the sense of meaning to their lives.

I hope that this research project will contribute to ways of understanding the individual living with chronic hepatitis C. It should, for example, uncover alternative metaphors to give health professionals other ways of talking about hepatitis C that is sensitive to the way that affected persons represent their bodies.

As previous research has shown that living with hepatitis C tends to be overshadowed by more immediate drug-use related problems in persons who still inject drugs, I would like to interview people who are currently *not* injecting drugs and those who have never injected drugs.

Volunteers will take part in a confidential, audiotaped interview. Your identity will not be made know to anyone but myself.

Anyone willing to be interviewed can contact Judith Pugh on [REDACTED] or by email:

[REDACTED]

Appendix C

Text of “Disclosure Statement January 2003”

The Cultural Construction of Hepatitis C in Australia: Metaphors, Discourse, and Personal Narratives

What is this study about?

This is a doctoral (PhD) study being undertaken by myself, Judith Pug, a student in the faculty of Communications, Health and Science at Edith Cowan University. The purpose of this study is to look at the way in which hepatitis C is portrayed or represented in medical writings, public health policy documents, the news media in Australia, and by persons living with chronic hepatitis C.

What are the expected benefits of this study?

The public health response to hepatitis C has been based on medical and scientific models of disease. The biographical, the personal and storied knowledge of hepatitis C take a back seat.

This research will contribute to ways of understanding the individual living with chronic hepatitis C. It aims to help others to see the world through the eyes of persons living with chronic hepatitis C. This topic and thesis are likely to be of interest to those diagnosed with the virus as well as doctors, nurses, scientists, community-based workers and policy makers. For example, the study will give health professionals (and others working in the field) another way in which they can talk about hepatitis C that is sensitive to the way in which affected persons regard their bodies. This interview is also an opportunity for you to guide others affected by hepatitis C.

How will this study be conducted?

This study has four parts: I will examine biomedical writings about hepatitis C; public health policy documents; print-based news stories and a small number of personal narratives (stories).

The purpose of this interview is to collect your story of what it is like to live with chronic hepatitis C. As someone with hepatitis C you are in a unique position to describe your knowledge and experience of the disease. That’s what this interview is about: your experiences with hepatitis C.

This interview will take between 1 to 2 hours of your time, and it will be tape-recorded. Care will be taken so that you will not be identified personally. Your name will not appear on any

documents, tapes nor computer files. Instead, I will use a pseudonym (alias or false name) in place of your name. I will transcribe this interview myself. Audiotapes will be erased once I have transcribed and analysed the interviews. All data relating to this research will be retained for five years from the date of submission then hard copies will be shredded and electronic copies erased. You are free to withdraw your consent to participate in this study at any time.

Hepatitis C information and support

If you would like to know more about hepatitis C or would like to discuss any concerns that you have with a counsellor, free and confidential one-to-one counselling is available by appointment at the Hepatitis Council of WA (Inc). The Council also runs support groups where you can share experiences with others who live with the virus. Telephone: (08) 9328 8538 Metro; 1800 800 070 Freecall country (Monday to Friday).

For more information about this study

If you would like to know more about this study or have any concerns you can contact:

Dr Arshad Omari, Acting Head of School
School of Communications and Multimedia
Faculty of Communications, Health and Science
Edith Cowan University
Ph: (08) 9370 6549
Email: a.omari@cowan.edu.au

You can also contact the investigator:

Judith Pugh, Postgraduate student
School of Communications and Multimedia
Faculty of Communications, Health and Science
Edith Cowan University
[REDACTED]

Appendix D

Text of “Consent Form”

The Cultural Construction of Hepatitis C in Australia: Metaphors, Discourse, and Personal Narratives

I _____ have read the information in the Statement of Disclosure and any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising I may withdraw at any time. Withdrawing from this research will not affect my membership of the Hepatitis Council of WA.

I agree that the research data gathered for this study may be published provided I am not identifiable.

I understand that I will be interviewed and the interview will be audio recorded. I also understand that the recording will be erased once the interview is transcribed and analysed. The data will be stored for five years, and at the end of that five-year period all records will be destroyed.

Participant: _____

Date: _____

Investigator: _____

Date: _____

(Researcher: keep signed copy; leave unsigned copy with the informant.)

Appendix E

Foreword to Australia's First National Hepatitis C Strategy

Foreword

Australia is leading the international community in responding to the hepatitis C epidemic, and this pioneering strategic document establishes a comprehensive framework to guide future action. Australia is recognised as a world leader in developing and implementing effective population health responses to other blood-borne viruses—and now we aspire to mirror these achievements for hepatitis C. These earlier lessons and experiences provide us with a platform to launch a renewal of our efforts to deal with the serious impacts of hepatitis C within the Australian community.

The hepatitis C epidemic is already well established in our community—more than 200 000 Australians are already infected—and a sense of urgency and momentum is now called for in the next phase of our response to this serious communicable disease. Our knowledge of the factors affecting transmission and progression to advanced illness is evolving, but we cannot defer further action until all the pieces of the puzzle are in place: we must act now, using the best available evidence while still pursuing an improved knowledge base. Responding to the challenges identified in this Strategy will help us to prevent the burden of disease increasing for those directly affected by hepatitis C as well as for the broader community.

The priority areas for action identified in this Strategy have been developed in response to a national population health review process followed by extensive community consultation during 1999; they are also supported by advice from the nation's foremost experts on hepatitis C. The contributions of all participants in these processes, especially State and Territory governments, are acknowledged and much appreciated.

