CHAPTER FIVE

HEPATITIS C POLICIES

The Terms of Reference for this Inquiry called upon the Committee to inquire into the adequacy of current Hepatitis C policies. The following discussion examines current policies, identifies their inadequacies and proposes a range of strategies to address these shortcomings.

5.1 CURRENT HEPATITIS C POLICIES

When the Committee asked NSW Health to identify its Hepatitis C policies, Departmental officers nominated a number of Departmental circulars that outline policy and procedures for publicly funded health services. These policies, according to the Department, also serve as "quasi-regulations" for the private health care sector. Policies identified to the Committee included:

90/11 Hepatitis C antibody screening of blood and blood products for transfusion;

95/13 Infection Control Policy (currently under review and expected to be published in December 1998);

96/36 Low Temperature Sterilisation;

98/11 Blood Borne Infections - Management of Health Care Workers Potentially Exposed to HIV, Hepatitis B and Hepatitis C; and

97/5 Section 100 Highly Specialised Drugs.

Two information bulletins and guidelines were also identified:

- Skin Penetration Guidelines (currently under review and expected to be released in December 1998) which are administered by Environmental Health and apply to skin penetration in non-medical settings; and

- IB 93/5 - Antenatal and Neonatal Infant Screening for Hepatitis C (which will be upgraded to a policy circular although as of mid August 1998 this work had not commenced).

At no time during the Inquiry process was the Committee directed to specific documents that clearly articulate the Department's policies on managing, controlling, and/or preventing Hepatitis C. While the Committee fully appreciates the importance of policies such as those identified which outline certain procedures in detail they would, given the framework outlined above, be considered administrative policies. None of these policies take a broad, macro view of the disease and give overall direction to the control, management, prevention of Hepatitis C and the care and support of those with the disease.

The only document identified by the Committee as coming anywhere near providing general direction is the Hepatitis C Taskforce Report summarised in Chapter One. However, at no time during the course of evidence, nor in their submission to the Committee did the Department identify this document as a policy statement. The only comment the Department made was in their submission where they noted that the report has “guided policy direction in NSW” .

Clearly it has not been assigned that status. This was confirmed by a representative of the Hepatitis C Council who informed the Committee that:

> *. . . the NSW Taskforce Report is a very good list of recommendations. But as a policy on its own, it is not really a policy because it does not have applied funding tied to it. It is a list of recommendations, some of which have been implemented, but from our point of view it seems that it is too little too late; it seems to be scratching at the surface* (Loveday evidence, 3 October 1997).

5.2 THE ADEQUACY OF THESE POLICIES: THE EXPERTS’ OPINION

During the course of the Inquiry, the Committee met with and took evidence from some of the nation’s most eminent Hepatitis C experts, including clinicians, epidemiologists and public health specialists. Amongst other issues, they were asked to comment on the adequacy of current policies. Without exception, these experts condemned current Hepatitis C policies at both the state and national level. Their comments are recorded in the following discussion.

Professor Geoff Farrell is the Robert W Storr Professor of Hepatic Medicine at Westmead Hospital’s Storr Liver Clinic. In March 1997 he participated in the United States National Institutes of Health Consensus Meeting on Hepatitis C. When asked to comment on current Hepatitis C policies during the course of his evidence, Professor Farrell stated that:

> *I think [Hepatitis C policies] are inadequate in terms of, first of all, an appreciation of the general impact of Hepatitis C in the community at large, including such fundamental facts as its incidence and its distribution through various subsections of the community* (Farrell evidence, 28 November 1997).

His comments supported observations he made in his submission to the Committee where he wrote that:

> *despite the high prevalence of Hepatitis C in NSW recognised since 1989, NSW Health polices have not adequately addressed the need for improved funding of health and community services* (Farrell submission).

He urged the Committee to peruse reports presented to the Department by successive Hepatitis C Committees making detailed recommendations to “ascertain why political and administrative actions resulting from them have been so minimal” (Farrell submission).

Expert witness Professor Robert Batey is Director of the Gastroenterology Department at Newcastle’s John Hunter Hospital and Clinical Coordinator of the National Data Base of patients treated with interferon. In addition, he was the Deputy Chair of the NHMRC Working Party on Hepatitis C, is a member of ANCARD and ANCARD’s Hepatitis C Subcommittee, amongst other positions. In his opinion, current policies are:

> *probably not adequate for the extent of the problem . . . I think they are not adequate because we have 150,000 people with a disease that probably does demand a little more active intervention than we are currently providing. It is interesting that after three years of the S100 scheme there are only 2800 people who have received interferon for the disease* (Batey evidence, 27 October 1997).

