

**TREATING AND MANAGING  
HEPATITIS C:**

**GETTING IT RIGHT**

The previous chapter identified the various policies and practices of treating and managing Hepatitis C. During the course of this Inquiry a number of inadequacies and shortcomings pertaining to these policies and practices were identified by witnesses and those making written submissions. The following chapter identifies the concerns that were raised and proposes a series of recommendations to address current difficulties experienced by those seeking treatment for their Hepatitis C and the health care professionals working with them.

## **8.1 INADEQUACIES OF CURRENT POLICIES REGULATING TREATMENT**

The Inquiry's Terms of Reference asked the Committee to comment on the adequacy of policies in relation to treatment. Approximately 2% of those known to have Hepatitis C have accessed the only approved form of treatment available. While some choose not to go on interferon therapy because of the drug's side effects, many are not given the option because of the strict criteria regulating who can and who cannot be given interferon. The Committee concluded that current policies regulating the treatment of Hepatitis C are clearly inadequate.

The following section looks at the adequacy of the policies that determine access to treatment, location of Interferon Prescribing Centres, pre-treatment assessment, interferon dosage schedule, and treatment assessment and monitoring.

### **8.1.1 POLICIES RESTRICTING ACCESS TO TREATMENT**

The current assessment criteria for interferon treatment under the S100 program were outlined in Section 7.1. The criteria were devised using the guidelines chosen for the AUSHEP 1 and 2 studies conducted in the early 1990s. Since that time, research has led to a clearer understanding of the drug, its efficacy, safety and potential toxicity.

However, it would appear that much of this research has yet to be taken into account by policy makers and as a result, the current criteria restrict a very large number of people with Hepatitis C accessing interferon therapy. What was appropriate in the early 1990s when the criteria for interferon under the S100 scheme were first developed is, in the light of such research, clearly inadequate. It is imperative that policies regulating the administration of interferon be reviewed and updated regularly to ensure research is taken into account.

Dr Crofts candidly explained the manner in which the criteria were originally established:

*I was a member of the first NHMRC working party on Hepatitis C and we had two major briefs. One was to make sure that blood supply was under control . . . And the other was to make interferon accessible to a select range of people. By "select" I mean not the 100,000, 150,000, 200,000 people who have got Hepatitis C, or at least that we estimate have got Hepatitis C in Australia, but a select group who would be pliant and*

*compliant and not disrupt the gastroenterologist's waiting room and not [be] too expensive. If we could find limiting factors so that interferon was made available and thereby get the flood of letters that were coming from the support groups and the drug companies off Graham Richardson's desk then we would be doing our job, but we had to limit that number (Crofts evidence, 28 November 1997).*

Various witnesses to the Committee expressed their concern at the exclusive nature of the criteria. Professor Farrell, for example, noted that:

*My reservations about treatment . . . [are about] the restricted bandwidth for patients getting interferon treatment (Farrell evidence, 28 November 1997).*

Other witnesses expressed concerns that the assessment criteria were discriminatory:

*Ethically I find that the S100 criteria are discriminatory against certain sections of the population. They may not have as much to gain as the others, but in the long term if we can help those people there will be less burden on the tax payer, even if we only help 15 per cent to 20 per cent of them, it is still of assistance to the community at large (Rallings evidence, 27 October 1997); and*

*these criteria . . . were totally and utterly discriminatory and had no basis for being there (Wodak evidence, 2 October 1997).*

Concerns from a legal perspective were also expressed:

*Legally people could look at us and say "what right do you have to exclude us from what is known to be a treatment which may be of benefit or at least have a try" (Rallings evidence, 27 October 1997).*

The NHMRC considers the guidelines to be "relatively restrictive" by excluding patients with cirrhosis, IDUs, heavy drinkers, patients co-infected with HCV and HIV+, and those with slightly raised ALT levels (NHMRC, 1997:35). In its 1997 report, the Council considered that each of these groups could "benefit" from interferon therapy and the Report makes a strong case for liberalising the availability of interferon for Hepatitis C and broadening the base of patients being treated with interferon on that basis that it is "not appropriate" to withhold potentially beneficial treatment from any patient group (1997:35). The Report's recommendation was that:

*all Hepatitis C antibody positive patients with any elevation of ALT should be considered for treatment with interferon alpha in standard dosage. Patients with normal ALT values should be monitored regularly by their clinician. World experience in the treatment of these patients should be evaluated (NHMRC, 1997:36).*

The approach sought by the NHMRC is considerably more flexible than the current arrangement. The Council proposed individual clinicians being given the option to choose to withhold treatment from individual patients after assessment and for this decision to be discussed in detail with each individual patient. The report calls for an “appropriate assessment” of the patient’s psychosocial status, psychological functioning and medical condition. Such an approach, the Report anticipates, will limit the number of people being placed on interferon in a “more equitable way” (NHMRC, 1997:35).

Material provided to the Committee by Schering-Plough compares the current S100 assessment criteria with recommendations made by the NHMRC and the National Institutes of Health (NIH). This table is reproduced in Appendix Four. Table Twenty-seven below summarises the comparisons and shows the degree to which both the NHMRC and NIH recommend less stringent criteria than are currently available.

**TABLE TWENTY-SEVEN**

**COMPARISON OF THE STRINGENCY OF ELIGIBILITY CRITERIA FOR PATIENT GROUPS ALLOWED ACCESS TO INTERFERON UNDER CRITERIA AS RECOMMENDED BY THE NATIONAL INSTITUTES OF HEALTH (NIH) AND NHMRC VERSUS THE SECTION 100 CRITERIA**

<b>PATIENT GROUP</b>	<b>NHMRC RECOMMENDATIONS</b>	<b>NIH RECOMMENDATIONS</b>
Hepatitis C patients with positive liver biopsy	Wider than Section 100	Wider than Section 100
Patients with elevated ALT levels	Wider than Section 100	Wider than Section 100
Patients with cirrhosis	Wider than Section 100	Wider than Section 100
HIV positive patients	Wider than Section 100	Wider than Section 100
Pregnant, lactating patients	Same as Section 100	---
Psychiatric illness, auto-immune disease and other contraindications	Same as Section 100	Wider than Section 100
Regular attendance for follow-up	---	---
Intravenous drug users	Wider than Section 100	Wider than Section 100
Relapsers/non-responders	Wider than Section 100	Wider than Section 100
Extrahepatic manifestations	Wider than Section 100	Wider than Section 100

Source: Schering Plough submission.

During the course of this Inquiry, a number of people gave their support to broadening the S100 assessment criteria. The submission from NSW Health, for example, stated that the Department supports the current recommendations of the NHMRC concerning

the criteria for interferon and calls for the criteria to be implemented “as a matter of urgency” (NSW Health submission). NSW Health also supports the notion that broadening the assessment criteria should be carefully monitored for a test period of at least two years with patient response data collected for a national data base (NSW Health submission).

The Hepatitis C Council encouraged the Committee to give its full support to NSW Health lobbying and encouraging the Commonwealth to expand the criteria in line with the NHMRC recommendations (Loveday evidence, 22 September 1997). The submission from NUAA also called for the “discriminatory barriers” to interferon treatment to be removed (NUAA submission).

In their submission to this Inquiry, ANCARD attached the submission they had made to the PBS to expand the interferon criteria.

During the course of the Inquiry in early 1998, the S100 criteria were changed giving access to interferon to two specific population groups: current injecting drug users and those coinfected with HIV. The Committee had already gathered considerable evidence supporting these changes which will be reviewed below.

- **Patients Co-Infected with HIV**

Until early 1998 patients testing positive for both HIV and Hepatitis C were unable to access interferon under the S100 program. A representative from the drug company Schering Plough pointed out to the Committee:

*There are difficulties in treating this group of patients . . . but I am not quite sure why they should be denied the treatment of their Hepatitis C; they already have enough problems with their HIV. Treatment of HIV is improving with the advent of triple treatment now and they are living longer and they could be treated for their Hepatitis C (Rallings evidence, 27 October 1997).*

Apparently at the time of conducting the AUSHEP 1 and 2 studies there were no helpful data indicating the effect of interferon on HIV+ patients and the course of either illness when both were present in the same individual. Erring on the side of caution, those establishing the original S100 assessment criteria excluded these patients.

By the time the NHMRC examined the guidelines in 1997 available research could find no evidence to suggest that Hepatitis C would worsen if treated in an HIV+ patient (NHMRC, 1997:36). The Council concluded that people with HIV infection may benefit from the administration of interferon and recommended the inclusion of this group of patients for interferon treatment. The NIH’s Consensus Development Conference on the management of Hepatitis C similarly recommended that patients who have stable

HIV infection with good clinical and functional status should be considered for interferon treatment (NIH, 1997:6S).

- **Injecting Drug Users**

At the commencement of this Inquiry, those accepted for interferon therapy under the S100 program must have not used illicit injectable drugs within the previous twelve months. The Committee received a number of different reasons for this criterion including the possibility of unknown drug interactions occurring if someone is taking drugs and being given interferon concurrently and the possibility of reinfection (Wilson evidence, 3 October 1997). Professor Farrell explained to the Committee that his hesitation regarding treating people who are actively injecting relates to the reinfection issue as well as being “an efficiency problem” as “many of those people do not attend follow-up visits” (Farrell evidence, 28 November 1997) and it is:

*potentially dangerous for people to not attend follow-up visits when they are on a dangerous form of therapy. It is certainly inefficient to start a course in expensive therapy when there is a significant chance that the course would not be completed (Farrell evidence, 28 November 1997).*

Dr Wodak informed the Committee that “there was both a rationale for this [policy] and also a reason why the rule was silly” (Wodak evidence, 2 October 1997):

*the rationale is that if someone has injected drugs in the last year there is a high risk that they might return to drug injecting. If we had eliminated the virus from their system and they returned to drug injecting and shared needles, syringes, spoons or cookers with another injecting drug user and became reinfected, several thousand dollars of scarce medication and resources would have been wasted. That was the justification . . .*

*. . . The criticism of that policy was: here is a population that has recently become infected, and we already know that this is the population that is most likely to benefit from an intervention (Wodak evidence, 2 October 1997).*

In response to such criticisms, the NHMRC recommended the S100 assessment criteria be broadened to include current injecting drug users. The Report suggests:

*all patients would be assessed individually by their managing clinician to determine whether there is any evidence of psychological instability. Patients should be fully informed of the risks of re-infection through unsafe injecting behaviour (NHMRC, 1997:36).*

NSW Health considers such a positive emphasis taken by NHMRC suggests:

*the lack of a clear rationale (other than short term cost saving) for the current year long waiting period for ex injecting drug users (NSW Health, tabled document).*

During the course of this Inquiry considerable support was given by experts to broadening the criteria for this group of people with HCV. NSW Health, for example, supports the NHMRC recommendation and wishes to see the new criteria monitored for a test period of at least two years. Support for broadening the criteria was also given by a number of agencies including ANCARD, NUAA, and the Hepatitis C Council.

While not personally “a great advocate” of providing interferon to injecting drug users, Farrell told Members of one of his patients who had recently stopped injecting but is unable to commence interferon therapy for another eight months. He stated that he would be “very happy” to start that person on treatment if he felt they were determined to remain clean of substance abuse (Farrell evidence, 28 November 1997). The current system does not provide any flexibility to administer interferon on a case by case basis.

In material provided to the Committee, NSW Health proposed a number of reasons for broadening this specific assessment criterion:

- cost projection estimates imply that, on fiscal grounds alone, there is a pressing need to halt or slow the current epidemic of HCV among injecting drug users;
- research suggests that interferon has a greater chance of clearing the Hepatitis C virus when administered early in the course of the disease. Requiring abstinence from injecting drug use for at least one year before treatment therefore reduces the chance of successful treatment;
- injecting drug users comprise the largest pool of infection. By excluding them from treatment, the prospects of effective treatment contributing to a reduction in disease transmission is significantly reduced;
- the exclusion of injecting drug users appears to be based on the assumption that all injecting drug users are addicted, continue to inject drugs using shared equipment and are at risk of reinfection with other strains of the virus. As will be discussed in Section 10.1 research findings question the validity of the popular stereotype of injecting drug users - many are employed, married with children and mortgages and use drugs only occasionally and recreationally; and
- the exclusion of injecting drug users from eligibility for interferon treatment is viewed by them as “punishment” for their illegal behaviour. Expecting a whole

year's abstinence from injecting drugs before consideration of the only available treatment option serves to "encourage a feeling of being punished and of being rejected from society in an already marginalised group, and does little to encourage rehabilitation" (NSW Health submission).

NSW Health suggested that given the current NHMRC recommendations:

*The continuation of the year long "waiting period" could be interpreted as a short term cost containment strategy for the S100 program and institutionalised discrimination against this population group (NSW Health submission).*

The NIH recommends treatment for patients who are actively using illicit drugs should be delayed until drug use has been discontinued for six months. They also recommend treatment for addiction should be provided before treatment for Hepatitis C (NIH, 1997:6S).

The Committee is pleased with the S100 changes that have been made enabling interferon under the S100 program to current injecting drug users. The Committee also considers it important that these patients be fully informed of the risks of reinfection through unsafe injecting behaviours.

- **Patients on a Methadone Program**

Under the current S100 criteria, interferon is not available to those on a methadone program. Evidence presented to the Committee suggested however that some people on methadone do access interferon under the S100 program. One witness told the Committee that:

*I think a person with less knowledge of the system than I would not be able to do it [access interferon while on methadone] how I did. I snuck through the edges of the system. I found doctors willing to look the other way for my wellbeing. The law was that if you were on methadone you could not access it. The doctors did not ask and I did not tell them that I was on methadone. It was an under-the-table way (Evidence, 6 November 1997).*

The NHMRC Reports suggests there are no convincing data at present to indicate that the combination of interferon and methadone is potentially hepatotoxic or damaging in any way. The Council therefore recommended patients on methadone programs should be considered for treatment with interferon but that, as with injecting drug users, the Council wishes to see these patients assessed by their managing clinician and by appropriate Hepatitis C clinicians to determine whether there are any medical or psychological contraindications to the use of interferon (NHMRC, 1997:36).

The Committee supports the availability of interferon on the S100 program to those on a methadone program.

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While some changes have been made to the S100 criteria, there remain several groups who are still exempt. Evidence presented and research findings support the following patient groups being eligible for interferon treatment:

- **Patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV RNA testing**

According to the current S100 assessment criteria patients have to have an ALT higher than 1.5 times the upper limit of the laboratory reference range on three occasions over a period of six months. However, not all patients with chronic Hepatitis C infection have ALT levels this high. A paper presented by Marcellin, Levy and Erlinger to the NIH's Consensus Conference on the management of Hepatitis C noted that, with the development of sensitive and specific means for detection of Hepatitis C in serum, it has become clear that a significant proportion of patients with chronic Hepatitis C infection are asymptomatic and have persistently normal serum ALT levels (Marcellin, Levy and Erlinger, 1997:133S). These patients are potentially infectious and, despite having normal liver tests, may suffer long-term consequences of the chronic liver disease (Marcellin, Levy and Erlinger, 1997:133S).

Marcellin, Levy and Erlinger argue that the absence of symptoms, the limited efficacy and costs of current therapies, and the potential of causing harm make it important to demonstrate clear efficacy in this specific group before the recommendations for patients with abnormal ALT levels can be applied to those with normal ALT levels (Marcellin, Levy and Erlinger, 1997:133S). They conclude by suggesting that there is currently no rationale to treat these subjects (Marcellin, Levy and Erlinger, 1997:136S).

The NHMRC took a slightly different management approach and recommended patients with normal ALT values should be monitored regularly by their clinicians (NHMRC, 1997:35). Patients with minimal ALT elevation or with normal liver function tests and positive HCV serology or HCV RNA testing should qualify for treatment (NHMRC, 1997:36).

In commenting on the current requirement for three ALT tests over a six month period, Schering-Plough argued that:

*many of these people have had the disease for some time, they have already got a well established history and to make them wait another six months while they get three blood tests which will confirm this fact is probably unnecessary if they have had the history and all it will do is lead to their being more likely to develop cirrhosis and then they will not be allowed treatment anyway in the long run; cirrhosis can develop quite quickly (Rallings evidence, 27 October 1997).*

While the Committee remains unconvinced that a significant number of cirrhosis cases will develop over the six month period it does see merit in the argument that requiring proof of a well established disease may be unwarranted.