This Strategy establishes an important foundation for action—a partnership between people affected by hepatitis C, governments at all levels, and medical, scientific and health care professionals—and acknowledges the need to work in a collaborative, non-partisan manner with all members of the partnership.

The Strategy also acknowledges that our response to hepatitis C cannot operate in isolation. Accordingly, it stresses the importance of establishing and maintaining operational links with other national population health strategies, in particular those concerned with HIV/AIDS and other blood-borne viruses,

the health of young people, the health of Aboriginal and Torres Strait Islander people, mental health policy, and policies and programs to improve the health of people living in rural, regional and remote areas of Australia.

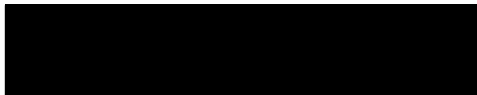
With over 90 per cent of all new hepatitis C infections occurring among people who inject drugs, the increasing use and injection of illicit drugs in Australia will have a powerful influence on the course of the hepatitis C epidemic here. The increased visibility of this serious population health problem has led to growing demand for, and pressure on, harm-reduction initiatives such as needle and syringe programs. In spite of this, preventing further transmission of hepatitis C remains a paramount concern, and these essential prevention measures must be maintained and, more importantly, enhanced. Preventing high risk behaviours such as injecting drug use will also be a valuable contribution to the aims of this Strategy. As a result, links and opportunities for joint efforts will be explored with the *National Drug Strategic Framework 1998–99 to 2002–03*, to ensure that health-promotion messages are well coordinated.

There are significant opportunities for coordinated efforts in many population health areas, particularly education, prevention and research. By situating this Strategy within a broader communicable diseases framework we create the opportunity to ensure that the overall health outcomes achieved are greater than the sum of the individual parts. It is the links between, and the integration of, these responses that will ensure both sustainability and maximum population health impact.

The Strategy has been drafted to operate as a flexible framework for responding to the challenges and opportunities that have been identified, as well as those that will undoubtedly emerge during the Strategy's five-year term. The Australian National Council on AIDS, Hepatitis C and Related Diseases will report to me on the Strategy's implementation and how best to respond to the challenges that have already been identified as well as those that emerge over time.

Successful implementation of the Strategy will depend on cooperation between the Commonwealth and State and Territory governments. The Strategy provides State and Territory governments with the flexibility to respond to the particular demands of the epidemic in their jurisdictions, while at the same time providing a framework for ensuring that consistent national standards are maintained. The Commonwealth will continue its strong leadership role in the Australian response to hepatitis C.

I commend to you the *National Hepatitis C Strategy 1999–2000 to 2003–2004*. It is my belief that this Strategy will consolidate the cooperative national approach to hepatitis C that has already been established and will provide an effective, flexible framework for responding to future challenges the epidemic may present.



Dr Michael Wooldridge
Minister for Health and Aged Care

Source: Commonwealth Department Health & Aged Care (2000b). National hepatitis C strategy 1999-2000 to 2003-2004. Canberra: Publications Production Unit (Public Affairs, Parliamentary Access Branch).

Appendix F

Membership of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis (MACASHH), 4 March 2004

Committee member	Category
Hon Michael Wooldridge (Chair), Former Minister for Health and Aged Care	Medical
Professor Frank Bowden (Chair of HIV/AIDS & STI Subcommittee), Professor of Medicine, Australian National University; Director Canberra Sexual Health Centre, The Canberra Hospital	Medical; academic &/or researcher
Professor Bob Batey, AM (Chair of Hepatitis C Subcommittee), Clinical Chair in Division of Medicine, John Hunter Hospital	Medical; academic &/or researcher
Associate Professor Cindy Shannon	Academic and/or researcher
Ms Angela Assaf	Public relations; managerial
Mr Nicholas Hobson, DFC AFC	General public
Emeritus Professor Peter McDonald AM, Retired Head of Department of Microbiology & Infectious Diseases, Flinders University	Science; academic &/or research
Major Brian Watters AO	Managerial alcohol & drug services;
Chair, National Council on Drugs; previously Commanded Salvation Army's Rehabilitation Services Command	Religious affiliation
Dr Darrell Crawford, Hepatologist Gastroenterology Department and Liver Transplant Unit, Princess Alexandra Hospital, Brisbane	Medical; research
Dr Greg Dore, Senior Lecturer in Epidemiology, National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales; Infectious Diseases Physician, St Vincent's Hospital, Sydney	Medical; academic &/or researcher
Ms Julie Flynn, Chief Executive Officer, Commercial Television Australia	Managerial; media
Professor Sue Kippax, Director, National Centre in HIV Social Research	Academic &/or researcher
Associate Professor Stephen Locarnini, Division Head of Research and Molecular Development, Victorian Infectious Diseases Reference Laboratory	Science; academic &/or researcher
Ms Annie Madden, Executive Officer, Australian Injecting and Illicit Drug Users League	Peer-based organisations for people who use(d) illicit drugs
Father Peter Norden SJ, Policy Director of Jesuit Social Services	Managerial; Social welfare services (policy); Religious affiliation
Mr Jack Wallace, Executive Officer, Australian Hepatitis Council	Hepatitis C-related support / consumer groups
Mrs Judith Wheeldon	General public

Source: Committee members listed by the Australian Government Department of Health and Ageing (2004b).