Professor Alex Wodak, Director of St Vincent’s Hospital’s Drug and Alcohol Services commented to the Committee that:

> *I do not consider that current policies are adequate and I do not know how anyone could consider our policies adequate when we are currently experiencing roughly one new infection of Hepatitis C through injecting drug use every hour in Australia . . . I do not think our policies are adequate and if you try to find national or state polices aimed at controlling this epidemic I think you will have great difficulty. There are no policies to try to control this epidemic* (Wodak evidence, 2 October 1997).

Wodak acknowledged that some policies have been developed in relation to specific stages of the epidemic. As he observed, there are, for example, “well-developed” policies in the areas of diagnosis (as will be discussed in Section 6.2) and treatment (to be discussed in Section 7.2) (Wodak evidence, 2 October 1997). However he noted that:

> *the closer you get to the public health and epidemiological side of this epidemic, the more apparent it is - or least to me - that we do not have any policies at all* (Wodak evidence, 2 October 1997).

Further, he considered it:

> *scandalous that an epidemic has been allowed to continue for this length of time without this community responding to it* (Wodak evidence, 2 October 1997).

In addressing the adequacy of policies in his submission to the Committee, Wodak commented that

> *in contrast to the dynamic and innovative response to HIV, Australia's response to Hepatitis C has been lacklustre at best . . . There have been a few national efforts to develop a response to Hepatitis C. These focused on diagnostic and treatment aspects and at best provided cursory attention to prevention. In my view, this state of affairs is very inadequate* (Wodak submission).

Dr Nick Crofts also appeared before the Committee in his position of Head of the Epidemiology and Social Research Unit at the Macfarlane Burnet Centre for Medical Research in Melbourne. He informed the Committee that he considers current policies to be:

> *inadequate at the moment. I think that the major issues around Hepatitis C at the moment are prevention of continuing transmission of Hepatitis C, provision of adequate care and treatment and support for those people who have got Hepatitis C . . . and amelioration of discrimination against people who have Hepatitis C. I do not consider that our current policies address any of those three areas nearly adequately enough. I think the fourth area is the area of research . . . and again I do not think our policies are adequately coping with the need for research or the need for funding for research* (Crofts evidence, 28 November 1997).

Appearing before the Committee as Chair of ANCARD and Chair, Central Sydney Area Health Services, Mr Chris Puplick commented that:

> *I do not think we yet have a really comprehensive understanding of statewide policies in relation to Hepatitis C but the steps that have been taken by NSW Health have been very positive and very encouraging* (Puplick evidence, 7 November 1997).

Further, he felt that:

> *there is certainly no incentive provided for Area Health Services, or anybody else for that matter, to try to address some of these matters in the absence of what is seen as coherent public policy which can then be translated through the Department of Health and the Area Health Services into services on the ground* (Puplick evidence, 7 November 1997).

Finally, the submission from the Hepatitis C Council of NSW offered the following comment on policy:

> *Both in NSW and nationally, a vacuum has existed in regard to leadership that would guide HCV prevention programs and initiatives. Despite awareness since the early 1990s of the alarming rate of ongoing new infections, no programs are yet in place that are having any impact whatsoever on reducing the spread of HCV. Treatment, care and support initiatives exist on the back of already overburdened and under-resourced general clinical services, with precious little psychosocial support for those diagnosed with HCV* (Hepatitis C Council submission).

The Council's publication, *The Hep C Review* also notes that:

> *In 1995, NSW Health released a report on HCV, but we are yet to see a clear and funded strategic plan for the state . . . Both in NSW and nationally a vacuum has existed in regard to leadership that would guide HCV prevention programs and initiatives . . . no programs are yet in place that are having any impact whatsoever on reducing the spread of HCV . . . the biggest hurdle to a better response is State and Federal commitment to funding* (Editorial, 1997:1, 3).

5.3 WHAT IS POLICY?

Such a resounding condemnation of polices relating to Hepatitis C prompted the Committee to ask "What is policy?" There are a myriad of definitions of policy - what it is; what it is purported to do; what its function is. The term is used in a variety of ways to cover many, and often quite different types of statements, intentions and actions. Policy may refer to any or all of the following:

- a very general statement of intentions and objectives;
- a past set of actions of government in a specific area;
- a specific statement of future intentions; or
- a set of standing rules that are intended as a guide to action (or inaction).