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The Committee supports the availability of interferon on the S100 program to those with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV RNA testing.

- **Patients with cirrhosis**

Interferon therapy is often more effective in those patients with recently acquired Hepatitis C rather than those who have had it for some time and have developed cirrhosis. The NHMRC Report reviewed available research on the success of interferon for patients with cirrhosis. Patients receiving the standard six month course of interferon demonstrate 8-10% sustained response rate (NHMRC, 1997:35). The AUSHEP3 study has documented a 14 per cent sustained response rate in patients treated with an increased (4.5MU) dose of interferon administered daily (rather than three times a week as is the standard practice) (NHMRC, 1997:35).

Despite these poor response rates, there was considerable support for patients with cirrhosis receiving interferon under the S100 program. Expert witness, Professor Farrell for example, supported these patients accessing interferon therapy (Farrell evidence, 28 November 1997). Schering-Plough considered it to be:

*rather discriminatory to remove them [patients with cirrhosis] because they are the ones who are nearest to the end stage disease. They are also the ones most at risk of getting hepatocellular carcinoma (Rallings evidence, 27 October 1997).*

The NHMRC recommended interferon be provided for cirrhotic patients in a dosage of 4.5 MU daily for six months (1997:36). In its submission to the Committee ANCARD also suggested that patients with cirrhosis should be allowed access to treatment given in a higher induction schedule with the aim of eliminating the virus and to document viral elimination with PCR testing (ANCARD submission).

On the other hand, the Panel Statement arising from the NIH Consensus Development Conference on the management of Hepatitis C does not support interferon therapy for patients with decompensated cirrhosis (NIH, 1997:6S). Their conclusion is however, based on the standard dose of interferon and relates to decompensated cirrhosis. Consideration is not given to the appropriateness of those with lesser degrees of cirrhosis receiving interferon and increasing the dosage of interferon for these patients.

Arguments supporting the availability of interferon to cirrhotic patients were often based on an economic imperative. Not only are there health care costs involved in managing cirrhosis but cirrhosis is a leading cause of liver transplants. The treatment protocols for both cirrhosis and liver transplants have been costed by Shiells, Briggs and Farrell (1994:269).

The total cost of asymptomatic cirrhosis has been costed (1994\$) at:

Specialist Visits (2)	\$145
Pathology Services (anti-HCV serology, liver function tests, alpha-fetaprotein, ultrasound, liver biopsy)	\$270
<b>Total Cost, per patient per year</b>	<b>\$415</b>

Treating liver failure has been costed (1994\$) at:

Without transplant (60% of patients), cost per patient	\$164,340
With transplant (40% of patients), cost of transplant	\$75,000
<b>Expected Cost, per episode</b>	<b>\$128,630</b>

It is imperative, from a costing point of view, if for no other reason, that every attempt be made to minimise HCV induced cirrhosis.

A number of those making submissions to the Inquiry mentioned that they had been excluded from interferon therapy due to their cirrhosis. One wrote:

*my understanding specialist informed me that, unfortunately, I would not qualify for government assistance with interferon treatment due to the presence of cirrhosis in my liver. This was a devastating blow to me as I had been led to believe that this was the only hope for at least some quality of life and hope for the future. My specialists arranged for me to purchase my own supply of interferon. Being unemployed and unable to continue my usual work as a labourer, I have had to borrow the \$1049 required each three months from my mother. The second three month supply was given free of charge by the pharmaceutical company in a humanitarian gesture (according to my specialist) (Submission 45).*

The Committee supports the availability of interferon on the S100 program to those with cirrhosis and that the dosage be increased to 4.5MU daily.

- **Relapsers and non-responders**

In 1997, the duration of interferon therapy was increased from six to 12 months. Directives from the PBAC made it very clear that non-responders or patients who relapsed were excluded from receiving the 12 month course of treatment. This is a cause of concern to a number of experts. Farrell, for example, informed the Committee that:

*we have been trying now for over two years to get re-treatment made available for people who have only had six months treatment . . . If you re-treat people for 12 months there is a 40 per cent chance you can cure them. . . We have been trying for at least 18 months to get that approved and there have been a lot of difficulties which I would regard as fairly pedantic interpretations of regulations and laws - there has certainly not been any accommodation of ways in which these matters can be brought forward with any haste (Farrell evidence, 28 November 1997).*

Professor Reed, the Chair of the NHMRC report into the management of Hepatitis C, has also expressed his concern that the revised PBS listing ruled out funding for retreatment of patients who had relapsed after a six month course of interferon:

*this is of particular concern because the evidence indicates that those patients who are re-treated for 12 months will have the same beneficial outcome as previously untreated patients (Reed, 1997).*

Not surprisingly, the drug company, Schering-Plough, also expressed concern at this limitation. In their submission they cite Alberti *et al's* 1997 research which suggests that:

*a significant number of patients who responded during the initial course but subsequently relapsed have a sustained response when re-treated with interferon (Alberti, 1997).*

The Committee supports the availability of interferon on the S100 program to relapsers and non-responders.

- **Patients with extrahepatic manifestations of Hepatitis C**

The NHMRC recommend that patients with conditions such as vasculitis, polyarteritis, nodosa, glomerulonephritis and cryoglobulinaemia - all extrahepatic manifestations of Hepatitis C that are life threatening in their own right - should be considered for treatment with interferon to address the primary cause of their immunological disorder (NHMRC, 1997:36). The Committee supports this recommendation.

Access to interferon under the S100 program is currently unavailable to those with a history of significant psychiatric illness because, as was discussed in Section 7.2.1, one of the side effects of interferon is depression. However Schering-Plough advised Committee Members that "if you screen them [psychiatric patients] well there is no reason why you should not treat them" (Rallings evidence, 27 October 1997) for

*there is no reason why you should not give anti-depressants with interferon, there is no interaction, there is no reason why you should not do that (Rallings evidence, 27 October 1997).*

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While the Committee can see some benefits in introducing a degree of flexibility that would enable appropriately screened and supervised patients with a psychiatric illness to access interferon, the Committee concluded that it had not received sufficient clinical evidence to recommend the availability of interferon on the S100 program to those with a history of psychiatric illness.

- **Conclusion**

Representatives from NSW Health informed the Committee that the current S100 scheme should be extended in line with the NHMRC recommendations (Wilson evidence, 22 September 1997). The Executive Officer of the Hepatitis C Council recommend that this Committee “give its full support” to NSW Health lobbying and encouraging the Commonwealth to expand the criteria in line with the NHMRC recommendations (Loveday evidence, 22 September 1997).

The Committee fully supports a broadening of the S100 assessment criteria as proposed by the NHMRC and supported by evidence to this Inquiry. Such changes would ensure those eligible for interferon include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;
- patients with cirrhosis;
- relapsers and non-responders; and
- patients with extrahepatic manifestations of Hepatitis C.

**RECOMMENDATION 46:**

That the Minister for Health urge his federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to broaden the assessment criteria for interferon drug therapy under the S100 Highly Specialised Drugs Scheme to include:

- patients with minimal ALT elevation or with normal liver function tests and positive hepatitis serology or HCV-RNA testing;
- patients with cirrhosis (dosage - 4.5MU daily);
- relapsers and non-responders; and
- patients with extrahepatic manifestations of Hepatitis C.

The Committee further recommends that the proposed new S100 assessment criteria for interferon be monitored for two years with patient response data continuing to be collected for the National Interferon Database.

- **The National Interferon Database**

As was discussed in Section 7.1, the National Interferon Database was established in 1994 to gather data on all patients receiving interferon therapy. Throughout the Inquiry, various comments were made as to the effectiveness of the Database.

The ANCARD submission to the Highly Specialised Drugs Program review noted, for example, that the Database is “operating below its optimum largely because of inadequate funding”. The submission also notes that:

*Some centres have complained that the extra workload, for which there is no financial compensation, interferes with their work as health care providers. There is inadequate follow-up by authorised prescribers of patients who have ended treatment, and inadequate follow-up (or reporting back) by general practitioners who manage patients post-treatment. The data base does not include those on clinical trials or compassionate access programs. It is unrealistic to expect that the pharmaceutical industry, by itself, will fund such a project to the appropriate level. A comparatively small input from government could be expected to be highly cost effective in improving surveillance, control and utilisation of expensive drugs (ANCARD submission to the Highly Specialised Drugs Program review - attachment to their submission to this Inquiry).*

According to Schering-Plough, one of the two drug companies that finances the Data Base, it is:

*a mechanism by which the Federal Government is able to control the type and number of patients treated, to minimise the total cost of treatment for Hepatitis C (Schering-Plough submission).*

The drug company elaborated further:

*the Database has turned out to be far more successful as a de facto gatekeeper, limiting entry to alfa interferon treatment in Australia. The data collected is incomplete and unreliable as some 88% of the patients have been reported to have data missing or do not have follow up treatment and observation data (28% had missing data and 60% did not have follow up data) (Schering-Plough submission).*

Despite criticisms levelled at the Database, it does remain the only source of longitudinal data on the approximately 3000 people who have commenced interferon therapy in Australia. Given that the total number of people is so limited, it is important, from a research perspective, that the only data bank remain in place.

The Committee understands, however, that the Database is facing funding difficulties. It therefore wishes to see the NSW Minister for Health encourage his federal counterpart to continue funding the operation of the National Interferon Database. The Committee considers government funding to be more appropriate than the current arrangement which depends on funding from pharmaceutical companies. Without wishing to question the integrity of such companies, the Committee is aware of their commercial interests and research priorities which compare drugs rather than examine other less expensive treatment strategies or preventive/educative approaches. It is the Committee's concern that limited government involvement in funding the Database could lead to higher overall treatment costs.

**RECOMMENDATION 47:**

That the Minister for Health urge his federal counterpart to ensure funding continues to be provided to maintain operation of the National Interferon Database and that the intellectual property of the Database remain with the government so that optimum treatment regimes can be ascertained.

- **Management of Patients not Receiving Interferon**

As has been discussed in Section 7.1.2 the majority of those with Hepatitis C cannot or will not undertake interferon therapy. In the opinion of the NHMRC

*The 99 per cent of patients who have not received interferon alpha clearly represent the most important group of patients with Hepatitis C at the present time (NHMRC, 1997:42).*

The report from the NHMRC urged that adequate counselling be made available to those patients not eligible for interferon therapy to provide information on the natural history of the disease as it is presently understood and on treatment options as they evolve (NHMRC, 1997:42). The NHMRC anticipates that this process will require at least annual contact with the patient to provide them with up-to-date information on the disease and its course. In the opinion of the NHMRC the patient's general practitioner is ideally placed to provide this input (NHMRC, 1997:42).

Support for counselling was also given by the Australian College of Sexual Health Physicians who noted in their submission that:

*Counselling remains one of the most important components of care in Hepatitis C due to the chronic nature of the infection and the limited range and success of treatment options (Australian College of Sexual Health Physicians submission).*

However, the Committee has heard that the task of managing those patients not able to access interferon requires more than providing them with information. A clinical nurse working in the area noted that:

*One of my main concerns is that patients who are not receiving interferon may not receive any health promotion education on Hepatitis C and cross-infection. I am unaware that any policy exists that stipulates educational requirements about Hepatitis C for these people. Family and friends of patients would not receive any education unless they directly sought it out themselves. Consequently, this could place them at some level of risk (Looby submission).*

The Committee shares Looby's concerns and considers there to be a very real need for appropriate education particularly as the majority of those with Hepatitis C do not access interferon therapy. The Committee considers it appropriate that the proposed Hepatitis C Policy Statement and Strategic Plan address the issue of managing those who are HCV positive and ineligible for interferon therapy to ensure they are provided with information on subjects including (although not limited to) the natural history of the disease, treatment options, health promotion and information on cross-infection and re-infection. Both the Policy Statement and Strategic Plan should address the counselling needs and psychosocial support for these patients and their families and the role of primary health care providers in giving such support.

**RECOMMENDATION 48:**

That the NSW Hepatitis C Policy and the NSW Hepatitis C Strategic Plan (proposed in Recommendations 28 and 31) address the management needs of those who are HCV-positive and ineligible for interferon therapy. Issues to be considered are to include (although not be limited to) (i) information on the natural history of the disease, treatment options, health promotion and cross-infection and re-infection; (ii) counselling needs and psychosocial support of these patients and their families; and (iii) the role of primary health care providers in giving this support.

**8.1.2 POLICIES LIMITING THE NUMBER OF INTERFERON PRESCRIBING CENTRES**

There are over 1000 public and private hospitals across Australia. Of these 66 are recognised Interferon Prescribing Centres. Within NSW there are 303 public and private hospitals, 24 of which are Interferon Prescribing Centres. These Centres and the policy establishing the criteria to be met by hospitals seeking to become Interferon Prescribing Centres were outlined in Section 7.2.1. During the course of this Inquiry, a number of issues concerning the location of these Centres were raised with the Committee.



A major criticism made to the Committee concerned the concentration of Interferon Prescribing Centres in the metropolitan region. The Committee heard, for example, that:

*the majority of [hospitals], like many health care services, tend to be concentrated in the metropolitan areas and the non-metropolitan country folk tend to miss out. This is a huge problem. Here you have people who live further out and they should come in to an approved centre and come in fairly regularly for treatment. It becomes a such a major burden that they therefore decide not to have the disease treated. It is unfortunate (Fong evidence, 27 October 1997).*

The Hepatitis C Council made similar comments:

*most people in rural areas who seek access to interferon are particularly disadvantaged because of the distance and expense involved in accessing treatment (Hepatitis C Council submission).*

Access to Interferon Prescribing Centres has been described as “limited” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission). ANCARD considered the situation to be akin to “centralisation of care” and saw this phenomenon as “a potential barrier to treatment for some people, particularly those in rural and outer suburban areas” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission). It called for options to make access “more accessible without compromising clinical standards or cost controls” (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).

Submission received by those with Hepatitis C identified some of the practical difficulties they experience as a result of this “centralisation of care”:

*The adequacy of diagnostic and treatment services in rural NSW is very poor. Only at the major centres (Wollongong and Canberra) can any form of ongoing treatment be obtained, and then the patient is at the mercy of bed availability or access to treatment programs. The local hospital has no blood transfusion facilities . . . so this means a costly and time consuming exercise of visiting a recognised treatment centre at Wollongong (Submission 39);*

*I moved from Sydney to Ulladulla and five months later I was diagnosed with Hepatitis C. What a bad move! I felt stranded!! Two hours drive to Wollongong to the nearest specialist (and to make matters worse we have to pay 80c/litre for petrol, so it makes it a \$40 trip each time) (Submission 38);*

and

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*I was referred to a local consulting physician and after blood tests I had my first liver biopsy at Grafton Base Hospital, the results were then referred to a gastroenterologist in Lismore, 150km each way (Submission 45).*

The Committee was concerned that there is just one treatment centre between Newcastle and Lismore, none west of Dubbo, and within the southern half of the state only two centres - those at Bega and Wagga Wagga. Professor Batey, based in the John Hunter Hospital, Newcastle, noted that:

*we have had patients from most of the major centres up to and including Grafton. Many people once they get to Grafton head north rather than come south. But we have certainly got patients from all the major centres coming to John Hunter and we treat them there (Batey evidence, 27 October 1997).*

Batey considers that:

*more centres should be able to assess, test and treat patients with Hepatitis C now that we have had this experience with 2,500 patients. This will occur in time (Batey evidence, 27 October 1997).*

While Batey may take comfort in more Centres being available “in time”, the Committee wishes to see the process speeded up to ensure assessment, testing and treatment are more accessible.

The limited number of Interferon Prescribing Centres is both a reflection of the criteria used to establish these Centres and available funding. Short of making additional funding available the Committee considers there to be several approaches to greater accessibility to assessment, testing and treatment. One approach would be to review, and if necessary, modify the current criteria used to establish Interferon Prescribing Centres.