Appendix G

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Appendix H

Position, Organisation and Category of 23 July 1998 Workshop Participants for Hepatitis C: A Review of Australia's Response (Lowe & Cotton, 1999)

Organisation	Category
A/Director HIV/AIDS and Hepatitis C Section National Centre for Disease Control Department of Health and Aged Care	Public / Population health
Executive Director National Public Health Partnership Department of Health and Family Services	Public / Population health
Manager Drug Strategy and Public Health Social Marketing Branch National Drug Strategy Unit Population Health Division Department of Health and Aged Care	Public / Population health
Director Evaluation and Research Unit National Population Health Planning Branch Population Health Division Department of Health and Aged Care	Public / Population health
Evaluation and Research Unit National Population Health Planning Branch Population Health Division Department of Health and Aged Care x 2	Public / Population health
Assistant Director HIV/AIDS and Hepatitis C Section National Centre for Disease Control Public Health Division Department of Health and Aged Care	Public / Population health
Chair Australian National Council on AIDS and Related Diseases Clinical Trials and Treatments Advisory Committee Flinders University	Advisory body
Australian National Council on AIDS and Related Diseases Working group representative of Salvation Army	Advisory body
Alcohol and Other Drugs Council of Australia	Advisory body
Sexual Health Program Health Department of Western Australia	Public / Population health
Manager HIV/AIDS & Related Programs Unit Communicable Disease Control Branch South Australian Health Commission	Public / Population health
Manager HIV/AIDS Unit Tasmanian Department of Health and Community Services	Public / Population health
A/Manager STD/Blood Borne Virus Program Victorian Department of Human Services	Public / Population health
Manager Infectious Diseases Unit Victorian Department of Human Services	Public / Population health
Principal Program Advisor HIV/AIDS and Sexual Health Section Queensland Department of Health	Public / Population health
Manager HIV/AIDS and Hepatitis C New South Wales Department of Health	Public / Population health
Coordinator, AIDS/STD Unit Disease Control Centre Northern Territory Health Services	Public / Population health
Manager Health Strategies Development Unit Australian National Territory Department of Health and Community Care	Public / Population health
Drug and Alcohol Services Council South Australian Health Commission	Public / Population health; Specialist clinical services
Director Gastroenterology Department John Hunter Hospital New South Wales	Specialist medical
Consultant Gastroenterologist Department of Medicine Monash Medical Centre Melbourne	Specialist medical
Deputy Directory Department of Gastroenterology St	Specialist medical

Vincent's Hospital, Victoria	
Infectious Diseases The Alfred Hospital	Specialist medical
Hepatitis C Nurse Coordinator Fremantle Hospital	Specialist medical
Director Alcohol & Drug Services St Vincent's Hospital, Sydney	Specialist medical
Royal Australian College of General Practitioners Coordinator National Hep C Education Program for General Practitioners	General medical practice
Eastern Sydney Division of General Practitioners	General medical practice
Dental Service South Australia	Other
Economist Department of Public Health and Community Medicine University of Sydney	Academic &/or Research
National Drug and Alcohol Research Centre University of New South Wales	Academic &/or Research
National Centre in HIV Epidemiology and Clinical Research x 2	Academic &/or Research
Deputy Director Centre for the Study of Sexually Transmitted Diseases	Academic &/or Research
Macfarlane Burnet Institute	Academic &/or Medical Research & Public Health
National Centre for Research into Prevention of Drug Abuse, Western Australia	Academic &/or Research
Assistant Commissioner Department of Corrective Services	Corrective services
Health Project Officer South Australia Offenders Services	Corrective services
Manager Offending Services South Australia Offenders Services	Corrective services
Director Kirketon Road Centre	Medical services; Injecting drug use (IDU) services; research; other
Australian Capital Territory Intravenous League	IDU organisation
QUIVA	IDU organisation
New South Wales Users & AIDS Association	IDU organisation
Director New South Wales Cancer Council	Other
Haemophilia Foundation Australia	Consumer / Support group
Executive Officer Hepatitis C Council of New South Wales	Consumer / Support group
President Australian Hepatitis C Council	Peak body (Hepatitis C)
Executive Director Australian Hepatitis Council	Peak body (Hepatitis C)
Australian Federation of AIDS Organisations	Peak body

Source: Workshop participants listed by Lowe and Cotton (1999, pp. 185-187).

Appendix I

Categories of Advisors for Hepatitis C: A Review of Australia's Response (Lowe & Cotton, 1999)