Equally there are a range of ways to classify policy. The OECD, for example, has identified four categories of policy including:

- normative - policies at this level indicate overall orientation and direction. Tend to be set with a long-term time frame and are typically made by political authorities at the highest decision-making level. As Jones has observed, policies at this level may be made by apparently powerful individuals, they may serve largely symbolic purposes rather than act as sufficient and concrete guides for development of programs and projects (Jones, 1985:3978-3979);

- strategic - policies at this level give direction and emphasis to future action and they are statements of the means or strategies to be used to translate the ideals found in the normative policies into action. As any one normative policy can be achieved in a number of ways, this level establishes the orientation and direction to be followed by subsequent programs;

- operational - policies at this level are statements of activities or projects undertaken within the context of programmes specified in the higher-order, strategic policies. They identify the way strategies are to be put into operation and as such tend to be short- to medium-term in their orientation; and

- administrative - statements at this level describe actions in response to daily demands so that the projects at the operational level can be implemented. By their nature administrative policies must be relatively unequivocal and narrow in focus.

These four dimensions represent four different levels of policy. Each is related to the other in a highly interdependent manner, ie normative policies are used as guidelines for strategic policies. Strategic policies, in turn, direct operational policies which influence the policies made at the administrative level. The administrative, or “routine” policies clarify the operational policies (OECD, 1977:7). The four levels range from the most general, normative policies to the most specific administrative policies (Soumelis, 1983:37).

Generally speaking, normative policies have to do with what <u>should</u> be done; strategic policies with what <u>could</u> (when and how) be done; operational policies with what <u>will</u> (when and how) be done; and administrative policies with what <u>is being</u> done (Soumelis, 1983:38). In this way, the framework resolves a common tension between what “ought” to be done and what “is” done for a workable translation of goals into action.

The Committee fully appreciates that such a framework is not the only way to design and formulate policy nor does it expect NSW Health to adopt this framework. However the example does demonstrate the inter-related nature of policies and the importance of different policies being developed for different purposes.

5.4 RECTIFYING CURRENT POLICY INADEQUACIES

As has been discussed, Hepatitis C is an epidemic impacting upon an estimated 90,000 people and their families in New South Wales alone (Loveday evidence, 30 March 1998). The response of NSW Health from a policy perspective has been limited. The Hepatitis C Taskforce report makes a number of recommendations for government action but there are no policies at the state level giving overall direction to the control, treatment, management or prevention of Hepatitis C. The Committee regards this situation to be totally inadequate.

The Committee considers a range of strategies are called for as a matter of priority to redress the current situation. In the Committee's opinion these strategies must be instigated and implemented at the three tiers of the state's health system that have responsibility for health policy and planning in this state: the Office of the Minister for Health, NSW Health - central agency, and the various Area Health Services across the state.

5.4.1 ACTION AT THE MINISTERIAL LEVEL: THE OFFICE OF THE MINISTER FOR HEALTH

For some time there has been a Hepatitis Advisory Committee which is responsible for making recommendations on aspects of HCV prevention, care, treatment and support. The Terms of Reference of the Committee are:

1. to advise the Chief Health Officer on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of the hepatides;

2. to liaise with other Departmental committees relevant to hepatitis;

3. to liaise with the Public Health Network on hepatitis issues; and

4. to review NSW Health documents that have relevance to any of the hepatides.

The Committee's membership has been described as "similar but more comprehensive" than the Hepatitis C Taskforce membership (NSW Health submission). In addition to Departmental officers acting as Chair and Secretariat, the Committee's membership includes:

- Professor Bob Batey — John Hunter Hospital
- Dr Ingrid van Beek — Kirketon Road Centre
- Professor Yvonne Cossart — Dept of Infectious Diseases, Sydney University
- Professor Geoff McCaughan — Royal Prince Alfred Hospital
- Mr Paul Harvey — Hepatitis C Council of NSW
- Dr Michael Douglas — Western NSW Public Health Unit
- Dr Alex Wodak — St Vincents Hospital
- Dr Brenton Wylie — NSW Blood Transfusion Service

The Committee meets four times a year in addition to *ad hoc* issue dependent meetings.