**RECOMMENDATION 49:**

That the Minister for Health seek the support of his Federal counterpart for a review of the criteria used to establish Interferon Prescribing Centres to enable the expansion of the limited number of hospitals allowed to dispense interferon without compromising clinical standards or cost controls.

The Committee feels that, while it has a role to play, the issue is not one of simply relaxing the current criteria. As will be discussed in Section 8.4.1 a range of models for managing the treatment of Hepatitis C patients must be made available. Such an approach would ensure assessment, testing and treatment are more accessible without compromising clinical standards or cost controls.

### 8.1.3 POLICIES LIMITING PRE-TREATMENT ASSESSMENT

There is considerable research suggesting that certain genotypes of HCV respond better to interferon therapy than others. Those with genotype 3, for example, appear to respond better to interferon than those with genotypes 1a and 1b. Measurements of viral genotype can therefore be indicative of a person's anticipated response to interferon therapy. Similarly viral load as measured by PCR testing can also be used to indicate the likely outcome of therapy as patients with a high viral load are less likely to respond to interferon therapy than those with low loads (NHMRC, 1997:38).

The availability of tests to ascertain genotype and viral load therefore has important ramifications both for assessing patients before commencing interferon therapy (enabling therapy to be tailored to individuals) and also during the course of their therapy.

With specific reference to pre-treatment assessment, the NHMRC has noted that:

*most recent studies highlight the importance of pre-treatment assessment, including the measurement of viral genotype and viral load . . . The role of genotype and viral load in determining disease outcome can now be predicted more accurately. In Australia, the epidemic is being largely caused by types 1 and 3 and it would seem appropriate to tailor therapy to the viral type causing the infection in individual patients (NHMRC, 1997:34, 38).*

Despite current research and the NHMRC's observations access to interferon under the S100 scheme is, at this point in time, determined by assessment criteria alone and "no attempt is made to identify either the genotype or viral load in patients presenting for treatment" (NHMRC, 1997:34). This means that some patients are receiving thousands of dollars worth of drug when it is evident that their success rate will be well less than 10 per cent (ANCARD submission).

The Medicare Benefits Schedule does not make it possible to receive a Medicare rebate for PCR testing of genotype or viral load. Currently most of the genotype data in Australia is being generated by using research funds (Farrell evidence, 28 November 1997).

The Committee considers the current limited assessment prior to commencing interferon therapy to be outdated and inflexible - in short, quite inappropriate. Clearly recent advances in testing have to be taken into account particularly when they have the potential to improve cost effectiveness and contribute to overall quality of life as ANCARD noted in their submission to the Review of Highly Specialised Drugs Program:

*improving pre-treatment assessment is unlikely to reduce direct expenditure, because the current interferon dosage is regarded as the*

*minimum level for HCV and assessment will also reveal cases in which higher doses are likely to be effective. However, genotype and viral load testing, when introduced, will also greatly improve cost effectiveness and, by withholding a comparatively toxic drug from people who are unlikely to benefit from it, contribute to overall quality of life (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).*

The NHMRC has recommended resources being made available to allow for routine testing of viral load and genotype in all patients assessed for treatment with interferon (NHMRC, 1997:54). The Council proposed that:

*Genotyping and viral load testing should be available for patients in Australia (NHMRC, 1997:38).*

Similar conclusions were made at a meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel, the Clinical Trials and Treatments Advisory Committee (CTTAC) and invited participants held in February 1998. At that meeting, a proposed Hepatitis C testing protocol was forwarded (see Table Twenty-Three in Section 6.2). Those at the meeting agreed that viral load testing was required before treatment (but not during or after treatment) as it would indicate the outcome of the treatment response, and genotype testing should be performed to advise therapy (ANCARD Hepatitis C Clinical and Virological Advisory Panel and the Clinical Trials and Treatments Advisory Committee, 1998).

During the course of this Inquiry, there was considerable support for genotype and viral load testing to be made more readily available. Not surprisingly the pharmaceutical company, Schering-Plough recommended interferon therapy should not be withheld on the basis of genotype. In their opinion:

*they should all at least be offered the treatment and given the chance. If at the end of three months they fail to respond and that is determined by their ALT, if it fails to fall then you know they are not going to respond and you take them off (Rallings evidence, 27 October 1997).*

ANCARD suggested (and the Committee fully agrees) that:

*it would be more appropriate now to be using genotyping to allow more rational approaches to induction therapy to be used (ANCARD submission).*

Professor Farrell would also like to see the test available. However he adds an important caveat - he would like to see them available on a "highly restricted basis" because:

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*it would be very wasteful for everybody on a curiosity basis, even though they might like to know their genotype, if they had very mild disease it is probably not relevant to know the genotype, and I would have a preference that the test be ordered by someone who is an expert in the area . . . someone who is trying to counsel a patient on whether to have treatment or not (Farrell evidence, 28 November 1997).*

The Committee is convinced that access to viral load and genotype testing would provide an important assessment tool prior to commencing treatment enabling those least likely to benefit from this particular form of therapy to be screened. NSW Health recognises the potential of such testing and the attendant funding advantages:

*funding specifically for this [genotype testing] could reduce health costs in the long term. For example a \$120 test could save \$6,000 of interferon treatment if the test result showed that the person was infected with a genotype of HCV non-responsive to interferon (NSW Health submission).*

#### **RECOMMENDATION 50:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to determine genotyping and viral load in the pre-treatment assessment for patients considering interferon (and other drug) therapy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

#### **8.1.4 POLICIES LIMITING INTERFERON DOSAGE SCHEDULE**

The current standard course of interferon therapy, as prescribed by PBAC is 3MU three times a week. All patients receive the same dosage schedule irrespective of their genotype, viral load, or complications such as cirrhosis, despite research demonstrating that cirrhotic patients often respond better when the dosage is increased to 4.5MU. The Committee agrees with the NHMRC who noted that:

*It is inappropriate to regard all chronic Hepatitis C patients as the same and as requiring the same therapeutic doses of interferon (NHMRC, 1997: 34).*

The ANCARD submission suggests that patients with cirrhosis should be allowed access to treatment given at a higher induction schedule. In its submission to the Review of Highly Specialised Drugs Program ANCARD went a step further and hypothesised that access to genotyping and viral load testing will result in future patients with responsive Hepatitis C (non-fibrotic, genotype 2 or 3, low viral load) receiving the standard course of interferon while those with more resistant disease will automatically receive a higher induction course which would be reduced to maintenance levels once the viral load falls. This would increase the cost of a 12 month course from \$3,500 to \$10,000. It may, however, still be cheaper than using

some of the new antiviral therapies. The cost of a course of Ribavirin is, for example, \$20,000 (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).

The ANCARD submission stresses that any discussion of increasing costs of interferon must be kept in perspective. Upward pressure on expenditure will continue to be limited by the side effects commonly associated with interferon and the therapy's limited efficacy (ANCARD submission to the Review of Highly Specialised Drugs Program - attachment to submission).

The Committee considers the current practice to be very inflexible with little regard for individual differences. It wishes to see flexibility introduced giving clinicians provision to take into account individual differences and scope to prescribe dosages appropriate to individual patients.

**RECOMMENDATION 51:**

That the Minister for Health urge his Federal counterpart to encourage the Pharmaceutical Benefits Advisory Committee to introduce a degree of flexibility into the S100 Highly Specialised Drugs Scheme enabling the interferon dosage schedule to be increased where necessary and appropriate such as in the case of cirrhotic patients.

**8.1.5 POLICIES LIMITING TREATMENT ASSESSMENT AND MONITORING**

PCR testing can be used to monitor the efficacy of therapy by measuring the viral load at intervals during therapy. The Committee was advised, for example, that evidence to date suggests that an 80 per cent drop in viral load within the first month of commencing interferon therapy is predictive of a long term response. The PCR test is sensitive enough to determine such a drop.

According to the drug company, Roche, the implications for PCR in the future is its potential to monitor the impact of interferon therapy on the patient. Using PCR to monitor the viral load at baseline and after one month of treatment will result in one of two options for patients:

1. If an 80% drop in viral load is detected, they are likely to be a "sustained responder" and hence continuation of therapy for the full 12 months is necessary; or
2. If there is less than 80% drop in viral load, future treatment strategies may include: increasing the interferon dosage, adding another agent or ceasing therapy altogether (Roche submission).

As Roche pointed out to the Committee, such an approach to treatment will result in:

- patients knowing early in their treatment the likelihood of response thus avoiding unnecessary/ineffective treatment;
- much greater response rates as treatment can be continued to those who are likely to respond; and
- potentially more patients with access to treatment and consequently a reduction in the overall costs of HCV to the Australian government (Roche submission).

The meeting of the ANCARD Hepatitis C Clinical and Virological Advisory Panel and the Clinical Trials and Treatments Advisory Committee (CTTAC) held in February earlier this year also supported the use of qualitative PCR testing after 12 weeks of interferon. The proposed testing schedule also included PCR testing at the end of interferon therapy, and follow-ups after six months and then again at 18-24 months (ANCARD, 1998).

Currently PCR testing is not freely available for assessing and monitoring interferon therapy. The Committee considers there to be a vital role for PCR, not only in pre-treatment assessment as has been discussed, but also in monitoring interferon therapy and tailoring therapy to ensuring maximum efficacy of treatment and efficient utilisation of resources available. It therefore wishes to see pressure put upon the Federal government to provide a Medicare rebate for PCR testing used to monitor and assess the efficacy of interferon treatment in Hepatitis C patients.

**RECOMMENDATION 52:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to monitor interferon (and other drug) therapy and tailor therapy to ensure maximum efficacy of treatment and efficient utilisation of resources to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

**8.1.6 POLICIES LIMITING PCR TESTING FOR HCV+ WOMEN CONSIDERING PREGNANCY**

PCR viral load testing can be used to predict the relative risk of vertical transmission during pregnancy. Such information would be of considerable importance to those women who are HCV+ and contemplating pregnancy and, as was discussed in Section 3.6, calls have been made for those contemplating pregnancy to ascertain their PCR status (Sladden *et al*, 1998:293). However, at this stage, testing conducted for this purpose is not covered by the Medicare Benefits Schedule.

During the course of this Inquiry, mothers recounted to Committee Members their angst as they awaited the results of pathology tests carried out on their children and the

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associated guilt and fear many carried before learning of their children's Hepatitis C status. One witness, a clinical psychologist with considerable experience in counselling those with Hepatitis C, stated that:

*PCR testing is needed to determine the viral load in the blood of a woman to know whether she has the right to be responsibly pregnant (Lamb evidence, 30 March 1998).*

Hepatitis C positive women wishing to conceive need to be provided with as much information as is available to enable them to make informed choices and decisions. The Committee therefore wishes to see the Medicare rebate on PCR viral load testing available to those women contemplating pregnancy.

**RECOMMENDATION 53:**

That the Minister for Health approach his Federal counterpart and seek his support for PCR testing used to predict the relative risk of vertical transmission during pregnancy to be fully covered either under the Medicare Benefits Schedule or hospital block funding.

## 8.2 INADEQUACIES OF THE CURRENT TREATMENT REGIME

In considering the adequacy of the current treatment regime, the Committee concurred with the comment made by a Schering-Plough representative who commented during the course of evidence that the current treatment is "far from optimal" (Kir evidence, 27 October 1997). As the Committee heard:

*you would have to be a super patient, first to qualify to get the treatment, and then once you qualify, to find the centre and find a specialist that actually has the time and the ability to see you (Matouk evidence, 27 October 1997).*

In considering the current treatment regime, the Committee identified two specific areas of inadequacy: the limited number of treatment options available and the limited success of the one available form of therapy. Both of these issues will be examined in the following discussion and a number of strategies to address these inadequacies proposed.

### 8.2.1 LIMITED TREATMENT OPTIONS

Proven and approved treatment options for those with Hepatitis C are limited to one: interferon. While other drug therapies are currently being tested, the Committee understands that their widespread introduction is still a number of years away. The



Hepatitis C Council advised that protease inhibitor drug therapy will not, for example, be available for another four to five years (Hepatitis C Council submission).

### **8.2.2 LIMITED SUCCESS OF AVAILABLE THERAPY**

As has been discussed, interferon therapy is only effective for approximately one in four of those treated. As more treatment options become available the success rate may improve, but the introduction of new treatment options is not imminent.

Not only is interferon of limited success, but many experience significant side effects. The Committee heard that these problems are exacerbated for women:

*when one's liver is not functioning properly, this is from observation rather than medical knowledge and from talking to lots of women with Hepatitis C, one cannot guarantee how one's hormones will function, and that can have disastrous effects . . . Women never knew when their periods were due, never knew anything like that. It is worse on interferon. It is a very difficult situation for women (Lamb evidence, 30 March 1998).*

Clearly the limited options for treatment, and the limited efficacy of the one approved treatment regime is a matter of grave concern not only to those affected by Hepatitis C and their families but state and federal governments responsible for the provision and funding of health services both now and in the future.

The Committee fully agrees with the Hepatitis C Council which observed that:

*there are still too few treatments available for people with HCV and . . . there is still a lot to learn about the response of the virus to new initiatives in this area. The advance of treatments for HCV should be strongly encouraged and supported (Hepatitis C Council submission).*

### **8.2.3 ADDRESSING CURRENT TREATMENT INADEQUACIES**

The Committee considered that action in at least four areas must be taken to address the identified current treatment inadequacies: further research into the treatment for Hepatitis C; support for those who do not respond to interferon; support for those on interferon and fast tracking of new drug therapies as they become available. Each will be discussed in the following section.

- **Need for Further Research**

Experts appearing before the Committee stressed the need for considerable research to be undertaken in the area of Hepatitis C. Professor Farrell, for example, commented on:

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*the considerable need for funding of research in this area . . . There is negligible Commonwealth, indeed State research investment in this disease (Farrell evidence, 28 November 1997).*

The Committee understands most research to be funded by pharmaceutical companies and that, during the last three years, less than \$150,000 per annum has been expended from the national medical research budget on Hepatitis C (Farrell evidence, 28 November 1997). Such figures “compare very unfavourably” with investment of research in the area of HIV-AIDS which is “several orders of magnitude greater than that” (Farrell evidence, 28 November 1997). Professor Farrell considers it:

*a national disgrace that not more money has been spent on research extending right from epidemiology, finding out how common it is, who has it, how they are still getting it, through to the social impact of the disease, which is the major thing, the morbidity of the disease, and then ultimately through to trying to prevent people actually dying of the disease (Farrell evidence, 28 November 1997).*

As has been discussed in Section 4.5, \$1million for Hepatitis C research was announced in early 1998. While welcoming this initiative, the Committee understands that most of the funding is already earmarked for social and behavioural research and drug trials were specifically excluded (Federal Parliament Liaison Group on HIV/AIDS and Related Diseases, 1998:3). As important as this research is, the Committee considers it to be unfortunate if that facet alone was to receive all funding allocations. Given the considerable numbers of those in the community with Hepatitis C, and the implications such numbers have upon the health care system (and budget) it is imperative that an effective form of treatment be found.

Funding research into clinical drug studies has traditionally been the domain of pharmaceutical companies. However, the Committee considers the need to find an effective treatment for Hepatitis C to be such a priority that it calls upon both federal and state governments to fund clinical studies to identify and understand new treatments for Hepatitis C.

**RECOMMENDATION 54:**

That the Minister for Health request his federal counterpart fund and support clinical studies to identify and understand new treatments for Hepatitis C and the impact upon patients (particularly female patients) of these new, and existing, treatments. The Committee further recommends that the state government match federal funding for this research on a dollar for dollar basis.