Advisor	Category
Advisory Committee Members	
Professor Bob Batey, Department of Gastroenterology, John Hunter Hospital, New South Wales	Medical; academic &/or research
Mr Steven Hall, Coordinator National Hepatitis C Education Program for General Practitioners, Royal Australian College of General Practitioners	Medical; public/population health
Dr Jim Butler, National Centre in Epidemiology and Population Health, Australian National University	Academic &/or research; public/population health
Dr Aileen Plant, Department of Public Health, University of Western Australia	Academic &/or research; public/population health
Mr Brendan Gibson, Director Evaluation and Research Unit, National Population Health Planning Branch, Population Division, Department of Health and Aged Care	Research; managerial; public/population health
Dr Lewis Marshall, Medical Coordinator of the Communicable Sexual Health Program, Health Department of Western Australia	Medical; managerial; public/population health
Mr Eamonn Murphy, Director HIV/AIDS & Hepatitis C Section, Communicable Diseases and Surveillance Branch, Population Health Division	Managerial; public/Population health
Mr Jack Wallace, Principal Program Adviser Hepatitis C, Communicable Disease Unit, Queensland Department of Health; Executive Director, Australian Hepatitis Council	Public/population health; peak body consumer group
Mr Jeff Ward, President Australian Hepatitis C Council	Peak body consumer group
Ms Michelle Kosky, Executive Director, Health Consumer Council (WA) Inc.; Chair, Australian National Council on AIDS and Related Diseases Hepatitis C Sub-committee	Consumer group; governmental committee
Dr Andrew Penman, Director of New South Wales Cancer Council	Consumer group
Mr Alex Wightman, QUIVA; Australian Intravenous League	Peer-based organisation for people who use(d) illicit drugs
Contributors to Chapters	
Mr Matthew Law, National Centre in HIV Epidemiology & Clinical Research, Faculty of Medicine, University of New South Wales	Academic &/or research
Ms Patty Correll (not specified)	
Mr Justin Rowe, former President, Hepatitis C Council of Victoria; Victorian Hepatitis C Educator & Counsellor 1995-1998	Consumer group
Ms Frances Byers, Evaluation & Research Unit, National Population Health Planning Branch Population Health Division, Commonwealth Department of Health & Aged Care	Public / population health
Mr Alan Shiell, Economist, Department of Public Health & Community Medicine, University of Sydney	Academic &/or research
Ms Catherina van Moort, Evaluation & Research Unit, National Population Health Planning Branch Population Health Division, Commonwealth Department of Health &	Public / population health

Aged Care	
Mr Scott Bowden, Victorian Infectious Diseases Reference Laboratory	Medical / scientific
Professor Stephen Locarnini, Victorian Infectious Diseases Reference Laboratory	Medical / scientific
Ms Margaret Macdonald, Researcher, National Centre in HIV Epidemiology & Clinical Research, Faculty of Medicine, University of New South Wales	Academic &/or research
Mr Alex Wightman, QUIVA; Australian Intravenous League	Peer-based organisation for people who use(d) illicit drugs
Mr Jeff Ward, President Australian Hepatitis C Council	Peak body, consumer group
Coordinators and Advisors	
Ms Frances Byers, Evaluation & Research Unit, National Population Health Planning Branch Population Health Division, Commonwealth Department of Health & Aged Care	Public / population health
Ms Catharina van Moort, Evaluation & Research Unit, National Population Health Planning Branch Population Health Division, Commonwealth Department of Health & Aged Care	Public / population health
Ms Sandy Smith, Department of Health and Aged Care	Public / population health
Mr Chris Puplick, Chairperson, Australian National Council on AIDS & Related Diseases	Advisory body

Source: Advisors acknowledged by Lowe and Cotton (1999).

Appendix J

Topics of News Items on Hepatitis C in Australian Broadcasting Corporation News Services, *The Australian* and *The Weekend Australian*, January 1996 to December 2003 Frequencies*

Ranking	Topic	<i>n</i>
1	National blood supply	59
2	Response by government/health authorities	38
3	Hepatitis C statistics	26
4	Hepatitis C transmission: injecting drug use	20
5	Hepatitis C epidemic	20
6	Report on research	15
7	Attention and funding for hepatitis C	11
7	Hepatitis C drugs: New treatment	11
8	Information: Hepatitis C	10
8	Risk of infection	10
9	Hepatitis C discrimination	9
9	Hepatitis C sentence	9
10	Disease: Liver disease (including prognosis)	6
10	Prisoners: Health	6
10	Medical technology: contaminated instruments	6
10	Stigma attached to hepatitis C	6
11	Occupational exposure: Australian healthcare workers	5
11	Incidents: Syringes	5
12	Expert warning	4
12	Injecting drug users: Health	4
13	Hepatitis C transmission: tattooing	3
13	Hepatitis C sufferers	3
13	Celebrity and hepatitis C	3
14	Injecting drug users: Culture	2
14	Hepatitis C scare	2
14	Conference: Hepatitis C	2
14	Cost to taxpayers	2
14	Body organs: the liver	2
15	Medical knowledge of hepatitis C	1
15	Lay knowledge of hepatitis C	1
	Other	5

*Up to five topics were coded for each news item.

Appendix K

Topics of News Items on Hepatitis C in the *Herald Sun*, January 1996 to December 2003 Frequencies*

Ranking	Topic	<i>n</i>
1	Risk of infection	26
2	Incidents: Syringes/needlestick	17
3	Report on research	15
4	Hepatitis C statistics	14
4	National blood supply	14
5	Response by government/health authorities	12
6	Hepatitis C sentence	10
7	Hepatitis C drugs: New treatment	7
8	Hepatitis C epidemic	5
8	Hepatitis C transmission: injecting drug use	5
8	Celebrity and hepatitis C	5
9	Hepatitis C assault/syringe threat	4
9	Medical technology: contaminated instruments	4
10	Attention and funding for hepatitis C	3
10	Cost to taxpayers	3
10	Information: Hepatitis C	3
10	Prisoners: Health	3
11	Expert warning	2
11	Hepatitis C scare	2
11	Hepatitis C transmission: body piercing	2
11	Hepatitis C transmission: tattooing	2
11	Stigma attached to hepatitis C	2
12	Hepatitis C discrimination	1
12	Hepatitis C sufferers	1
12	Occupational exposure: Australian healthcare workers	1
	Other	4

*Up to five topics were coded for each news item.