The Hepatitis C Council considered the current Advisory Committee to be a "useful avenue" for giving advice (Harvey evidence, 3 October 1997). However, in the Council's opinion:

> *it could take on a much more effective role by taking on more of a planning and development role, more of a proactive role. At the moment it just responds to issues and questions* (Harvey evidence, 3 October 1997).

The Committee does not have the status of a Ministerial Advisory Committee and as such does not report to or directly advise the Health Minister. The Council is concerned with the status of the Committee as they "do not believe it is being given the right level of profile within NSW Health" (Loveday evidence, 3 October 1997).

During the course of this Inquiry, it was suggested to the Committee that there would be advantages in upgrading the status of the Hepatitis Advisory Committee to that of a Ministerial Advisory Committee. The Hepatitis C Council, for example, fully supported such a move along with Puplick who noted that:

> *I would have no difficulty at all with the [Hepatitis C] Committee having ministerial status in line with the Ministerial Advisory Committee on HIV which currently exists* (Puplick evidence, 7 November 1997).

The Ministerial Advisory Committee on HIV referred to by Puplick reports directly to the Minister for Health. Its Terms of Reference include:

1. advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic direction for HIV services;

2. liaise with other Committees and professional groups of relevance to HIV; and

3. promote research and training in HIV.

The Committee, which includes 12 experts and three ex officio Departmental officers, meets every six weeks, with two full day meetings each year.

In terms of giving Hepatitis C a higher profile and involving the Minister for Health more directly, the Committee wishes to see the Hepatitis Advisory Committee upgraded and given the same status as the Ministerial Advisory Committee on HIV. The Terms of Reference for the Ministerial Advisory Committee on Hepatitis C would include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;

2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;

3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and

4. to promote research and training in Hepatitis C.

RECOMMENDATION 27:

That the Minister for Health upgrade the Hepatitis Advisory Committee to become the Ministerial Advisory Committee on Hepatitis C. The Committee further recommends that the Terms of Reference of the Ministerial Advisory Committee on Hepatitis C include:

1. to advise the Minister on clinical, education/prevention, health promotion and surveillance policy and strategic directions for the prevention, care and treatment of Hepatitis C;
2. to participate in the design and development of the statewide policy statements and strategic plans for Hepatitis C;
3. to liaise with other Committees and professional groups of relevance to Hepatitis C; and
4. to promote research and training in Hepatitis C.

As the Terms of Reference suggest, the Committee anticipates that the Ministerial Committee would be involved in driving policy at the macro level and having direct and substantial input into the design and development of the Hepatitis C Policy Statement as will be proposed in Recommendation 28.

5.4.2 ACTION AT THE DEPARTMENTAL LEVEL:CENTRAL AGENCY - NSW HEALTH

- **Development of a NSW Hepatitis C Policy Statement**

The Committee considers the first step in addressing the current Hepatitis C epidemic must be the development of a set of sound policies giving overall direction to the control, management and prevention of Hepatitis C along with the care and support of those with the virus. At present no such document is available.

The Committee is aware of the Department's experience in preparing the type of statement it considers to be essential. *The NSW Aboriginal Mental Health Policy* (1997), for example, goes some way in meeting the Committee's expectations. That document contains a broad vision statement, and explicitly states the guiding principles and aims of the policy. The second section of the policy statement deals with strategy and enunciates the policy's four strategic directions and an implementation timetable for each of these strategies.

While the Committee fully appreciates the development of a Hepatitis C policy statement may take on a different form to the Aboriginal mental health policy or any other policy statement of the department, it does call upon the Department to produce such a statement and to use it as the basis of all future Hepatitis C action and allocation of funding. It also considers it essential that, as a minimum, the proposed policy statement include a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

RECOMMENDATION 28:

That the Minister for Health direct NSW Health to design and develop a NSW Hepatitis C Policy Statement to give overall direction to the control, treatment, management and prevention of Hepatitis C and the care and support of those with the disease.

The Committee further recommends that the proposed NSW Hepatitis C Policy Statement include, as a minimum, a broad vision statement of the direction to be taken in Hepatitis C support, control, treatment, management and prevention, along with supporting guiding principles and policy aims.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Policy Statement in January 2001 to assist in determining future responses and directions.

RECOMMENDATION 29:

That the NSW Hepatitis C Policy Statement proposed in Recommendation 28 be the basis for all future planning and funding for Hepatitis C in the state.