- **Need for Support for Those who do not Respond to Interferon**

As was stated in Section 7.1.2, the Committee has adopted the statistic of one in four as the number of people for whom interferon is effective. While this statistic is alarming, the converse of this statistic also needs to be considered: interferon therapy is unsuccessful for three out of four of those who commence therapy and, for those with certain genotypes, the rate of failure can be as high as 90%. Such a high failure rate has its consequences. The Committee heard that:

*these people who have seen interferon as the only opportunity to improve their health, become disappointed and angry (Hepatitis C Council submission).*

Similar comments were made to the study conducted by the National Hepatitis C Council's Education Reference Group. The study's final report notes that:

*several participants who had 'failed' on interferon were very angry at the lack of counselling or follow-up provided when they left the programme. They had been told that interferon was the only treatment available so that failing the programme left them in a state of hopelessness (National Hepatitis C Council's Education Reference Group, 1996:29).*

A psychiatrist commented to the Department of Health that:

*They [ex-interferon patients] may have difficulty in dealing with uncertainty or the disappointment that will accompany treatment failure (Ryan correspondence, attachment to NSW Health submission).*

From information provided to the Committee, it would appear that there are very few support services available to those who do not respond to interferon. The Hepatitis C Council advised the Committee that:

*Few services currently exist to provide counselling and support to those who have 'failed' on interferon. In interferon treatment centres staff who provide information and monitor people's progress while on treatment are overburdened and under-resourced. When people leave treatment there are few follow-up and counselling services available (Hepatitis C Council submission).*

The Committee is concerned with the limited support mechanisms available for those who fail interferon. It considers it essential that adequate support be provided to these patients to assist them come to terms with their disappointment and anger.

**RECOMMENDATION 55:**

That the Strategic Plan proposed in Recommendation 31 consider the provision of adequate support mechanisms for people who do not respond to interferon therapy. The Committee further recommends that the Strategic Plan set targets for the establishment of support services in inner city, metropolitan and regional/rural locations.

- **Need for Support for those on Interferon**

As was described in Section 7.1, the side effects of interferon can be quite severe and many of those on the drug therapy find the twelve month period to be a very difficult time both physically and emotionally. Clinical nurse consultants working in the liver clinics are available to provide support for these patients. However it has been suggested to the Committee that the demands placed upon these nurses are such that they have little time to give the support needed by the patients on interferon. To lessen the load of the clinical nurse consultants, the Committee would like to see a range of other health care professionals available to provide support for those on interferon.

Within the health care system, there are a number of professionals who currently provide psychosocial support to those with chronic illness. It is possible that social workers, counsellors, chaplains, drug and alcohol workers could, with training, provide the support needed.

**RECOMMENDATION 56:**

That NSW Health provide HCV specific training (both initial and ongoing) to existing providers of psychosocial support for people with chronic illness employed within the health care system, such as social workers, counsellors, chaplains, drug and alcohol workers enabling these professionals to provide support to those on interferon therapy.

- **Liver Transplants**

As experts such as McCaughan and Batey reminded Members Hepatitis C is the main indication for liver transplantation in Australia (McCaughan evidence, 23 March 1998 and Batey evidence, 27 October 1997). McCaughan observed this implies more people are being referred to liver transplant units with end-stage liver disease associated with Hepatitis C (McCaughan evidence, 23 March 1998). While liver transplantations started as a federally funded national program, the programs became a state responsibility about three years ago costing approximately \$100,000 - \$120,000 per case (McCaughan evidence, 23 March 1998).

In terms of waiting lists for liver transplants, the Committee heard that:

*the waiting list for transplantation is blowing out now but the donor rate has not changed that significantly; it has not increased. We used to run a program up until about three years ago in which we had a waiting list of between five and ten people - people tended to die or get a transplant. Now we regularly run a waiting list of between 20 and 30 patients and a third of those now are Hepatitis C . . . That will mean that many people will die before they get a transplant (McCaughan evidence, 23 March 1998).*

In terms of future needs, McCaughan advised that “it is likely that the number of organs will not match the demand” (McCaughan evidence, 23 March 1998). Mr Harvey from the Hepatitis C Council told Committee Members that:

*estimates are that the demand already outstrips the number of suitable donors and that will increase substantially as more and more people who are now in their 40s become older and these problems develop . . . I cannot see anything on the horizon that is going to improve that, so it is going to be a bad situation (Harvey evidence, 3 October 1997).*

Australia has one of the lowest rates of organ donations amongst developed nations, an issue which is of concern to health departments across the nation. The Committee is concerned with the general issue of organ donations and liver donations in particular and wishes to see increased attention be given to the subject to find innovative and effective solutions to the problem.

#### **RECOMMENDATION 57:**

That the Minister for Health, through the forum of the Australian Health Ministers' Council, urge his federal, state and territory counterparts to recognise Australia's low rate of organ donation and consider innovative and effective ways to increase the donations of organs in general and liver donations specifically.

### **8.3 INADEQUACIES OF CURRENT SERVICE DELIVERY**

During the course of this Inquiry, a number of comments were made concerning the adequacy, or otherwise, of current service delivery. The following discussion looks at issues raised pertaining to three levels of service - the state/health area level; hospital level; and general practitioner level.

In forming its assessment of inadequacies in the current system of service delivery, the Committee wishes to state clearly that its comments are in no way a reflection on the expertise and commitment of those health care workers within the system. Throughout

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the course of this Inquiry, the Committee was deeply impressed with the dedication of those health care professionals it met with, many of whom are working within extremely tight budgetary constraints, heavy schedules and competing demands of clinical management, teaching, research and administration.

### **8.3.1 INADEQUACIES AT THE STATE AND AREA HEALTH LEVEL**

The Committee received comments on the inadequacies of the provision of services at all three levels of service delivery: the state; area health boards; and specific hospitals.

In commenting on the statewide situation Batey noted that, “at the moment resources are less than adequate” (Batey evidence, 27 October 1997). In terms of specialist services, Farrell noted that:

*At the level of speciality services with which I am most familiar because I am a specialist in the area of liver disease there has been no expansion at all of services for the very large number of persons with this disorder, despite clear evidence of its high prevalence, despite evidence of difficulties of patients getting access to special clinics, despite evidence of Hepatitis C becoming the single most common cause for adults requiring liver transplantation in New South Wales during the last five years and despite published evidence of a considerable increase in cases of liver cancer, some of which is attributable to Hepatitis C. At the moment the services that are available are threadbare (Farrell evidence, 28 November 1997).*

At the level of Area Health Boards, the Chair of the Central Sydney Area Health Board advised the Committee that:

*From the perspective of the area health board, I would have to say that we are not providing the full range of adequate services I should like to be in a position to provide. We are short of both personnel and the necessary financial resources to do so (Puplick evidence, 7 November 1997).*

### **8.3.2 INADEQUACIES AT THE HOSPITAL LEVEL**

In terms of individual hospitals, the Committee heard that both RPA and Westmead hospitals provide a full range of diagnostic and treatment services but they are “underfunded and under-recognised” (Puplick evidence, 7 November 1997). Mr Puplick added that the provision of services at Royal Prince Alfred and Concord hospitals are “inadequate” (Puplick evidence, 7 November 1997).

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Also citing the experience of Royal Prince Alfred Hospital the hospital's Nurse Consultant/Coordinator, Hepatitis C Services advised that:

*We have had no increase in our services since Hepatitis C really took off, since 1990. The only thing that has happened is that my position [nurse consultant/coordinator, Hepatitis C services] has been created . . . there has been no provision for an increase in services (Pritchard-Jones evidence, 2 October 1997).*

As was shown in Table Six Central Sydney Area Health Service has the second highest notification rate of Hepatitis C patients in the state, possibly Australia. This has led to increases in referrals but, not the Committee heard, an increase in services:

*there has certainly been no increases in our bed allocation numbers, and so patients are having to wait three weeks or so to come in for a transplant assessment (Pritchard-Jones evidence, 2 October 1997).*

Not only are patients having to wait for their assessment, but when they are able to have the assessments done, it is frequently undertaken on an outpatient basis:

*Quite often they are now having to have their transplant assessment done, which involves coming into hospital and having a significant amount of testing done, such as angiography, CT scans, etc., on an outpatient basis (Pritchard-Jones evidence, 2 October 1997).*

The Committee heard that such an arrangement:

*is not really adequate but there is really no other way we can run things at the moment (Pritchard-Jones evidence, 2 October 1997).*

- **Waiting Lists**

The pressure on clinical services is, not surprisingly, resulting in waiting lists. The Chief Health Officer of the NSW Department of Health admitted to the Committee that

*there is a significant delay in that primary assessment process and referral process (Wilson evidence, 3 October 1997).*

The Red Cross confirmed that waiting time for metropolitan liver clinics can vary from "weeks to months" (Red Cross submission) while Batey informed Members that:

*In the major clinics when we last looked at waiting times they were anything from three to twelve months to get an appointment to see a hepatologist to be assessed for treatment . . . I think that waiting time may well have come down, it has certainly come down for me to less than six months now (Batey evidence, 27 October 1997).*

According to the NSW Department of Health, waiting times for interferon assessment and liver biopsy vary widely depending on the individual clinician and centre involved. Waiting times for liver biopsy also depend on the extent of assessment by the general practitioner before referral to a gastroenterology clinic. However, the Department did provide several examples of waiting times which are recorded in Table Twenty-eight.

**TABLE TWENTY-EIGHT**  
**EXAMPLES OF WAITING LISTS IN NEW SOUTH WALES**

	<b>ASSESSMENT BY REGISTRAR</b>	<b>ASSESSMENT BY SPECIALIST</b>	<b>LIVER BIOPSY</b>
John Hunter	3 weeks	3 months	1 month
Royal Prince Alfred Hospital	6 weeks	4 months	1 month
Lismore Base	3 months	3 months	3 months

Source: Wilson evidence, 3 October 1997

In reporting to the Committee on waiting lists in his liver clinic, Professor Farrell advised that, as of late November 1997, the waiting time for new patients to attend Westmead's clinic was nine weeks and the follow-up visit, ten weeks. Such current delays are "not quite as bad as it has been at times" (Farrell evidence, 28 November 1997).

Without appropriate intervention, the problem of waiting lists is set to worsen as those with Hepatitis C move into the chronic stages of their disease. The Committee considers it essential that measures be put in place as a matter of priority to ensure current numbers are handled before the influx occurs and there is a total blowout.

- **Inadequate Provision of Specialist Services**

Professor Farrell advised the Committee that:

*there are some areas in Sydney where Hepatitis C is exceptionally common where there is not a single liver specialist, South Western Sydney [Area Health Service] is one such example. There does need to be some more specialist services* (Farrell evidence, 28 November 1997).

Farrell also noted that:

*the South Western Sydney Area Health Services is an area where there is a dearth of specialised liver clinics and liver specialists coordinated with other services in a way to provide treatment and counselling of Hepatitis C* (Farrell correspondence, 6 October 1998).



The lack of a liver specialist or availability of a gastroenterology outpatient liver clinic in the South Western Sydney Area Health Service (SWSAHS) is inappropriate given that, according to Table Six, the area has the third highest notification rate of Hepatitis C in the state. SWSAHS has a large Vietnamese community and the Committee heard that many of those with Hepatitis C travel from the south west to Concord hospital where there is a Vietnamese gastroenterologist who “has a big Vietnamese clientele” (Pritchard-Jones evidence, 2 October 1997).

- **Inadequate Provision of Hepatitis C Clinical Nurses**

As a result of limited financial resources many nurses in clinical management are financed by drug companies. Not all of those appearing before the Committee supported this practice. ANCARD, for example, observed:

*it seems inappropriate that drug companies should be providing health department positions to deal with a disease which is causing a considerable load on liver clinics throughout the state (ANCARD submission).*

The issue was taken up when ANCARD Chair, Mr Chris Puplick, appeared before the Committee. He noted that:

*the general question of allowing any financially self-interested element within the health system is a potential distortion in a way that leads to the interests of the pharmaceutical provider prevailing over the interests of, first, the patient, and second, the public health system. It is not just in relation to liver clinics, it is in relation to just about anything else which is likely to be done on a fee-for-service basis (Puplick evidence, 7 November 1997).*

Professor Farrell also brought the issue to the attention of the Committee:

*the staffing of a clinic such as my own is heavily embellished by staff who are employed on research funds, not on funds for clinical services . . . There are very few [clinical nurse consultants] engaged in Hepatitis C work and , as far as I can see, very few, if any, of them are supported by the state health budget most of them are supported by research funds for educational grants and pharmaceutical companies who have a vested interest in treatment programs (Farrell evidence, 28 November 1997).*

Farrell concluded such a practice to be “very unsatisfactory” (Farrell evidence, 28 November 1997). Given the potential for a conflict of interest, the Committee considers it inappropriate that nursing staff of liver clinics be financed by drug companies.

- **Inadequate Allocation of Funding**

The inadequate provision of services, waiting lists and lack of specialist services are all directly related to funding, or lack of it. The Committee heard that:

*there has been no additional state or federal funding for additional liver specialists and nurses to adequately provide treatment and management of Hepatitis C at these [approved] centres (Schering-Plough submission).*

Schering-Plough noted such a need:

*available evidence on the natural history of the disease shows that if more funds are not made available in the short term, there will be a greater need for even more funds in the medium to longer term to support the more costly, later stages of this disease (Schering-Plough submission).*

Farrell suggested that:

*What we do need is a very modest but identifiable expansion of clinical services which may be of the order of not more than \$5 million (Farrell evidence, 28 November 1997).*

### **8.3.3 INADEQUACIES AT THE GENERAL PRACTITIONER LEVEL**

A recurring theme in both evidence and submissions was the limited knowledge and inexperience of many general practitioners in relation to Hepatitis C, its treatment and management. Both experts and people with Hepatitis C acknowledged this to be an issue of concern.

Expert witness, Dr Wodak, for example, noted that “general practitioners are not yet well educated about Hepatitis C” (Wodak evidence, 2 October 1997) and as a result:

*general practitioners often refer their patients to liver clinics and the liver clinics in this state and the rest of the country are swamped with people with Hepatitis C (Wodak evidence, 2 October 1997).*

The Red Cross advised the Committee that:

*the majority of general practitioners and other doctors have only basic knowledge about Hepatitis C and its natural history. Most are inexperienced in the interpretation of serological tests and have no experience in providing lifestyle advice to individuals who are HCV positive (Red Cross submission).*

Drawing upon his experience in working with general practitioners, Hall noted that:

*Because of a lack of information, specialists and especially general practitioners have been feeding patients with inaccurate, inconsistent or incomplete information. In our understanding of Hepatitis C a lot of information is still evolving, so it is very easy for a GP to give a fudgy, confusing piece of information to patients. That has fed a great deal of patient distrust of the medical system and a great deal of confusion (Hall evidence, 6 November 1997).*

A number of submissions from HCV+ people cited difficulties experienced with general practitioners:

*the treatment by local general practitioners is largely a hit and miss affair (Submission 39);*

and

*My general experience with general practitioners and experiences my friends who have HCV share is that when going to the local GP you have him tell you either "I don't know anything for your HCV" or "take a couple of Panadol and lie down". The majority of general practitioners in the community really have no idea at all (Submission 66).*

The submission from an infected health care worker reported an incident that occurred while in a waiting room waiting to see her general practitioner. When the doctor about to treat her discovered her status from the admission notes:

*He 'freaked' when he read my chart, walking over to the nurse who was in the large room with other patients... and shouted 'This lady is HCV+. What are we going to do with her? Why wasn't I told?' He went on and on until eventually the nurse said 'Look, she's still over there; she's been through here three times before when we didn't know so just get on with your job' (Submission 81).*

During the course of her evidence, another witness recounted the following series of interchanges with doctors, the first in response to her blood tests:

*he [the doctor] said, "well, it says that you have got Hepatitis C". I said, "What is that?". He said, "Nothing to worry about. It's passed on by dirty hands. You probably got it when you were overseas". This was from a professor of haematology. I thought, "No I don't believe you". I went to my local doctor and told him. He said, "Oh that's bad . . . I don't know anything about it. It has only recently been diagnosed". I went to another doctor and he said "That's good. You've got antibodies in your blood. It means you will never get it" (Lamb evidence, 30 March 1998).*

It would appear that the result of this limited knowledge and inexperience is the inappropriate referral of patients to liver clinics and specialists at tertiary hospitals:

*If they are detecting and diagnosing Hepatitis C they then refer cases to specialists who do specialist work that is costing a lot of health dollars inappropriately . . . At the moment specialist liver clinics are clogged up with inappropriately referred patients* (Hall evidence, 6 November 1997).