Appendix L

**Topics of News Items on Hepatitis C in Australian Broadcasting Corporation
News Services, *The Australian* and the *Herald Sun* Combined, January 1996
to December 2003, Frequencies***

Ranking	Topic	<i>n</i>
1	National blood supply	73
2	Response by government/health authorities	50
3	Hepatitis C statistics	40
4	Risk of infection	36
5	Report on research	30
6	Hepatitis C epidemic	25
6	Hepatitis C transmission: injecting drug use	25
7	Incidents: Syringes/needlestick	22
8	Hepatitis C sentence	19
9	Hepatitis C drugs: New treatment	18
10	Attention and funding for hepatitis C	14
11	Information: Hepatitis C	13
12	Hepatitis C discrimination	10
12	Medical technology: contaminated instruments	10
13	Prisoners: Health	9
14	Stigma attached to hepatitis C	8
14	Celebrity and hepatitis C	8
15	Occupational exposure: Australian healthcare workers	6
15	Expert warning	6
15	Disease: Liver disease (including prognosis)	6
16	Cost to taxpayers	5
16	Hepatitis C transmission: tattooing	5
17	Hepatitis C scare	4
17	Hepatitis C sufferers	4
17	Hepatitis C assault/syringe threat	4
17	Injecting drug users: Health	4
18	Hepatitis C transmission: body piercing	2
18	Conference: Hepatitis C	2
18	Injecting drug users: Culture	2
18	Body organs: the liver	2
19	Medical knowledge of hepatitis C	1
19	Lay knowledge of hepatitis C	1
	Other	9

* Up to five topics were coded for each news item.

Appendix M

Media Coverage of Hepatitis C: News Headlines in Australian Broadcasting Corporation News Services, *The Australian* and the *Herald Sun*, January 1996 to December, 2003

ABC news and information services

07/12/2003 Hepatitis C: Too hard to talk about? Radio National
12/11/2003 Tony Abbott defends 'tough on drugs' stance; PM, ABC Radio
12/11/2003 Abbott and Hepatitis Council argue over health strategy; PM, ABC Radio
25/10/2003 New drug hope for millions of hepatitis C victims; ABC Online News
25/09/2003 Australia can lead world in fight against hep C; The World Today, ABC Radio
24/09/2003 Fed govt creates new AIDS body; ABC Online News
24/09/2003 Hepatitis needs greater national attention: Hepatitis Council; PM, ABC Radio
24/09/2003 Wooldridge to head new AIDS, Hep C body; PM, ABC Radio
02/09/2003 Aussie boffins given grant to trial new hepatitis C treatment; ABC Online Health News
28/08/2003 Hepatitis C—the neglected epidemic; Radio National
28/08/2003 ACT report calls for syringe vending machines; ABC Online News
22/08/2003 Call for health minister to act on hepatitis C report; AM, Radio
22/07/2003 Recycling risk; ABC Online News
18/06/2003 National AIDS Council fears lives lost through needle and syringe exchange program closures; The World Today, ABC Radio
13/06/2003 Claims that zero tolerance has provoked rise in hepatitis C infections; PM, ABC Radio
13/06/2003 Minister denies concealing hepatitis C report; ABC Online News
15/05/2003 Tainted blood prompts inquiry demand; ABC Online News
15/05/2003 Tainted blood reports; PM, ABC Radio
15/05/2003 Tainted blood report findings; The World Today, ABC Radio
07/04/2003 Hepatitis C vaccine, phase-one trials to begin in the US; The World Today, ABC Radio
18/03/2003 Find out more about hep C; ABC Hobart
05/03/2003 War against drugs pushes addicts underground; Lateline, ABC TV
15/10/2002 Bloody gifts; Perspective, Radio National
23/09/2002 Blood bank protesters make voices heard outside Red Cross HQ; ABC News Online
23/09/2002 Tainted blood protest; The World Today
07/08/2002 Inquiry into blood contamination; AM, ABC Radio
28/07/2002 Health Dept contacting hip surgery patients after blood scare; ABC News Online
03/07/2002 Health Dept to investigate contaminated blood claims; ABC Sci-Tech
01/07/2002 Red Cross Blood Bank under fire; The World Today
01/07/2002 Health Dept to investigate infected blood claims; ABC News Online
01/07/2002 Health Dept to investigate contaminated blood claims; PM, ABC Radio
12/06/2002 Red Cross Blood Bank facing class action; AM, ABC Radio
26/03/2002 Raising awareness about hepatitis C; Life Matters, Radio National
21/01/2002 Hepatitis C; Health Minutes
16/11/2001 Hep C update; Radio National Breakfast
31/07/2001 Syringe standards; Radio National Breakfast
14/06/2001 Hepatitis C thrives in jails; 7.30 Report
15/03/2001 Inquiry launched into Hepatitis C discrimination; The World Today
13/03/2001 Hep C discrimination; Radio National Breakfast
12/02/2001 Hepatitis C discrimination; AM, ABC Radio
03/07/2000 Long-term response to Hep C treatment; ABC News in Science, Health News
29/6/2000 Figures highlight Hep C deaths; PM, ABC Radio
29/06/2000 Government launches strategy to curb spread of Hepatitis C; PM, ABC Radio
27/03/2000 Australian Hepatitis C epidemic; The World Today
28/02/2000 Hepatitis C increasing to epidemic proportions; 7.30 Report
10/01/2000 Melbourne beaches in spot light after syringe accident; AM, ABC Radio
11/10/1999 Liver cancer; The Health Report
08/10/1999 Alarming rates of liver cancer in Australia; PM, ABC Radio