To ensure the policy statement proposed in Recommendation 28 is relevant, adequate and appropriate the Committee considers it vital that the major stakeholders be involved in the policy development process. The Committee anticipates this would include, though not be limited to, representatives of the Hepatitis C Council, and relevant community groups such as NUAA, and appropriate medical specialists (for example liver/hepatic specialists, epidemiologists, public health experts, and clinical nurse consultants). The Committee also considers there to be value in involving the Ministerial Advisory Committee on Hepatitis C in designing and developing the proposed Policy Statement.

RECOMMENDATION 30:

That the Minister for Health ensure adequate consultation with the major stakeholders during the process of designing and developing the NSW Hepatitis C Policy Statement proposed in Recommendation 28. Those consulted are to include, yet not be limited to, representatives of the Hepatitis C Council and relevant community groups such as NUAA, liver specialists, public health experts, epidemiologists, clinical nurse consultants.

The Committee further recommends that the Ministerial Advisory Committee on Hepatitis C be actively involved in the design and development of the NSW Hepatitis C Policy Statement proposed in Recommendation 28.

- **Development of a NSW Hepatitis C Strategic Plan**

As has been discussed, broad policy is usually formed to give direction to future action which may be spelt out in detail in subsequent documents such as departmental strategic plans. In the latter stages of this Inquiry, it was brought to the Committee’s attention that the Department had commenced developing a Hepatitis C Strategic Plan.

While the Committee welcomes this long overdue initiative, it finds it curious that a strategic plan can and is being developed in the absence of a broad policy statement. The Committee questions the basic premises upon which such a plan is based as these have never been publicly enunciated or made available. Until the Department identifies and articulates **what** it wants to achieve in terms of Hepatitis C control, treatment, management, prevention, care and support, it is difficult to identify appropriate strategies to address the practicalities of **how, when** and **where**. Once the policy statement called for in Recommendation 28 has been developed, it is then important that a strategic plan be devised to spell out in detail the approaches to be used to meet the policy’s vision and aims. It would be erroneous and extremely shortsighted to develop a statewide strategic plan in a policy vacuum.

RECOMMENDATION 31:

That the Minister for Health direct NSW Health to develop a NSW Hepatitis C Strategic Plan within the context of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and that the Strategic Plan clearly articulate how, when and where the state will address all facets of Hepatitis C control, treatment, management and prevention along with care and support for those with the disease.

The Committee further recommends that NSW Health undertake an evaluation of the NSW Hepatitis C Strategic Plan in January 2001 to assist in determining future responses and programs.

The Committee's call for the development of a Hepatitis C Strategic Plan brings New South Wales into line with most other Australian states and territories that have already developed and are in the process of implementing such plans. The Committee considers this to be the absolute minimum the Department can do to address the Hepatitis C epidemic in this state.

The Committee is aware that strategic plans have been developed by Queensland (Queensland Health, 1998), Victoria (Victorian Department of Health and Community Services, 1995), the ACT (ACT Department of Health and Community Care, 1998) and South Australia (South Australia Health, 1996). Each of these plans have various strengths and weaknesses and the Committee feels that there is much NSW Health can gain from reviewing these documents. Several features of the Victorian strategy particularly appealed to Committee Members. Each issue covered in the strategy contained stated goals, key strategies, and in some cases, guiding principles. The ACT strategy similarly spelt out its goals, objectives, strategies and actions and included a detailed three year implementation plan for each objective.

These attributes of the Victorian and ACT plans are routine features of a strategic plan. The Committee however wishes to ensure that they are features included in the Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 32:

That the NSW Hepatitis C Strategic Plan proposed in Recommendation 31 identify goals, objectives and key strategies along with detailed implementation plans for each objective.

The Victorian strategic plan is available on the Internet (http://hna.ffh.vic.gov.au). The Committee considered this to be a very appropriate approach and wishes to see NSW Health adopt a similar practice.

RECOMMENDATION 33:

That NSW Health ensure the NSW Hepatitis C Policy Statement (proposed in Recommendation 28) and NSW Hepatitis C Strategic Plan (proposed in Recommendation 31) are placed on the Department's website.

- **Adequate and Dedicated Hepatitis C Funding**

Policy is mere rhetoric if it is not backed up with adequate and recurrent funding. During the course of the Inquiry, a number of specific comments on current funding levels were made to the Committee. The Hepatitis C Council, for example, noted that:

> *It is clear that the response to Hepatitis C has been slow and that funding levels are inadequate to manage the growing numbers of people with HCV . . . this area lacks clear strategies, coordination, adequate funding . . . given the large numbers of infected people in NSW* (Hepatitis C Council submission).