The Committee appreciates that the reported reluctance of general practitioners to be actively involved in the management of Hepatitis C patients may not always be a reflection of lack of desire or interest. It may reflect their limited knowledge and understanding of the virus. The Committee heard, “currently there are no consistent resources across the board for general practitioners to tap into in relation to information or education” (Hall evidence, 6 November 1997). Hall further admits “to be fair, they [general practitioners] have not been well placed to take up that role” (Hall evidence, 6 November 1997). Wodak also acknowledged this:

*One of the ways in which we have been slow to respond is getting education materials out to general practitioners who are the first port of call for people who discover they have Hepatitis C. Many general practitioners are not at the moment well equipped to handle this problem* (Wodak evidence, 2 October 1997).

The Committee understands that, unlike complex diseases such as HIV, the management of Hepatitis C is relatively simple. The Committee heard, for example, that “Hepatitis C generally is a fairly straightforward health issue that can be dealt with by general practitioners at a clinical level” (Hall evidence, 6 November 1997). In Hall’s opinion:

*general practitioners should be the central medical care providers for Hepatitis C patients . . . Because of the long-term chronic nature of Hepatitis C and the long time in which a patient has no symptoms at all, but may have other needs, general practitioners should be the central care providers* (Hall evidence, 6 November 1997).

There is clearly a need to educate general practitioners in the management of Hepatitis C. The NHMRC recognised this need and recommended that:

*additional efforts be made to improve the education of physicians and general practitioners in the use of interferon alpha and the appropriate responses to variations in liver functions tests in patients* (NHMRC, 1997:38).

### **8.3.4 CONCLUSION**

The Committee considers the current inadequacies in service delivery - at all levels of the system - to be unacceptable. In response, it calls upon the government to state its commitment to providing adequate and appropriate treatment and management service to those in NSW who are HCV+ and that these service be provided at all levels of health care - from primary through to tertiary health care. The Committee further calls upon the government to state this commitment in its Hepatitis C policy statement which the Committee proposed in Recommendation 28 and identify in the Strategic Plan (proposed in Recommendation 31) the way this commitment will be realised.

#### **RECOMMENDATION 58:**

That the Minister for Health state his government's commitment to providing adequate and appropriate health care - from primary through to tertiary health care - to all those in NSW who are Hepatitis C positive.

#### **RECOMMENDATION 59:**

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 clearly enunciates the Minister's commitment to providing adequate and appropriate health care to all those in NSW who are Hepatitis C positive. The Committee further recommends that the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 clearly identifies the way in which the Minister's commitment will be realised along with appropriate time frames and funding allocations.

#### **RECOMMENDATION 60:**

That the NSW Hepatitis C Strategic Plan be the basis upon which NSW Health allocates funding to treat and manage Hepatitis C.

### **8.4 RESPONDING TO CURRENT INADEQUACIES**

The Committee could readily make specific recommendations to address any one of the inadequacies identified in the preceding discussion such as the appointment of a liver specialist or the establishment of an outpatient liver clinic in the South Western Sydney Area Health Service. However, such a measure would not overcome what appears to be a systemic problem that pervades the state's health system in terms of treating and managing Hepatitis C.

The NSW Hepatitis C Taskforce examined the issue of clinical services and clinical management and identified a number of deficiencies in the then current services which had come about due to “the lack of increased resources at several levels in the face of an expanding clinical need” (NSW Health 1995:30). The deficiencies were similar to those identified during the course of this Inquiry and included:

- delay for patients to be assessed by gastroenterologists and hepatologists;
- a lack of counselling service for patients at the nurse consultant level;
- the huge size (up to 50 patients per session) of some clinics assessing and processing patients;
- the lack of day stay beds in some institutions for liver biopsies; and
- lack of availability of interferon therapy outside the S100 guidelines (NSW Health 1995:30-31).

The Taskforce Report recommended initiatives to overcome the deficiencies in both the short term (1-2 years) and long term (two years and beyond) and at two levels of care: the hospital level and the general practitioner level.

As an overall recommendation, the Taskforce recommended some enhancement of HCV consultant services in most health areas (1995:6). It also recommended that, as a matter of urgency, a comprehensive needs assessment and services planning project be undertaken and minimum service levels, based on a health outcomes approach, be set.

As an interim measure, the Taskforce further recommended the guidelines of the Report’s text be used as the basis for developing a comprehensive HCV clinical capability in New South Wales. The recommended minimum levels of service provision were:

- one nurse consultant/educator per Health Area;
- 1.5 hepatologist (full time Hepatitis C) per 600,000 population;
- 0.5 resident medical officer (full time Hepatitis C) per 600,000 population; and
- adequate liver biopsy day stay beds and adequate ultrasound facilities (NSW Health, 1995:6-7).

The Committee understands that these recommendations were never implemented. The response of the Department to these recommendations was that:

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*consultation with the relevant Departmental Branch suggested that further data are required to justify the stated resource recommendations. Perceptions of needs for clinical services will be re-examined in the light of the evaluation of the current Hepatitis C demonstration projects and a service development exercise is being considered for commencement in 1998 (tabled document - NSW Health, 3 October 1997).*

In commenting on the Department's lack of response to these recommendations, Professor McCaughan noted that they were:

*never delivered, and were thought by the NSW Department of Health to be some sort of pie-in-the-sky overestimation of the need (McCaughan evidence, 23 March 1998).*

Given the inadequacies identified by expert witnesses and discussed above, the Committee considers the Department's response to the Taskforce recommendations to be totally inadequate. The Committee also considers it likely that, had the Department implemented these recommendations in 1995-96 when originally proposed, current inadequacies and shortcomings - or the extent and severity of these shortcomings - may have been avoided.

Having considered all possible options to overcome current inadequacies, the Committee has decided to support fully the original recommendations made by the NSW Hepatitis C Taskforce. This time, the Committee wishes to see the recommendations implemented fully and, as is suggested by the six month deadline proposed, promptly.

**RECOMMENDATION 61:**

That NSW Health conduct a comprehensive needs assessment and service planning exercise within six months of this Report being tabled. This exercise is to include the provision of services in all health areas and all public hospitals.

The Committee further recommends that the Department set minimum service levels based on a health outcomes approach.

**RECOMMENDATION 62:**

That NSW Health incorporate the implementation of the results of the needs assessment and the service planning exercise into the Strategic Plan proposed in Recommendation 61.

**RECOMMENDATION 63:**

That the Minister for Health allocate funding for the implementation of the results of the needs assessment and service planning exercise proposed in Recommendation 61.

The Committee is aware that needs assessment and service planning activities have and are being conducted across the state, albeit in a somewhat *ad hoc* manner. In May 1997, for example, a review of the Hepatitis C services was undertaken in the Central Sydney Area Health Service (CSAHS). The aim of the mapping exercise was broader than that proposed above and included mapping out the range of HCV surveillance, prevention, counselling and treatment services within CSAHS provided by the public, private and non government organisations. The exercise also sought to identify the needs and gaps in the services and propose strategies to meet these gaps; identify ways to improve the coordination of HCV services; and secure commitments to develop a more integrated service with defined referral and continuum of care pathways (Morrow Centre submission). In informing Members of the mapping exercise McCaughan noted that it:

*tried to pull together people in the Central Sydney Area Health Service outside of the gastroenterology and liver programs who should be coming in contact with a lot of Hepatitis C patients . . . the mapping exercise pushed Hepatitis C in the face of all those groups who should have been making a major contribution to the handling of the illness. That started to bring Hepatitis C much more into focus amongst those groups. They have responded and are now starting to make available more significant time and resource commitments for Hepatitis C which they were not doing before (McCaughan evidence, 23 March 1998).*

The Committee is also aware that most, if not all, of the demonstration projects reviewed in Section 8.4.2 include a mapping component.

Having addressed the issue of needs assessment and service planning, the Committee then considered two questions pivotal to responding to current inadequacies: who should treat and manage Hepatitis C patients?; and where should these patients be treated and managed? Traditionally Hepatitis C has been treated and managed by specialists and clinical nurse consultants in liver clinics in tertiary level hospitals. The problems that have arisen through such an approach have been identified and discussed above. Clearly there is a need for different models and approaches to be introduced to overcome these inadequacies.

**8.4.1 WHO SHOULD TREAT AND MANAGE HEPATITIS C?**

Hepatitis C has primarily been treated by hepatologists and gastroenterologists with minimal involvement from general practitioners. Two projects are currently underway



to encourage greater involvement of general practitioners: the national shared care program which envisages general practitioners working with specialists to treat and manage Hepatitis C; and the national Hepatitis C education program for general practitioners which seeks to educate general practitioners in a number of Hepatitis C related issues such as detection and management (though not necessarily treatment). Both programs are reviewed in the following discussion.

- **Specialists and General Practitioners Working Together: the Hepatitis C National Shared Care Project**

Dr Kaldor noted that:

*up until now under the models of care for Hepatitis C, you can get a diagnosis of Hepatitis C from a general practitioner or you can get advanced forms of care at hospital-based sites, but there has been very little development of shared care models or indeed ways of getting a better level of Hepatitis C care in primary health settings. It has been very much the model of referral to hospital specialists and hospital specialists, if they were to try to deal with the number of people who actually have the infection, would be soon overwhelmed (Kaldor evidence, 3 October 1997).*

Shared care is a clinical management principle that refers to general practitioners and medical specialists “sharing” the care of patients. The concept is already common in a number of medical disciplines such as mental health, HIV/AIDS, pediatrics and obstetrics and is gaining increasing support as a management tool for patients with Hepatitis C. Dr Gold, Director of the Albion Street Centre told the Committee that:

*shared care has been one of the stable underpinnings of medicine ever since there was a division between general practitioners and specialists. There has always been a concept of shared care between day-to-day management by general practitioners and intermittent management by clinical specialists (Gold evidence, 26 February 1998).*

In the past patients on interferon have attended specialist liver clinics every one to two months to have their therapy monitored. But as Farrell observed:

*a lot of that monitoring obviously can be done in general practice. It can be done safely by general practitioners who are well educated. That would be more user friendly to the patients because they would not have to wait as long, they could go to their local general practitioner who they know . . . (Farrell evidence, 28 November 1997).*

The NHMRC (1997) saw the potential of shared care in the treatment and management of HCV+ patients and recommended its introduction in its report:

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*Care of patients may be initiated in the approved centres and carried on for the first three months by providers in other towns or in other parts of the same city. The practitioners providing follow-up care may be specialist physicians, gastroenterologists, or in some cases, general practitioners. It is evidence from experience that appropriate education can be provided to facilitate the care of many patients living distant from treatment centres (NHMRC, 1997).*

The report went so far as to propose a protocol for shared care (see Table Twenty-nine below) and management guidelines for general practitioners (see Appendix 1, NHMRC, 1997:59).

**TABLE TWENTY-NINE**  
**SHARED CARE PROTOCOL AS PROPOSED BY THE NHMRC**

WEEK	REVIEW	INTERFERON PRESCRIPTION	LIVER FUNCTION TEST	FULL BLOOD COUNT	REPORTING	TSH <sup>1</sup> TEST
0	Liver clinic	X		X	X <sup>2</sup>	
2	GP		X		X <sup>3</sup>	
4	Liver clinic	X	X		X <sup>2</sup>	X
8	GP		X		X <sup>3</sup>	
12 <sup>4</sup>	Liver clinic	X	X	X		X
16	GP		X		X <sup>3</sup>	
20	Liver clinic	X	X		X <sup>2</sup>	X
24	Liver clinic	X	X	X	X <sup>2</sup>	

<sup>1</sup> Thyroid Stimulating Hormone test

<sup>2</sup> the liver clinic is required to forward patient management data to the National Hepatitis C-Interferon Database, John Hunter Hospital, Newcastle

<sup>3</sup> following each GP visit the practitioner must provide relevant clinical information to the treating liver clinic and the National Data Base

<sup>4</sup> if ALT abnormal at 12 weeks, subsidy for treatment will cease

Source: NHMRC, 1997:71

The Committee understands that the process of putting the concept of shared care into practice is currently underway in the form of a project known as the National Shared Care Project. The project is being coordinated by the Royal Australian College of General Practitioners, the Australian Gastroenterology Institute and Schering-Plough. The focus of the project is to develop a coordinated, shared care program between gastroenterologists and general practitioners in the treatment and management of Hepatitis C (Schering-Plough submission).

Schering-Plough advised the Committee in early October 1998 that the Shared Care protocol was ready and expected to be launched in November 1998 (Nair correspondence, 3 October 1998).

The Committee fully supports the concept of joint patient management between gastroenterologists and general practitioners. It wishes to see opportunity made available for patients to be managed jointly by a liver clinic and an accredited GP under a "shared care" protocol.

**RECOMMENDATION 64:**

That the Minister for Health accept the principle of shared care as a viable and practical clinical management tool for Hepatitis C and ensure NSW Health takes all possible measures for shared care of Hepatitis C patients to be introduced into the New South Wales health care system.

- **A Greater Role for General Practitioners: the National Hepatitis C Education Program for General Practitioners**

The National Hepatitis C Education Program for General Practitioners is sponsored by the Royal Australian College of General Practitioners (RACGP). It is a two year Commonwealth funded project. The project is staffed by a full time coordinator and a part time (two days a week) clerical assistant.

The Program's mission statement is:

*to enable general practitioners to respond effectively to the challenges posed by Hepatitis C infection, to contribute in minimising the spread of the infection, caring for those already infected, reducing discrimination and educating others (RACGP, 1998:1)*

During the course of evidence, the program's coordinator, Mr Steven Hall, commented that:

*the general goal of the project is to help GPs to feel more confident and competent in dealing with Hepatitis C, ranging from detection, diagnosis, management and prevention . . . The project involves developing a program with a range of resources and program services and working with existing projects and people working in the field from around Australia (Hall evidence, 6 November 1997).*

The goals of the Program include:

- to enable general practitioners to diagnose Hepatitis C infection, provide
-

counselling, advice and support on management, treatment and care for people affected by Hepatitis C;

- to provide a trained general practitioners workforce for the care and management of people with Hepatitis C infection; and
- to promote prevention and public health measures to minimise the impact of Hepatitis C infection both at an individual level and at a community level (RACGP, 1998:1).

Outcomes of the Program include:

- ensuring that general practitioners recognise Hepatitis C are able to take measures to minimise the spread of the infection, manage those who are infected and can assess up-to-date information on its management;
- identification of general practitioners education and support needs in relation to Hepatitis C;
- identification of core knowledge, skills and attitudes for general practitioners in the detection and management of Hepatitis C in a communicable diseases framework;
- provision and reinforcement of core information;
- development of supporting educational material which takes into account new information and technology;
- establishment of sustainable educational initiatives, where applicable, within existing general practitioner structures; and
- establishment of a national network to support, sustain and assist with on-going education in relation to Hepatitis C (RACGP, 1998:3).

The program is made up of a series of components. The first component looks at roles, infrastructure and coordination. It aims to develop sustainable and coordinated infrastructure and policy that defines and supports the primary role of general practitioners in the long-term shared care of HCV positive patients, in collaboration with other health care services. The objectives of this component of the program include:

1. RACGP and Australian Gastroenterology Institute (AGI) to provide collaborative leadership to support Division-based initiative and specialist services;
  2. to define, endorse and support the primary role of general practitioners in the long-term, shared care of HCV positive patients;
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3. to link all general practitioners with liver clinics, specialists and other relevant health care services;
4. to link and support all general practitioners with a special interest in HCV with Division-based clusters (Tabled document, 6 November 1997).

The program's second component is concerned with programs/services and resources. This facet of the program aims

*to ensure all general practitioners are able to effectively detect, diagnose, manage and prevent HCV infection, in collaboration with other health care workers (Tabled document, 6 November 1997).*

Its objectives include:

1. all general practitioners to understand their primary role in health promotion, as well as the clinical management of HCV infection;
2. all general practitioners to have ongoing access to consistent, up-to-date, relevant and sustainable core information and education programs/services and resources;
3. division-based clusters of general practitioners, with a special interest in HCV, to access further relevant education, information and support (Tabled document, 6 November 1997).