04/08/1999 Go-ahead expected for new blood screening test; AM, ABC Radio
 02/08/1999 New blood screening techniques; Health Report, Radio National
 24/03/1999 Figures highlight hep C deaths; News in Science
 24/03/1999 NZ patients face HIV tests after instrument cleaning fails; ABC News in science,
 15/01/1999 Govt warned that HIV, Hep C transmissions could soar ABC News in Science,
 Health News

The Australian

04/10/2003 Challenges await new minister
 03/10/2003 Labor softens hardline drugs policy
 25/09/2003 Wooldridge appointed to HIV post
 22/08/2003 Funding lags rate of new sufferers
 22/08/2003 Line drawn on disease, Shane gets back to life
 22/08/2003 Hepatitis C 'spreading unchecked'
 June 2003 Disease catches minister (Letters to the Editor)
 13/06/2003 Law blamed for hep C epidemic
 13/06/2003 Secret report hid hep C 'epidemic'
 07/04/2003 Vaccine in sight for hepatitis C
 13/08/2002 Biota-GSK to take on Hep C
 03/07/2002 Hepatitis sufferers sue over bad blood
 22/03/2002 Baywatch star stricken by deadly virus
 13/10/2001 Body parts: the liver
 03/10/2001 Hope for hepatitis sufferers
 28/04/2001 Hep C rife in jails
 07/04/2001 Hearing will fight hepatitis C discrimination
 21/11/2000 Tattooed men mourning after the night before
 16/10/2000 Hepatitis 'epidemic' fuels doubling of liver cancer rate
 21/09/2000 Trade-off: riskier blood or shortages—Blood risk concerns
 16/08/2000 Viruses no barrier
 24/05/2000 Hep C jab accident after 1hr training
 19/05/2000 Musician strikes life-saving chord
 29/04/2000 Hep C spread culprits widen
 24/01/2000 Hep scare ignites review of blood law
 17/01/2000 Hep C in addicts declines
 06/11/1999 Hepatitis C now the most worrying infection
 04/08/1999 Push to tighten blood screen tests
 28/07/1999 The vein of truth / HIV—THE SCREENING CRISIS
 19/06/1999 Virus threat to industry workers eases
 06/03/1999 Experts push dual treatment for hepatitis C
 01/03/1999 Hepatitis C forgotten at expense of HIV
 16/02/1999 Hep C rife for jailed drug users
 01/12/1998 HIV message a rule for other diseases
 21/11/1998 Hidden epidemic
 26/10/1998 Ansett needle bins win support
 24/10/1998 Jail health is sickening
 28/09/1998 Hepatitis C survives weeks in syringe test
 21/02/1998 Canberra hit by hepatitis row
 20/09/1997 Amrad joins forces in push for Hep C cure
 30/08/1997 Hepatitis C treatment bans under attack
 27/08/1997 Service failure hurts hepatitis C patients
 24/04/1997 Hospital oversight highlights dangers of nasties in the works
 21/04/1997 Hunt for patients in hospital bungle
 19/04/1997 Hospital bungle: 123 face HIV test
 21/04/1997 Patients sought in hospital bungle
 30/08/1996 Gene patent fight settled out of court
 17/03/1997 Hepatitis C warning to snort, not inject
 17/03/1997 Snort, don't shoot, drug users told
 03/02/1997 Prisons a breeding ground for hepatitis
 21/06/1996 Scientists in battle on hepatitis gene patent
 03/06/1996 Healthcare workers face hepatitis C risk
 09/04/1996 Drug-use hygiene cuts hepatitis C

Herald Sun

23/10/2003 Pamela's agony
19/10/2003 Instant test for hepatitis
16/10/2003 Check up: Kiss fears
15/05/2003 Hep C concern
15/05/2003 Blood payouts revealed
09/04/2003 Bad blood gave hundreds hep C
22/03/2003 Body piercings a risk to public
10/12/2002 Life blood
09/10/2002 Your say: Crisis with hepatitis
06/10/2002 Hepatitis C crisis
01/08/2002 Council considers needle machines
19/07/2002 Little risk, public told
18/07/2002 Dr Deadly, 17 doctors, dentists hide HIV and hepatitis status, Doctors' deadly secret
05/05/2002 Rock KO'd by Pam's illness
22/3/2002 Pammy blames ex Tommy for hep C
17/01/2002 \$260,000 for prick of needle
11/11/2001 THE HEP C untouchables—one every hour
02/09/2001 Hep C 'plague' outrates AIDS
25/08/2001 Hepatitis C fear at hospital
30/05/2001 Sharp end of the body art craze
17/05/2001 Teens at risk
30/04/2001 Needle ban pushed
19/03/2001 Fatal diseases on the march
17/12/2000 Cabbie pricked by used syringe
05/12/2000 Vegemite a key to new drug
20/07/2000 Hepatitis C hope
06/06/2000 Hep C link to mozzie
30/04/2000 HIV scare for 32
07/04/2000 Four caught by surgery bungle
17/03/2000 Dad's fearful wait
17/03/2000 Jab doctor unaware
17/03/2000 Jab doctor unaware 2
14/03/2000 Alarm at syringe
13/03/2000 Probe called on hospital syringe case
12/03/2000 Dad's terror in syringe bungle
17/02/2000 Exchange failure
16/02/2000 Hepatitis blitz
29/01/2000 Beach jab threat goes up in smoke
23/01/2000 Lifesavers play it safe
20/01/2000 Addiction is not the point
14/01/2000 Syringe pricks foot at beach Tests for needle boy
13/01/2000 Needles puncture beach lifestyle
11/01/2000 Hep C is biggest risk
11/01/2000 Long wait filled with hope and hard work
11/01/2000 Long wait filled with hope and hard work 2
19/12/1999 Needlestick horror
19/12/1999 Free needles a 'triumph'
12/12/1999 Needles 'spread death'
30/10/1999 Health focus on hepatitis
28/10/1999 Hospital's hep C scare
05/10/1999 Hepatitis drug hope
28/07/1999 Hep C robbery link
04/07/1999 Blood lines
01/04/1999 Rural hep C study
09/03/1999 Prevention part of the cure
12/01/1999 Drug hope in hepatitis C battle
08/01/1999 Bad blood blamed for deaths
07/01/1999 Red Cross in hep C claims
20/12/1998 HIV bungle at hospital
04/12/1998 Inmate hep C alarm
28/11/1998 Hep C case settled