The Council's submission also noted that:

> *The biggest hurdle . . . is state and federal commitment to funding. In comparison to best standard models . . . the amount of money allocated to meet Hepatitis C needs is grossly inadequate* (Hepatitis C Council submission).

In evidence Mr Loveday stated that:

> *national and state funding has been one of too little too late. Various Federal and State policies have recommended that action be taken in specific areas, but these recommendations have not to date been translated into strategic plans of action with dedicated funding allocated to them. . . Overall budget allocations to date have been very ad hoc and grossly insufficient. Often they are year-end underspends relating to other areas of the budget where, because of time pressures, their allocations cannot be properly planned and consultation is certainly made all the more harder. To their credit, NSW Health has sought support from the Commonwealth and other States for matched funding arrangements similar to HIV, but with the coming of the public health agreements between the states and the Federal Government, this was really unlikely to succeed and, of course, did not get up* (Loveday evidence, 30 March 1998).

In his submission to this Inquiry, Professor Farrell notes that NSW Health has instituted Hepatitis C projects at a total cost of $600,000 to "try and devise appropriate shared-care programs and to promulgate attempts to prevent the disease". As Farrell notes:

> *to have reached this stage by 1997 when we have known about the importance of this 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 for efficient, shared-care, diagnostic and management services* (Farrell submission).

In its submission to this Inquiry, ANCARD noted that "very little direct funding" has been put into Hepatitis C services despite the thousands in the state who have the disease (ANCARD submission).

NSW Health currently provides recurrent funding for Hepatitis C specific programs.

Departmental allocations to these initiatives are summarised in Table Nineteen below.

TABLE NINETEEN
CURRENT NSW HEALTH HEPATITIS C EXPENDITURE

PROGRAM	AMOUNT OF FUNDING	TYPE OF FUNDING
Hepatitis C Council of NSW	$215,400	Recurrent
Hepatitis C Lookback Program	$480,000	Spread over two years
Printed information to medical practitioners & other health care workers	$95,000	One off
Hepatitis C Taskforce implementation funding	$250,000: 1995-96 $500,000: 1996-97 $515,000: 1997-98	

Source: NSW Health submission

Additional funding is also available for a range of services set up primarily in response to HIV/AIDS such as needle and syringe exchanges and funding for organisations such as New South Wales Users and AIDS Association (NUAA), Transfusion Related AIDS and Infectious Diseases Unit (TRAIDS) and the Haemophilia Foundation. In each case, the role of these services has been broadened to take on additional HCV responsibilities. These services and the amounts allocated to them are recorded in Table Twenty.

TABLE TWENTY
AIDS PROGRAM FUNDED HEALTH SERVICES WITH PARTIAL HCV WORKLOAD

PROGRAM	AMOUNT OF FUNDING	TYPE OF FUNDING
Needle and Syringe Program	$7,527,497	Recurrent
NSW Users and AIDS Association	$885,500	Recurrent
TRAIDS	$150,519	Recurrent
Haemophilia Foundation	$59,200	Recurrent

Source: NSW Health submission

The submission from NSW Health provides information on the costs of fully implementing the recommendations contained in the Taskforce Report. As has been discussed in Section 1.2.2 a comprehensive program of appropriate activities under the health portfolio is estimated to require additional funding of approximately $3,240,000 annually with an additional $1,690,000 in 1998/99 to initiate appropriate actions, making a total of $4,930,000 in 1998/99 (NSW Health submission).

The submission also notes that, within the context of negotiations with the Commonwealth Department of Health and Family Services regarding the establishment of a Public Health Outcomes Funding Agreement, recurrent funding of $3,250,000 for Hepatitis C had been sought. However, at the time of preparing their submission, NSW Health advised the Commonwealth had indicated such funding would not be provided (NSW Health submission). In a supplementary submission provided to the Committee in August 1998 the Department advised "it is likely" NSW will be successful in securing in excess of $1million for a range of Hepatitis C projects under the Public Health Outcomes Agreement. This will, according to the NSW Health "facilitate most of the non-recurrent recommendations of the Taskforce being implemented" (NSW Health supplementary submission). The supplementary submission also noted that the state government had sought to establish a cost-shared program with the Commonwealth through which additional funds could be made available. NSW Health advised that these negotiations have been "unsuccessful" (NSW Health supplementary submission).