The third component involves vocational training and undergraduate education. This component seeks to:

*prepare registrars to deal confidently with the detection/diagnosis, management and prevention of HCV infection and to expose undergraduate medical students to generic Hepatitis C competencies (Tabled document, 6 November 1997).*

The objective of this component include:

1. registrars to develop core HCV competencies (specific and generic) within the Vocational Training Program;
2. undergraduate medical students to be exposed to generic HCV competencies, integrated within relevant parts of the teaching program;
3. undergraduate education and vocational training curriculum to be consistent and complementary (Tabled document, 6 November 1997).

The Program has been instrumental in devising a series of Hepatitis C management guidelines in partnership with the Gastroenterology Society of Australia (GESA) - Hepatology Section. The guidelines are currently in draft form and endorsement by both the RACGP and GESA of the complete management guide is being sought before its planned release in October 1998 (Hall, 1998:799).

The series of charts that make up the guidelines are a step-by-step guide to managing and caring for Hepatitis C patients who are:

- HCV sero-status unknown;
- antibody testing equivocal or positive;
- have chronic Hepatitis C;
- Hepatitis C and the antenatal patient;
- post interferon management (Hall, 1998:799-803).

The Committee fully supports the GP education program and agrees with ANCARD which suggested that:

*the GP education program in Hepatitis C care and management being developed by the Royal Australian College of General Practitioners should be implemented and appropriately resourced on a national basis (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).*

The program is working to a two year time frame and, at this stage, it is too early to comment on its effectiveness. Tenders to evaluate the project have been called for and consultants appointed. They anticipate presenting a draft final report to the College's Reference Group in November 1998 (Mackdacy correspondence, 23 July 1998).

The Committee wishes to congratulate the RACGP for its initiative in introducing and sponsoring the program and its commitment to general practitioner education on this vital issue.

**RECOMMENDATION 65:**

That the Minister for Health ensure all measures are taken for the full and unhindered implementation of the National Hepatitis C Education Program for General Practitioners in New South Wales.

- **Training Those who Treat and Manage Hepatitis C**

Pivotal to the successful treating and managing of those with Hepatitis C is adequate training for the health care professionals. This issues has been pursued by the Hepatitis C Council, which in July 1998 conducted a Hepatitis C Health Care Worker Education Planning Workshop funded by NSW Health (Hepatitis C Council, 1998b). The key findings of the workshop were that:

- the current medical and illness focus does not provide the range of information and services needed for people living with Hepatitis C, of for health care workers;
- there is considerable ignorance of all aspects of Hepatitis C, which is contributing to discrimination, fear based behaviour and impacts on the quality of care;
- the lack of a central coordination point results in lack of knowledge of existing resources and initiatives and duplication of effort;
- there needs to be a broad base of concern and action, involving all health care workers and associated administrators and managers;
- there will be increasing demand for education services; however resources will not increase significantly;
- there is a need to target education processes, based on the role and experience of health care workers;
- existing education and learning processes are not always appropriate and relevant, and are not always accessible to all health care workers, particularly in rural areas;
- education and learning related to Hepatitis C needs to be integrated with other health education processes, and draw on the experience and diverse needs of people living with Hepatitis C;
- education and learning processes developed for health care workers are often also appropriate for increasing awareness and understanding in the general community; and
- any strategy needs to draw on the skills, expertise, resources, influence of other health and education organisations and recognise the cultural diversity of society (Hepatitis C Council of NSW, 1998b:1-2).

The Workshop identified the need for a Hepatitis C education strategy for health care workers and proposed a range of strategies including:

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- increased coordination through a clearinghouse;
- identification of health care workers' role and their learning needs;
- establishment of partnerships and alliances;
- greater involvement of people living with Hepatitis C; and
- the development of an integrated education and learning strategy (Hepatitis C Council of NSW, 1998b:3-6).

The Committee fully supports the development and introduction of a Hepatitis C education strategy for health care workers. The Committee anticipates that the focus of the strategy would be to ensure that appropriate material, resources and training are available, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the education strategy be integrated with other education and training activities and initiatives.

**RECOMMENDATION 66:**

That the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) address the issue of a Hepatitis C Education Strategy for Health Care Workers. The Education Strategy is to ensure that appropriate material, resources and training are available to health care workers throughout the state, enabling those responsible for delivering health care to access relevant information. Wherever possible, the Committee would like to see the Education Strategy be integrated with other education and training activities and initiatives. The Committee further recommends that the Minister for Health ensure the Hepatitis C Education Strategy for Health Care Workers is adequately funded.

**8.4.2 WHERE SHOULD HEPATITIS C BE TREATED AND MANAGED?**

Given current waiting lists and crowded specialists liver clinics, there is a need for alternative venues to be found for treating and managing Hepatitis C. Several options were raised with Members during the course of the Inquiry. Sladden, for example, outlined to Members his "best practice model":

*if we look at a clinic that might be the best practice, the model for it would include counsellors, perhaps a part-time gastroenterologist and general practitioners who could attend the clinic, and a clinical nurse consultant who could assist with procedures conducted by the clinic. It could provide the routine range of services for people with Hepatitis C, such as liver function tests and biopsies and interferon prescribing, all of the current treatment practices . . . Furthermore, such a clinic could be*



*combined with a support group for other forms of support for people with Hepatitis C (Sladden evidence, 30 March 1998).*

Sladden envisaged his model being incorporated into a “shopfront” or clinic that provided health services enabling those wishing to access the service as much confidentiality as possible (Sladden evidence, 30 March 1998).

The Committee made site visits to observe first hand two different models of service delivery: the Kirketon Road Clinic (Kings Cross) and the Albion Street Centre (Darlinghurst). Both of these contain elements which the Committee considered important in appropriate service delivery. The Albion Street Centre is, for example, a centre for clinical management as well as a service directed at support for and education of health care workers including the Centre’s national information reference centre for Hepatitis C, the NSW infection control resource centre and the NSW needle-stick injury hotline (Gold evidence, 26 February 1998).

One of the Committee’s more mature witnesses was very specific in identifying where she did not want to go for treatment and management:

*quite often community health centres [in rural areas] are run with skeleton staff and the services tend to get bunged in all together. For instance, on the Central Coast one went to the sexual health clinic to get information and help on Hepatitis C, and I objected to going to the sexual health clinic. It seemed inappropriate, when I was not sexually active, to go to the sexual health clinic. It is rather ironic (Evidence, 30 March 1998).*

The Committee is aware that, in addition to these examples of service delivery presented to, or observed by Members, NSW Health is currently sponsoring four demonstration projects and federal and state funding has been made available to a Hepatitis C coordinated care trial known as HepCare. Each of these projects is reviewed in the following discussion.

- **The NSW Health Demonstration Projects**

NSW Health is currently financing four 12 month demonstration projects in Hepatitis C prevention, treatment and care across seven of its Health Areas. According to the Department, these projects aim

*to improve HCV case management by developing a system of integrated and sustained arrangements that offer equitable access; and to establish closer links between prevention, surveillance, treatment and care services to facilitate the control of HCV (NSW Health supplementary submission).*

McCaughan put it a slightly different way:

*the aim of [the projects] is to try to develop much stronger community links with various groups that have involvement with Hepatitis C, to take a little bit of the pressure off our services (McCaughan evidence, 23 March 1998).*

The specifications of the projects require HCV services to:

- be integrated;
- be multidisciplinary;
- be accessible and acceptable to the majority of people with HCV;
- provide a high standard of care including education, information and counselling;
- ensure appropriate assessment and follow up of people with HCV;
- provide access to specialist hepatology and pathology/laboratory services;
- include policy research;
- improve HCV surveillance; and
- reduce duplication of clinical services (NSW Health supplementary submission).

The four demonstration projects are being carried out in the following Health Areas:

1. Northern Rivers/Mid North Coast/New England: the aim of this project is to improve access to treatment and support for people with HCV in rural areas and to improve the coordination of their care. The project commenced in October 1997;
2. Central/South Eastern Sydney: this project aims to set up specialist mobile HCV clinics outside traditional settings to improve access to, and coordination of care for, groups such as injecting drug users and other marginalised groups who often do not access traditional clinical and support services. The project will also upskill general practitioners in the area. The project commenced in November 1997;
3. Western Sydney: this project will develop a model of care for HCV positive methadone clients as well as develop a counselling/psychosocial support model for HCV in conjunction with the Liver Clinic and the Department of Psychiatry at Westmead Hospital. The project commenced in December 1997; and

4. South Western Sydney: this project aims to address the specific issues of access, information, treatment and care for people from non English speaking backgrounds. The project commenced in February 1998 (NSW Health supplementary submission).

The objectives for each project are in Appendix Five.

The projects will map current services and resources in each of the Health Areas and develop models of service provision for people with HCV, including shared care models. Each will include a substantial education component for general practitioners and other health care workers including the development of management protocols for HCV (NSW Health supplementary submission).

Support for the demonstration projects was given by a number of expert witnesses appearing before the Committee. McCaughan, for example, said that the projects are to be “applauded” (Evidence, 23 March 1998).

However, a number of concerns were raised relating to the delay in introducing the projects, the limited funding allocated to each and the short time frame.

Farrell was critical of both the department’s delay and the limited funding made available:

*NSW Health has instituted Hepatitis C projects (total cost \$600,000) to try and devise appropriate shared care programs and to promulgate attempts to prevent the disease. To have reached only this stage by 1997 when we have known about the importance of the disease in NSW since 1989 is simply a disgrace. There is an overdue need for significant recurrent funding, of the order of \$3-5 million per annum to introduce appropriate policies of efficient, shared care, diagnostic and management services (Farrell submission).*

Pritchard-Jones also commented on inadequate funding for the Central Sydney/South Eastern Sydney Area Health Service demonstration project she is involved in: “the funding is \$150,000 which is not adequate for what we have to do” (Evidence, 2 October 1997). Professor McCaughan also noted that the projects are “grossly underfunded” (McCaughan evidence, 23 March 1998).

McCaughan also commented on the one year time frame of the demonstration projects:

*just as we get the [project] off the ground, maybe get them started and have some sort of idea about how effective they are and whether they can take pressure off bottlenecks in the system, we are not sure whether they will continue to be funded (McCaughan evidence, 23 March 1998).*

Loveday of the Hepatitis C Council commented that the four demonstration projects across seven health areas are “just scratching at the surface of need” (Evidence, 30 March 1998).

- **The Hepatitis C Coordinated Care Trial (HepCare)**

In 1996/97 the Commonwealth Department of Health and Family Service sought submissions from state and territory governments to trial a different way of delivering health care. The aim was to test a model of coordinated care that was able to maintain health outcomes and decrease health care costs. NSW Health invited the Northern Sydney Area Health Service to prepare a proposal for a hepatitis C trial. The Hepatitis C Coordinated Care Trial, known as HepCare, was one of 12 trials that received federal funding to commence stage one of the trial process - the development stage. Through a process of negotiation with staff of NSW Health, the Hunter Area Health Service and the Northern Sydney Area Health Services it was decided that the Northern Sydney Area Health Service should be the trial intervention area and the Hunter Area Health Services the trial control area.

The aim of the HepCare Management Trial is to enhance the health outcomes and well being of those with HCV. The primary objective is to develop, implement and test models of case management for persons with hepatitis C that:

- are responsive to participants' assessed needs;
- are organised through individual care plans based on clinical guidelines;
- are not detrimental to equity, access to care and privacy issues;
- result in improved health and well being of participants; and
- result in identifying the total health care expenditure of persons with Hepatitis C against this model (NSW Health, 1997a:5).

HepCare will test the models of case management with persons with Hepatitis C to examine the extent to which they:

- contribute to improved delivery of services which are individually and collectively more responsive to participants' assessed needs;
- are more efficient in delivering services; and
- result in improved health outcomes and well being of the participants (NSW Health, 1997a:5).

The trial is testing two basic models of case management. Both have a range of core services including case management; provision of services based on assessment

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through existing service providers and reduction in the duplication of assessments and service provision. The models will differ in terms of the nominated case manager. In one model the designated case manager is a general practitioner. In this model the number of participants per case manager will be in the order of 1:5 to 1:10. In the other model the case manager is a non-general practitioner responsible for ensuring all the defined functions of case management are carried out in partnership with the general practitioner. In this model the number of clients will be approximately 1:70 (NSW Health, 1997a:6).

The trial is unique in that there is no single mechanism that currently supports the improvement of health care for persons with Hepatitis C. The trial will coordinate the care of participants by the use of individual case managers. A person with Hepatitis C, in the absence of case management, may visit multiple health care providers and receive conflicting management. One very significant difference for persons in this trial is the capacity to work with a case manager to plan all their health care needs. This mechanism has not previously been trialed and is not accessible within any other framework than that offered by this trial (NSW Health, 1997a:8).

Mr Graham Stone, HepCare Manager told Committee Members that:

*we are . . . trying to maximise access to health care and welfare services for people with Hepatitis C. We are looking at whether, as a result of developing a single point of accountability through the processes of care planning, that a person's health care outcome may alter. Essentially we are looking at whether we can, in layman's terms, rejig the system in a slightly better way . . . there are a number of aims of the project but clearly it is to see whether the way in which we structure this trial will make any difference to the way existing health care has been provided (Stone evidence, 27 February 1998).*

The project is receiving just over \$1 million in funding from both NSW Health (\$250,000) and the Commonwealth (\$830,000 including the evaluation costs) (Stone evidence, 27 February 1998). The Commonwealth also contributed \$600,000 from February 1997 to October 1997 to instigate the project. The project has, not surprisingly, been labelled "Australia's best funded initiative to improve care and support" (Loveday evidence, 30 March 1998).

As of late February 1998, when the HepCare Manager gave evidence, just under 500 participants had been recruited. Stone envisaged the trial cohort of approximately 800. Ages range from 13 years through to people in their 60s and 70s with the average age from about 27 through to 48 years. The recruitment strategies encourage people from diverse cultural backgrounds and range of areas to be involved (Stone evidence, 27 February 1998).

It is anticipated that the trial will be completed in December 1999 with the evaluation completed by 1 March 2000.

### 8.4.3 CONCLUSION

The Committee considers it vital that best practice models for service delivery be found to ensure existing health care is more responsive to the clinical needs of those with Hepatitis C than it has been in the past. These models must take into account the two questions posed at the beginning of this section: who should treat and manage Hepatitis C and where that treatment and management should occur. The models also have to provide flexibility to meet the diverse needs and localities of those with Hepatitis C. It is likely, for example, that an appropriate model for service delivery for a retired health care worker living in the far north coast would differ from that appropriate for a young injecting drug user living in the inner city or a recent migrant with limited English skills from south western Sydney.

In devising best practice models for service delivery, the Committee considers it important that NSW Health utilise the results of evaluations shortly to be conducted on the various projects and trials currently in place such as the RACGP's National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects and the HepCare trial. In addition, the Committee expects that the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 will also provide substantial material that can be used in devising best practice models for service delivery.

**RECOMMENDATION 67:**

That NSW Health develop a model of best practice for the delivery of services to those with Hepatitis C in New South Wales. The Committee stipulates that the best practice model be flexible to provide delivery services in a range of formats appropriate to the diverse needs (including geographical location) of those with Hepatitis C. The Committee further recommends that NSW Health take into account the evaluations of the RACGP's National Hepatitis C Education Program for General Practitioners, the four NSW Health demonstration projects, the HepCare trial and the results of the comprehensive needs assessment and service planning exercise proposed in Recommendation 61 in developing best practice models for the delivery of services to those with Hepatitis C.

**RECOMMENDATION 68:**

That the strategies to be implemented in establishing the model of best practice for the delivery of services to those with Hepatitis C in NSW be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 69:**

That the Minister for Health ensure adequate funding is available for the implementation of the model of best practice for the delivery of services to those with Hepatitis C in NSW.

## **8.5 TREATING HEPATITIS C WITH COMPLEMENTARY THERAPIES**

As was discussed in Section 7.2 many people use complementary therapies as an alternative to conventional medicine or to treat specific aspects or symptoms of their illness. Many of those with Hepatitis C report considerable success yet the medical profession remains wary of the benefits. With the exception of the Chinese herb trials conducted at John Hunter Hospital, little scientific testing has been undertaken to determine empirically the efficacy of these treatments. It was proposed to the Committee by the Hepatitis C Council that there is a need for trials of specific complementary therapies. Given the limited treatment options available to those seeking to relieve either the symptoms of Hepatitis C or the side effects of interferon, the Committee supports this proposal of the Council's.