21/11/1998 Sean is winning virus battle
21/11/1998 \$3.2BIL epidemic
21/11/1998 Virus a \$3.2B epidemic
21/11/1998 Hepatitis C crisis looms
13/11/1998 Hep C on rise
19/10/1998 Prison disease threat
10/10/1998 Hepatitis linked to surgery
09/10/1998 Bias allowed
09/07/01998 Hepatitis hits migrants
16/05/1998 Police blood fear
01/05/1998 Stuntman help plea
11/04/1998 Blood bank calling
20/03/1998 Hepatitis fear for children
19/03/1998 Grubby dental surgery fears
16/02/1998 \$1M to fight hep C
17/02/1998 Oral sex no safer
16/02/1998 Hep C funds
03/11/1997 Hep C risks known
20/09/1997 \$50M bid by AMRAD
13/09/1997 The agony of Debra Byrne
26/08/1997 Hepatitis threat 'severe'
10/06/1997 Upset mum's long day's night
07/07/1997 Hep C mystery
10/05/1997 Smear claim
16/04/1997 Jail term for syringe threats
20/03/1997 Syringe stab threat terror
20/03/1997 Blood stab virus threat
17/03/1997 Hepatitis crisis plea
15/02/1997 Cupful of disease
03/02/1997 Prison health fears
12/09/1996 Herb hope for hep C
02/09/1996 Move for hep-C donor organs
02/09/1996 Dental fakes a risk to public health
16/05/1996 Treatment action plea
15/05/1996 Study warns of hepatitis risks
06/05/1996 Strain of hepatitis
23/03/1996 Blood study a first

Appendix N

Sample of News Coverage for the Topic Category “National Blood Supply”: Comparison with *Herald Sun* Article “Bad Blood Blamed for Deaths” (1999)

<div> <div>Attributes of “Bad Blood Blamed for Deaths”</div> <div>News items</div> </div>	Headline pejorative	Grammar & semantic features			Vocabulary	Blood with hepatitis C virus worthless, harmful, causes ill health; hepatitis C fatal
		Attributes agency to Australian Red Cross Blood Service	People who inject drugs endanger others, contaminate blood supply	People with iatrogenic hepatitis C innocent victims		
Figures Highlight Hep C Deaths. (1999, Mar 24). <i>ABC News in Science</i> .	X	X		X		X
The Vein of Truth/HIV—The Screening Crisis. (1999, Jul 28). <i>The Aus.</i>	X		X		X	
New Blood Screening Techniques. (1999, Aug 2). <i>Health Report, ABC</i> .				X		
Kerin, J. (1999, Aug 4). Push to Tighten Blood Screen Tests. <i>The Aus.</i>				X		X
Kerin, J. (2000, Jan 24). Hep Scare Ignites Review Blood Law. <i>The Aus.</i>	X	X		X		
Kerin, J. (2000, Sep 21). Trade Off: Riskier Blood or Shortages—Blood Risk Concerns. <i>The Aus.</i>	X	X		X		
Red Cross Blood Bank Facing Class Action. (2002, Jun 12). <i>AM, ABC</i> .	X	X	X	X		X
Kerin, J. (2002, Jul 3). Hepatitis Sufferers Sue Over Bad Blood. <i>The Aus.</i>	X	X		X		X
Red Cross Blood Bank Under Fire. (2002, Jul 1). <i>World Today, ABC</i> .	X	X		X		X
Health Dept to Investigate Contaminated Blood Claims. (2002, Jul 1). <i>PM, ABC</i> .	X	X		X	X	X
Health Dept to Investigate Infected Blood Claims. (2002, Jul 1). <i>ABC News Online</i> .	X	X				
Health Dept to Investigate Contaminated Blood Claims. (2002, Jul 3). <i>ABC Sci-Tech</i> .	X	X				
Inquiry into Blood Contaminations. (2002, Aug 7). <i>AM, ABC</i> .	X	X				
Tainted Blood Protest. (2002, Sep 23). <i>World Today, ABC</i> .	X	X		X		X
Tainted Blood Reports Findings. (2003, May 15). <i>PM, ABC</i> .	X	X		X		X
Tainted Blood Prompts Inquiry Demand. (2003, May 15). <i>ABC News Online</i> .	X					
Tainted Blood Reports Findings. (2003, May 15). <i>World Today, ABC</i> .	X	X		X		X

Appendix O

Transcript of 7.30 Report, "Hepatitis C Increasing to Epidemic Proportions"

Hepatitis C increasing to epidemic proportions

KERRY O'BRIEN: When it comes to the deadly blood-borne viruses, HIV, of course, receives most of the attention and the funding.