**RECOMMENDATION 70:**

That the Minister for Health urge his federal counterpart to encourage the NHMRC to support and fund research trials of complementary therapies designed to relieve the symptoms of Hepatitis C.

## **8.6 DIFFICULTIES ENCOUNTERED IN TREATING AND MANAGING HEPATITIS C POSITIVE INMATES IN THE STATE'S CORRECTIONAL SYSTEM**

From his extensive experience in delivering specialist health care to Hepatitis C positive inmates, Lloyd identified two critical issues that must be considered:

*the Hepatitis C infected individuals in the prison and the adequacy of their care, and the transmission within prisons. I believe those issues have great grounds for concern (Lloyd evidence, 30 March 1998).*

Having considered the evidence it received, the Committee concurs with Lloyd that the issues are of "great" concern. The issue of preventing transmission within prisons is thoroughly addressed in Section 10.2. The following discussion examines Lloyd's other concern: the adequacy of treating and managing those infected with Hepatitis C in the correctional system. The following discussion identifies a number of problems and shortcomings that were raised during the course of the Inquiry.

In forwarding the following recommendations for treating and managing Hepatitis C positive inmates, the Committee fully appreciates that, given the inherent nature of prisons, there will always be difficulties in the provision of health care within the corrections system. The Committee heard, for example that:

*there are added constraints that do not exist outside in the general community. There is no intrinsic antagonism to providing these things; it is just that it is such a vast problem . . . Everything is a challenge in the prison. Health care delivery is not the priority. In general, health care delivery struggles to get maintained in the custodial priority (Lloyd evidence, 30 March 1998);*

and

*there is a lack of control over activities of daily living, meal times and sleeping times . . . There is little control over the diet, exercise patterns . . . limited access to inmates is one problem. Within each gaol there are structured days on which inmates have to be at certain points at certain times, and health is slotted into that structured day. There are many competing priorities (Christensen evidence, 23 March 1998).*

While there are problems, the Committee is aware that, for many inmates, incarceration provides an opportunity for them to be tested for Hepatitis C and have access to specialist services:

*the clients will tell you that they have never had such a good service . . . but like everything, once you identify a need and meet it there is then an expectation to expand on it. That is where we are at now (Harper evidence, 23 March 1998).*

### **8.6.1 TREATING AND MANAGING THE DISEASE**

When asked to comment on the adequacy of treatment and management services, Christensen, who has considerable experience in working with Corrections Health Service told the Committee that:

*management practices are not adequate at this stage to meet the needs of Hepatitis C given the prevalence of Hepatitis C positive inmates in the system (Christensen evidence, 23 March 1998).*

As she told the Committee:

*The service is in its evolutionary phase although we are in 1998; it is slowly developing (Christensen evidence, 23 March 1998).*



Four specific issues relating to treatment and management were identified by witnesses.

- **Limited Numbers of Health Care Professionals**

The Committee was advised that five designated nurses and two visiting clinical specialists provide the health care to all Hepatitis C positive inmates within the state's correctional system. This limited number of health care workers has a number of implications including:

- limited number of specialist Hepatitis C clinics;
- limited locations of clinical services; and
- limited choice for inmates.

### **Implication One: Limited Number of Specialist Hepatitis C Clinics**

The limited number of specialists working with Hepatitis C positive inmates means that there are limited numbers of Hepatitis C clinics. As has been discussed, specialist Hepatitis C clinics are held twice a month at the Long Bay complex. The Committee does not see the limited provision of clinical services as a reflection of the commitment of the visiting specialists, rather a comment on the low priority assigned to Hepatitis C and related health care within the corrections system.

In commenting on the service he provides, Professor Lloyd informed the Committee:

*We make no attempt to seek referrals, substantially, of the vast number of inmates. Predominantly we service a very select subgroup which happens to be located on the Long Bay site. But we really do not provide a statewide service to prisoners who have Hepatitis C . . . There is a huge yawning gap between the small amount of clinical services I provide and the identification of infected individuals on entry (Lloyd evidence, 30 March 1998).*

### **Implication Two: Limited Location of Clinical Services**

The specialist Hepatitis C clinics are based solely at Long Bay. Inmates in correctional centres other than Long Bay are required to travel to Sydney to obtain specialist care. The Committee heard that these prisoners, particularly those in rural correctional centres, are "disadvantaged" because they do not have ready access to the kinds of services available to those prisoners in metropolitan areas (Cregan evidence, 23 March 1998).

Witnesses identified a number of problems encountered by inmates seeking to access the specialist clinics in Sydney. Harper identified a range of problems including:

*trucks breaking down and causing delays. If a stop-work meeting or a search is taking place, if someone has hung himself or slashed out, or if there has been a bashing, all movement ceases at Long Bay. You may get the 10 or 12 inmates to Long Bay from various country gaols. They are housed in that particular gaol but then everything at that gaol stops (Harper evidence, 23 March 1998).*

Christensen identified similar difficulties:

*There are transport difficulties because the services are concentrated in the metropolitan area. For example, if an inmate from Grafton wants to avail of hepatitis services, he has to get on transport from Grafton down to Long Bay. There may be one truck a week that comes to Long Bay. He comes down and has to wait a week in the Long Bay gaol . . . He may not get to the clinic; there may be security problems the day of his appointment, a lock-down, a shortage of officers or security complications that mean the inmate does not get to the clinic. He may have to wait until the next clinic or, if he does get seen, he may have to wait two to three weeks and go through three gaols to get back to his gaol classification. That causes problems (Christensen evidence, 23 March 1998).*

As a result of such difficulties, some “inmates find it too arduous and do not want to come down to the services” (Christensen evidence, 23 March 1998). The Hepatitis C health care needs of these inmates are therefore simply not met.

### **Implication Three: Limited Choice for Inmates**

A third implication arising from the limited numbers of health care workers is that the choice of inmates to health care workers is limited. As the Committee heard:

*in gaol there is often only one doctor who visits, who may not visit every day and it is difficult to see anybody else. That doctor services the gaol and the inmate therefore sees that doctor, so there is a lack of choice in prison (Christensen evidence, 23 March 1998).*

- **Inmates’ Diet**

Many with Hepatitis C find a low fat diet to be easier on their liver than a heavier, high fat diet. While in prison, however, inmates have little choice in their diet and, as Lloyd noted, “if you wanted to give all Hepatitis C positive inmates a special diet, half the prison population would be on a special diet” (Lloyd evidence, 30 March 1998).

The Committee heard of attempts by nursing staff to obtain low fat diets for their clients:

*we always put in a request for a special diet but that did not always translate into them receiving a special diet. That request would go down to the kitchen, the inmates prepared the meals and we would have ongoing battles. I have been to a kitchen about 40 times to try to ensure that one or two inmates got a low fat diet. It is an ongoing problem and it has to be done on a one-to-one basis. There are policies in place and there are all types of procedures, but it often breaks down because of the number of people involved in the chain of command (Christensen evidence, 23 March 1998).*

The Department of Corrective Services representative informed the Committee that,

*with so many Hepatitis C positive inmates we are looking at such options as providing a liver-friendly diet (Vumbaca evidence, 23 March 1998).*

- **Lifestyle Unit**

Several witnesses commented on the role of the Lifestyle Unit in assisting inmates to manage their Hepatitis C. As has been discussed (see Section 7.3.2) the number of places available is severely limited yet there are no plans to expand the Unit:

*at this stage there are no plans to expand the lifestyle unit from eight beds. The issue always comes down to money . . . The budget does not exist to expand that program (Vumbaca evidence, 23 March 1998).*

In addition, provision is currently not available for women inmates to participate in the program. The Committee heard however that:

*The Department of Corrective Services has said that there should be a duplicate service or a service created for women that is equitable to that . . . It is quite difficult with communal living to have a mixture of male and female (Christensen evidence, 23 March 1998).*

The Committee heard of strategies either in place or proposed to enable female inmates to access the Lifestyle Unit program:

*the people who run the Lifestyle Unit . . . spend a day a week in the therapeutic unit at Mulawa running the program there. They focus mainly on Hepatitis C issues but they also run nutrition classes as well as healthy lifestyles and feel-good-about-yourself classes . . . Also there is an opportunity being investigated now by the department . . . The Lifestyle Unit now has a separate entrance and has been dedicated as a separate area. The opportunity now exists for the department to expand services*

*to women by bringing an all-female residence group into the centre, and that may or may not go through (Vumbaca evidence, 23 March 1998).*

The Committee is aware of the results of the 1997 evaluation study of the Lifestyle Unit and the recommendation that report made to discontinue the integration of inmates with Hepatitis C into the Lifestyle Unit program (Recommendation 25) (Department of Corrective Services, 1997:20). The report recommended that “serious consideration” be given to the establishment of a separate unit and program, with the same philosophical ideology as the Lifestyle Unit, to cater to the needs of those inmates with Hepatitis C (Department of Corrective Services, 1997:20). The evaluation’s results and recommendations were not raised by the Department during the course of the Inquiry either in their submission or during the course of evidence.

The Committee considers there to be potential in the program offered at the Lifestyle Unit and wishes to see the program expanded to reflect, more accurately, the prevalence of Hepatitis C within the corrections system. It also considers it imperative that, given the prevalence of Hepatitis C amongst women prisoners which is substantially higher than among male inmates (see Section 3.2.2), the program be expanded to enable female inmates to participate.

#### **RECOMMENDATION 71:**

That the Minister for Corrective Services ensure the program offered at the Lifestyle Unit be expanded (in both scope and size) to respond more adequately to the prevalence of Hepatitis C within the corrections system. The Committee further recommends that the program be extended to include female inmates who are Hepatitis C positive.

- **Post-release Care**

The Committee heard that, in relation to post-release care:

*inmates are given copies of their serology and follow-up liver function tests to take with them on release. Discharge planning is done for specialist services such as the specialist HIV and hepatitis clinics but in the main it is not done. That needs to be addressed for the continuum of care both in and out of gaol (Christensen evidence, 23 March 1998).*

The Department’s reason for not providing post-release care and discharge planning was that “at the moment the volume is too great” (Vumbaca evidence, 23 March 1998). The Committee considers such a response to be totally inadequate.

Vumbaca considered the pilot HepCare program (reviewed in Section 8.4.2) to be a possible option for post-release care but he did admit that:

*it is only for the Hunter and the northern Sydney areas. A large number of people will miss out because they will not fall within those residential areas when they leave (Vumbaca evidence, 23 March 1998).*

### **8.6.2 MANAGING THE HEPATITIS C TREATMENT REGIME**

With regard to managing the Hepatitis C treatment regime within the corrections system, the Committee heard that, inmates' health status and management requires ongoing monitoring and that this "proves to be a continuing difficulty within the prison system" (Christensen evidence, 23 March 1998). Five specific issues were raised by those working with inmates.

- **Limited Numbers of Inmates on Interferon Therapy**

Data tabled by Ms Parsons, a Clinical Nurse Specialist with the Corrections Health Service, show that, as of mid March 1998, a total of 22 inmates had commenced interferon with five on interferon at that time (Parsons evidence, tabled material). Lloyd thought the total number who had completed interferon to be 25 and felt that there were more than five currently on therapy (Lloyd evidence, 30 March 1998). He admitted the numbers to be a "tiny microcosm" of the whole Hepatitis C infected prison population (Lloyd evidence, 30 March 1998).

When asked to comment on the limited number of inmates who have, or who are currently receiving interferon Lloyd said that it is:

*Partly a reflection of our limited service capacity, partly a reflection of the fact that we have adopted a very conservative stance in the application of the S100 assessment criteria (Lloyd evidence, 30 March 1998).*

In noting the increasing number of inmates diagnosed with Hepatitis C, the submission from Department of Corrective Services noted that:

*there is also a corresponding increase in demand for the limited treatment options available. The Department of Corrective Services therefore fully supports the expansion of the criteria for access to treatments, such as interferon, for inmates (Department of Corrective Services submission).*

- **Difficulties in Administering Interferon within the Prisons System**

In the general community many find that administering their interferon in the evening minimises side effects. For inmates, however the Committee heard that:

*in prison that is difficult because inmates have to have their medication at prescribed times because of the structured day and clinical operations.*

*That causes a lot of problems initially in trying to get patients their interferon at a time suitable for the gaol and for the inmate (Christensen evidence, 23 March 1998).*

Administering interferon is complicated in some instances such as:

*If a person is on protection it is difficult to get him to the clinic. If there has been a bashing or a riot it is difficult to get the men to the clinic on time. Inmates may have been given their doses in the morning (Parsons evidence, 23 March 1998).*

- **Training Health Care Workers to Administer Interferon Therapy**

Evidence presented to the Committee suggests the need for nurses working with Corrections Health Service to be trained to understand the interferon regime and possible side effects. The Committee heard for example that:

*nurses in the clinics are very entrenched. They run the clinics almost in a military style as well, so that apart from the names of new treatments like interferon or a combination of anti-retroviral treatments that come in being quite foreign to them, they have a very set mind fix that it will be given at a particular time and no other time. We have had to be quite up-front with them and we have had a few battles ourselves in letting them know that they do not dictate the times that are the most suitable for the inmate, that this is self-administering and they are self-monitoring. It has been a new learning curve for them and we still have a long way to go. Certainly the nurses need a lot of education to get out of that entrenched way of thinking (Harper evidence, 23 March 1998).*

Christensen suggested there needs to be “upskilling” so medical and nursing staff feel more “comfortable and competent” managing Hepatitis C in the prison environment (Christensen evidence, 23 March 1998). She also noted that:

*in regard to those inmates who come through the Hepatitis clinics and are prescribed interferon, a whole range of activities are put in place to try to educate the nurses in the local clinic about interferon, its effects and side effects, and patient management issues. It is all done on a one-to-one basis and it is very time consuming (Christensen evidence, 23 March 1998).*

- **Payment of Interferon**

Under present arrangements between the Commonwealth and the states, remuneration of medical expenses is subject on the patient holding a Medicare card. Upon

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incarceration, a person loses access to their Medicare number. As a result when expensive drugs, especially S100 drugs are prescribed, instead of being a charge against the Commonwealth and Medicare, they potentially become a charge against the NSW Health Department through the Corrections Health Service. Such was the situation with regard to interferon at the outset of this Inquiry. As the Committee heard,

*that body [Department of Corrective Services] is fairly cash strapped and as a result does not go out of its way to ensure that access to interferon and other treatments, for example, other hepatitis vaccinations, are made readily available (Puplick evidence, 7 November 1997);*

and

*the departments [of Corrective Services] feel they are unable to meet such commitments out of their present budgets, with the result that prisoners in need of these medications may not receive them (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).*

In a letter to the Commonwealth Human Rights Commissioner the Chairman of ANCARD described this situation which limits access to prescribed treatment as a denial of “basic human rights”:

*I believe that prisoners have specific health care needs which are not currently being recognised or addressed. Such lack of access surely contravenes a prisoner’s human rights, that of access to prescribed treatment for a chronic illness for which the accepted treatment or therapy is considered standard for all other eligible Australians (ANCARD submission to the Highly Specialised Drugs Review - attachment to submission).*

In addressing this issue when appearing before the Committee, Puplick suggested that:

*the states should be more aggressive in demanding that the Commonwealth stop transferring this financial burden on to them (Puplick evidence, 7 November 1997).*

In late 1997 this situation changed. Under a Commonwealth initiative, drugs on the Highly Specialised Drug Program, including interferon, are now funded by the federal government. The only proviso placed on state and territory governments was that essential hospital based specialist care required to administer and monitor the medication be provided.