As a result, the number of new cases of AIDS has dropped dramatically in recent years.

But that's not so with the virulent hepatitis C virus, with the number of new infections increasing to epidemic proportions, by 11,000 a year.

Hepatitis C is also a major killer, most patients developing chronic liver infections.

But for the first time, hepatitis C sufferers can now allow themselves to hope for a cure, thanks to a new treatment being trialled in Melbourne.

Jacinta Tynan reports.

ALAN MORGAN, HEPATITIS C SUFFERER: The most difficult thing is, I suppose, the fatigue.

It's nauseatingly difficult to just even get up in the morning.

Day by day, it gets harder and harder even to climb a flight of stairs.

It got to the point where I literally have found it difficult just to crawl out of bed.

JACINTA TYNAN: It wasn't so long ago that a game of tennis was out of the question for Alan Morgan.

He was diagnosed with the hepatitis C virus seven years ago after a routine medical examination.

ALAN MORGAN: When I actually found out that I actually had hepatitis C then I started to realise, well, this isn't something I'm going to get over.

This is something that's going to get worse, this is something that's only going to deteriorate further.

And it's not exactly an exciting thing to look forward to.

JACINTA TYNAN: But thanks to a radical new treatment, Alan's life has been turned around.

Dr Stuart Roberts is heading the Australian research team involved in worldwide clinical trials of combination therapies for hepatitis C patients.

The trial combines the standard treatment for hepatitis C, injections of the chemical stimulant interferon three times a week, with a pill known as 'ribavirin'.

DR STUART ROBERTS, HEPATITIS C SPECIALIST: Alan's had an excellent response. He had a full year of treatment and has now completed his six months follow-up. We've had a good response in Alan.

There's no traces of detectable virus in his blood and his tests have come back to normal.

ALAN MORGAN: The final result of the test was that there was no trace of a positive hepatitis C result in my blood system, which was fantastic.

Again, I think I pretty much knew.

I was skipping down the hallways at the hospital.

Like, you pretty well know.

DR STUART ROBERTS: What we know with the treatments now is that the responses are that for every ten people that we treat, four people will have a good long-term outcome, loss of virus from the blood and improvement to normal in their liver function tests.

JACINTA TYNAN: Researchers are also refining a longer-acting dose of interferon injected just once a week, which they expect to be even more effective.

DR STUART ROBERTS: Now studies are under way to look at the effectiveness of that when combined with the tablets, ribavirin, to see what improvement one can achieve on the 40 per cent response rate that we have already with standard therapy.

ALAN MORGAN: It's given me the opportunity, I suppose, to look forward into the future and start to create a life again and start to build a career and start to look forward to, actually, a retirement, which is fantastic, and a healthy retirement.

JACINTA TYNAN: The treatment is the best news yet for hepatitis C patients, for whom the future is usually grim.

85 per cent of carriers will develop a chronic liver infection, one-quarter develop cirrhosis of the liver and many, liver cancer or failure.

It is now regarded as the biggest threat to public health in Australia.

JILL MEADE, HEPATITIS C COUNCIL OF VICTORIA: At the moment, we have approximately 200,000 people infected with hepatitis C and the rate of new infections on an annual basis is 11,000.

So, it is at epidemic proportions.

JACINTA TYNAN: More than 20,000 new cases of hepatitis C were reported last year, compared with some 600 cases of HIV.

But AIDS research still receives the bulk of funding and doctors believe hepatitis treatments would be even more advanced if they'd been given the same attention.

DR STUART ROBERTS: Hepatitis C is too well stereotyped, in that the only people that have been believed in the community to be affected by this have been those who have used intravenous drugs.

We know, however, there are a lot of other groups as well who have developed this infection and that the large numbers of Australians who have evidence of hepatitis C can only make people realise that it is a major health problem and that more dollars need to be spent in this area.

JACINTA TYNAN: While doctors are hailing this treatment as the most major medical breakthrough in the treatment of hepatitis C, it's not a panacea.

60 per cent of patients failed to respond to the treatment and for those who do, the long-term impact of the drugs is still unknown.

JILL MEADE: There is hope being offered, which is the first time that people with hepatitis C have had that sort of hope.

But I think we have a long way to go before we can actually say that, you know, that we're reaching a cure stage because, certainly, at this stage, currently, there is no cure for hepatitis C.

JACINTA TYNAN: But Alan is one who's benefited from the research, living proof to thousands of other people with hepatitis C that it may not have to be for life.

ALAN MORGAN: I've been basically told that it's negative in my system now and I'll take that as "thank you very much" and I'll move forward.

If it changes, well, we go maybe back to the drawing board and start again and go through the whole cycle again, but I'm convinced that it's gone and I doubt very, very much that it would come back.

KERRY O'BRIEN: Good reason for optimism, it seems.

Source: Tynan, J. (2000, February 28). Hepatitis C increasing to epidemic proportions. *7.30 Report*. [Australian Broadcasting Corporation Television online transcript]. Retrieved October 31, 2002, from <http://www.abc.net.au/7.30/stories/s104145.htm>