- **Length of Stay in Prison**

The Committee heard that, for some inmates, the length of their stay in prison can determine whether they commence interferon therapy:

*The length of stay can also be an issue affecting the commencement of interferon. If inmates are not going to be in gaol for the period of time that they are on interferon, often they will not be started but will be referred to an outside agency (Christensen evidence, 23 March 1998).*

- **Limiting Progress to Minimum Security Prisons**

The Committee also heard that those patients on interferon are kept in metropolitan gaols as “often it is difficult to get the treatment to them in remote sites”. The result of this is that sometimes:

*being kept in the metropolitan area can sometimes stop progression to gaols of minimum classification (Christensen evidence, 23 March 1998).*

### **8.6.3 MANAGING THE SIDE EFFECTS OF HEPATITIS C AND INTERFERON**

As has been discussed in Section 7.2.1 many people on interferon experience physical and emotional side effects which can range from mild to chronically debilitating. Inmates are no exception and similarly experience a range of side effects. However, there appears to be little accommodation of these within the corrections system. With particular reference to the common side effect of depression, Cregan noted that:

*The stress of the environment can increase whatever depression is brought on either by Hepatitis C or the effects of interferon treatment, and those effects can be quite severe. Suicide is a problem in the prison system, as we can see a potential for the effects of the prison environment, coupled with Hepatitis C infection or treatment, to increase the risk of a suicide whilst a person is in prison. Ideally, we would like to see that problem addressed by an increased availability of psychological services, ranging all the way from clinical nursing, through to psychologists, drug and alcohol professionals and psychiatrists (Cregan evidence, 23 March 1998).*

Cregan also noted the effects of lethargy:

*The primary effect of Hepatitis infection is . . . lethargy. Given that the educational level amongst prison staff and administrators about Hepatitis C and its effects is really at a pretty low level at this stage, we see a potential for anyone who is suffering the effects of that Hepatitis C-*



*induced lethargy to be put in a difficult position in regard to his or her requirements to work, or to attend education, or asking to be included on a clinic list. Obviously, lethargy is traditionally associated with malingering, and malingering is a perennial sort of thing that comes up in the correctional environment (Cregan evidence, 23 March 1998).*

- **Requests for Light Duties and other Dispensations**

Those providing health care to HCV+ inmates referred to attempts to “negotiate arrangements” with prison officers to get “a little bit of a soft deal” for those experiencing Hepatitis C and/or interferon related side effects (Lloyd evidence, 30 March 1998):

*We try to get people put on light duties if they are having problems as a result of interferon. We try to modify their diet and to get them special dispensation in relation to exercise and resting in the cell (Christensen evidence, 23 March 1998).*

However, despite these attempts, the Committee heard that:

*If inmates are having health-related problems from the interferon, it is very difficult for them to get what is called a “sick in cell” or rest for the day. They have to go through lengthy procedures so that they are not out in the common yard all day or at work all day (Christensen evidence, 23 March 1998).*

In addressing this issue Lloyd, very bluntly, suggested that:

*They have to work fairly hard to get things to operate even slightly in their favour. If there is an opportunity to have a lighter workload or a better diet, whatever it may be, and they perceive that Hepatitis C may make that happen, they would not hesitate to manipulate that setting. That is being a bit callous, but I know that happens (Lloyd evidence, 30 March 1998).*

- **Training Prison Officers to be Aware of Hepatitis C/Interferon Side Effects**

It was suggested to the Committee that prison officers are often not aware that certain behaviours or moods of inmates may be due to either Hepatitis C or interferon. As the Committee heard that:

*officers need to be educated about interferon because people on interferon can experience mood change and anxiety. They can become irritable, which is drug related. Therefore, inmates need access to their cells and the clinic needs to be notified. The inmates are feeling quite*

*horrible and do not want to be told; they simply want to lie down and rest. The officers have to realise that these guys can become moody although they were not previously . . . the officers need education about who is on interferon and how we manage it (Parsons evidence, 23 March 1998).*

#### **8.6.4 PROPOSED MODEL OF SERVICE DELIVERY**

During the course of his evidence, Professor Lloyd tabled a document he and colleague, Dr Haber, had prepared at the request of Dr Phillip Brown of Corrections Health Service. The paper identifies the “urgent” need to establish a “permanent and integrated clinical service” to address current Hepatitis C needs within the corrections system (tabled document) and identify the components of such a model to be introduced on a state-wide basis.

Lloyd described the principles of the model to Members:

*the principles of the model are the same sort of things that have been called ‘shared care’ in the general community. It is a hierarchical model using health-care providers of all different levels; educators, counsellors, nurses, general practitioners and at the end of the hierarchy, specialists, gastroenterologists or infectious diseases physicians (Lloyd evidence, 30 March 1998).*

The proposed control and management model is divided into three levels of care:

Level One care commences once an inmate’s HCV antibody test is known to be positive. Trained nursing staff will provide education and counselling. Protocol-driven additional investigations will be performed and periodic liver function tests will also be performed every two months for six months. Inmates who are seronegative for HBV will be offered Hepatitis B immunisation under the existing arrangements. Lloyd outlined this level to Members:

*in the prison system the idea is to have the same sort of screening program that currently happens for all new inmates, although we would like to have the voluntary uptake rate in testing increased from 30% to a majority at least so that all individuals who come in are screened. We would like to capture those individuals by identifying them as being infected, educate them about the disease which they have and the way in which it is transmitted. . . these tasks to be undertaken by the public health nursing unit in Corrections Health Service (Lloyd evidence, 30 March 1998).*

Level Two care refers to the planned assessment by medical staff at the gaol where the inmates are housed. This will primarily involve clinical and laboratory assessment for chronic Hepatitis. The assessment will evaluate the inmate as to his/her suitability for

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interferon therapy. A protocol will be prepared to assist career medical officers (CMO who are equivalent to GPs outside the system) in country centres with this structured assessment. Lloyd told Committee Members that this level would:

*undertake a structured routine of liver function testing, trying to identify the individuals who are chronically infected versus those who are antibody positive but uninfected or have resolved the infection and then have them evaluated by staff medical officers in the prison system - that step would evaluate individuals clinically and make some sense of whether they have other compounding medical diagnoses, whether they are co-infected with other things, use alcohol or have other issues and perhaps undertake investigation on site in Grafton or wherever (Lloyd evidence, 30 March 1998).*

Level Three care is planned to involve specialist treatment of chronic hepatitis and will include the use of interferon in selected individuals under the S100 scheme. This phase required specialised nursing, medical, drug and alcohol, and psychiatric staff. Liver biopsies and specialised pathology would also be performed with inmates' consent. Lloyd described this level to Members as "at the end of the model there would be very selected individuals who would have an evaluation with a view to treatment in prison" (Lloyd evidence, 30 March 1998).

Lloyd's paper identified the additional staff required to implement the model and a draft budget. Staffing requirements and annual budget details include:

LEVEL ONE CARE:

2 fulltime nurses @ \$35,000	\$70,000
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LEVEL TWO CARE:

3 CMO sessions per week @\$163 per session	\$25,000
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LEVEL THREE CARE:

4 VMO physician sessions per wk @ \$500 per session	\$104,000
2 VMO physician sessions per wk (biopsies)	\$52,000
1 VMO psychiatrist session per wk @ \$500 per session	\$26,000
1 D&A counsellor session per wk @ \$120 per session	\$6,000
1 clinical nurse specialist	\$52,000

<b>TOTAL</b>	<b>\$335,000</b>
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Having outlined his proposed model for Hepatitis C care in the corrections system, Lloyd informed Members that:

*this is not the first time that I have presented [this model] to the Corrections Health Board. I did the same thing 18 months ago with exactly the same suggestion, which ultimately went in the form of an*

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*enhancement request to the Health Department - it got nowhere. The grapevine tells me that it may have more success this time round (Lloyd evidence, 30 March 1998).*

The Committee can see considerable merit in Lloyd's model of care which, if implemented, would address many of the concerns pertaining to treating Hepatitis C positive inmates that were brought to the Committee's attention. It does not however consider itself to be in a position to recommend the adoption of this particular model by the Department of Corrective Services and Corrections Health Service. However, it is clear to Members that a model of best practice must be adopted and implemented within the corrections system as a matter of priority.

**RECOMMENDATION 72:**

That the Department of Corrective Services and Corrections Health Service recognise the extraordinarily high rates of Hepatitis C amongst inmates in the state's correctional system and develop a Best Practice Model for the delivery of Hepatitis C health care services to these inmates as a matter of priority. The Committee believes that the Best Practice Model must provide specific care to male and female HCV+ inmates located in both rural and metropolitan correctional centres. The Committee further recommends that the Best Practice Model must overcome shortcomings in the current provision of health care identified in this Inquiry, including the shortage of available health care professionals, the limited number of inmates able to access interferon therapy, and the difficulties currently experienced in administering interferon to inmates.

**RECOMMENDATION 73:**

That the strategies to be implemented in establishing the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 74:**

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of the model of best practice for the delivery of health care to those with Hepatitis C in the state's correctional system.

Recommendations 72 to 74 address the issue of treating Hepatitis C in the corrections system. However, the introduction of a model of best practice will not necessarily address the management issues identified in the preceding discussion. Clearly this

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issue must also be addressed. The Committee considers it imperative that the Department of Corrective Services and Corrections Health Service give serious and urgent consideration to the appropriate management of the growing number of Hepatitis C positive inmates. To facilitate this process, the Committee would like to see these two agencies devise a strategic plan for Hepatitis C management in the corrections system and give a sincere undertaking to implement it as a matter of priority.

As always, the Committee is loathe to recommend government agencies form committees or taskforces to consider issues. However, in this particular case, it can see no other option. Considerable thought must be given to the diverse management concerns the Committee has identified and input has to be provided by those involved. The Committee therefore would like to see representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses) form an intersectorial committee to design and develop a strategic plan for Hepatitis C management in the corrections system. This committee is to be serviced by the Department of Corrective Services. Issues to be considered are to include, though not be limited to, provision of low fat diets to HCV+ inmates, availability of light duties for those experiencing Hepatitis C and/or interferon side effects, the education of prison officers on Hepatitis C and/or interferon side effects, in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes, the design of post-release care plans for HCV+ inmates and management difficulties experienced by those on interferon therapy.

**RECOMMENDATION 75:**

That the Minister for Health and the Minister for Corrective Services form an Intersectorial Committee made up of representatives from Department of Corrective Services, Corrections Health Service, NSW Health and specialists (both medical practitioners and clinical nurses). This Committee should be required to develop a strategic plan to address issues including, though not be limited to:

- provision of low fat diets to HCV+ inmates;
- availability of light duties for those experiencing Hepatitis C and/or interferon side effects;
- the education of prison officers on Hepatitis C and/or interferon side effects;
- in-service training for public health unit nurses on a range of Hepatitis C related issues including interferon therapy regimes;
- the design of post-release care plans for HCV+ inmates; and
- management difficulties experienced by those inmates on interferon therapy.

**RECOMMENDATION 76:**

That the implementation details of the strategic plan for the management of Hepatitis C in the state's correctional system proposed in Recommendation 75 be incorporated in the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

**RECOMMENDATION 77:**

That the Minister for Health and the Minister for Corrective Services ensure funding is available for the implementation of strategic plan for the management of Hepatitis C in the state's correctional system.

**8.6.5 PROVIDING HEALTH CARE WITHIN A DUAL DISCIPLINE FRAMEWORK**

Health care within the corrections system operates within a dual discipline framework with health related services provided by Corrections Health Service within Department of Corrective Services institutions. The relationship between the two agencies was described to the Committee as "symbiotic" (Christensen evidence, 23 March 1998).

According to their Annual Report, the Corrections Health Service's mission is to provide medical and health care for inmates comparable to the standard of care and access provided to members of the general public (Corrections Health Service, 1995:6). The Service's objective and goals include the implementation of all appropriate public health initiatives to ensure the health of the inmate population and to improve the health of inmates through health education, promotion and preventative actions (Corrections Health Service, 1995:6).

As the Committee heard:

*the challenge is to deliver objective health care - try never to get caught up in someone's crime or to run a punitive health system because often there can be a blur* (Christensen evidence, 23 March 1998).

The day to day realities of health care providers working within the corrections system were described to Committee Members in the following way:

*we work within a dual discipline framework, that is, with the Department of Corrective Services . . . we rely very heavily on them for our security. Basically if there is no officer there is no work. If the officers walk off the job for the day we are paralysed as far as accessing inmates. That is a fairly powerful discipline within which to work . . .*

*. . . In the past Dr Philip Brown [CEO, Corrections Health Service] had an agreement with Ron Woodham [Assistant Commissioner, Operation, Department of Corrective Services] to allow all the outpatient clinics to flow. However, you must remember that only two or three officers may work on that particular day. You are talking about powerful unionist stuff. You are talking about males and brute force, control and subjugation - I could go on. You may have an agreement so the process could be very slow. You may have three officers instead of eight conducting an outpatients' clinic with five visiting specialists so it is a go slow. Short of Woodham marching down from Roden Cutler House and standing there, which does not happen, you are at their mercy (Harper evidence, 23 March 1998).*

The representative from Department of Corrective Services appearing before the Committee considered his Department's relationship with Health to be "a strong working" one:

*Regular meetings occur at the policy and program levels to ensure consistent delivery of service in both departments. The Department of Health provides us with a great deal of guidance and assistance in developing our programs to ensure that they are consistent with what is available in the community. It is a very successful relationship and hopefully, it will continue in the future (Vumbaca evidence, 23 March 1998).*

Vumbaca recognised "a strain on the relationship at the moment" due to:

*the need to use existing funds only, HIV funds, to cover a whole range of issues in the system. That is probably the main area of contention - how we keep providing all these new programs and services within the existing budget. We are taking from one area to pay for another (Vumbaca evidence, 23 March 1998).*

Christensen stated that the relationship between the two agencies "sometimes gets strained" (Evidence, 23 March 1998). From her experience she called for "greater collaboration" between the Department of Corrective Services and Corrections Health Service as "sometimes these systems run parallel" (Christensen evidence, 23 March 1998). As Christensen noted:

*for the maximum outcome of patient support, there needs to be more collaboration between those groups (Christensen evidence, 23 March 1998).*

The Committee is aware of mechanisms in place to ensure communication and relationships between the two organisations are optimal. At the highest level, for example, two senior officers from the Department of Corrective Services and the

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Department of Health sit on the Corrections Health Service Board (Corrections Health Service, 1995:15). A Corrections Health Service and Department of Corrective Services Liaison Committee of the most senior officers also meets regularly to consider “matters of operational concern” between the two organisations and to review policies and procedures that impact upon both (Corrections Health Service, 1996:16). A number of conjoint *ad hoc* committees were established to address problems such as the transfer of clinical files with inmates and the extension of the methadone maintenance program (Corrections Health Service, 1996:16).

In its submission to this Inquiry, the Department of Corrective Services called upon the Committee to “enhance and build upon” the relationship that exists between Corrective Services and Health if “beneficial outcomes are to be achieved efficiently” (Department of Corrective Services submission).

Successfully treating and managing Hepatitis C within the corrections system is, and will continue to be, an enormous task. The comments made by witnesses suggest that the mechanisms currently in place may not be sufficient to ensure adequate collaboration between Department of Corrective Services and Corrections Health Service takes place. The Committee wishes to see the Ministers for both agencies take active steps to ensure officers (at all levels) collaborate effectively.

**RECOMMENDATION 78:**

That the Minister for Health and the Minister for Corrective Services take active steps to ensure officers from the Department of Corrective Services and Corrections Health Service/NSW Health (not only at the central agency level, but at the local correctional centre level) collaborate effectively.

**8.6.6 CONCLUSION**

Given the numbers of Hepatitis C positive inmates in the state’s correction system, treating and managing those patients is, the Committee has come to appreciate, an enormous task. Vumbaca summed the situation up succinctly when he commented that:

*The list of issues to be addressed goes on and on . . . With HIV we are dealing with 18 to 20 inmates; it is easy to deal with that level in the system. When you are talking about thousands it becomes a nightmare for us in terms of all the issues that need to be addressed (Vumbaca evidence, 23 March 1998).*

The Committee anticipates that the mechanisms it has proposed to address the treatment and management of Hepatitis C in the corrections system will go some way to rectify the current “nightmare”.



## **8.7 CONCLUSION**

Giving Hepatitis C's epidemiology, treating and managing the disease will be an enormous task. Clearly models of service delivery are urgently required to be put in place to treat and manage the Hepatitis C epidemic. The Committee anticipates that the proposals it has forwarded will provide an adequate framework for both inmates in the state's corrections system and those in the wider community.