Any consideration of funding requirements must be made with a full appreciation of the economic impact of Hepatitis C which was discussed in Section 4.3.2. As that discussion noted, the long term financial impact of the disease upon injecting drug users alone is anticipated to be in excess of $4 billion.

The Committee considers it imperative that financial allocations to Hepatitis C be based upon the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Strategic Plan proposed in Recommendation 31. The Committee also considers federal Hepatitis C funding to date to have been inadequate given the rates of Hepatitis C in New South Wales. The Committee wishes to see the Commonwealth government provide funding allocations which reflect more accurately the rate of Hepatitis C in this state and the need for support services and prevention strategies.

RECOMMENDATION 34:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

RECOMMENDATION 35:

That the Minister for Health urge his federal counterpart to provide funding allocations which reflect more accurately the rate of Hepatitis C in New South Wales and the state's need for support services and prevention strategies.

- **Adequate and Appropriate Staffing: Central Agency**

The Department of Health advised the Committee that the staff allocation in the Department's central agency dedicated to Hepatitis C policy work is 4.2 which is made up of the following:

(1.0) Hepatitis C Policy Analyst (Evaluation)
(0.8) Policy Analyst Hepatitis
(0.8) Needle Exchange Policy Analyst
(0.4) Manager HIV/AIDS/Hepatitis
(0.3) Social Research Policy Analyst
(0.3) Surveillance Officer
(0.2) Medical Epidemiologist
(0.2) Infection Control Policy Analyst
(0.2) Director AIDS/Infectious Diseases Unit

TOTAL: 4.2

By comparison, 5.7 staff are allocated to HIV policy work at the central agency. These include:

(1.2) Needle Exchange Policy Analysts
(1.0) HIV/AIDS Policy Analyst
(1.0) Surveillance Officer
(0.7) Social Research Policy Analyst
(0.6) Manager HIV/AIDS/Hepatitis
(0.6) Clinical Services Policy Analyst
(0.2) Medical Epidemiologist
(0.2) Infection Control Policy Analyst
(0.2) Director AIDS/Infectious Diseases Unit

TOTAL: 5.7

This central agency staffing allocation is in addition to Area HIV/AIDS Managers deployed throughout the Department's Area Health Services.

A different perspective on staffing was provided to the Committee by representatives from the Hepatitis C Council, who informed the Committee that:

> *Apart from temporary project staff working in one-off projects, NSW Health has only one dedicated Hepatitis position in the AIDS and Infectious Diseases Branch. This position makes recommendations on policy and on program funding to a manager with overall responsibility for HIV and Hepatitis. This is clearly not enough to match the size of the Hepatitis C problem in NSW, when say, compared with HIV* (Hepatitis C Council submission).

In evidence before the Committee and in response to the Department's advice that 4.2 staff are allocated to Hepatitis C policy work, Mr Loveday skeptically added that:

> *I suppose if you take 0.1 or 0.2 or a day here and a day there of staff members' time, and added it to the two Hepatitis-designated workers, perhaps it might add up to 4.2* (Loveday evidence, 30 March 1998).

He further commented that:

> *the Hepatitis policy analyst at NSW Health, not the Hepatitis C policy analyst, as the Health Department stated in their evidence in October last year, looks after all hepatitises, which is a much, much bigger case load than Hepatitis C. The Hepatitis C Evaluation Officer is on a one-year contract and works primarily with the four demonstration projects. So doubtless management and other staff do spend time on hepatitis C policy development work* (Loveday evidence, 30 March 1998).

In Mr Loveday's opinion, staff are "completely snowed under" (Loveday evidence, 30 March 1998). To illustrate his claim he cited the following examples:

> *a temporary departmental post to oversee and consolidate Hepatitis C surveillance in NSW was unable to be filled, because initially there was no budget to employ them and then no office space could be found for them, and this is to oversee surveillance in New South Wales. Another example, updates on basic Health Department produced information leaflets about other hepatitises gets put on endless backburners. It happened with Hepatitis C as well, until the community group produced one* (Loveday evidence, 30 March 1998).

In their submission to this Inquiry, the Hepatitis C Council called for an expansion of dedicated Hepatitis C staffing positions within the AIDS and Infectious Diseases Branch, NSW Health to "enable adequate overview and coordination of the response to HCV" (Hepatitis C Council submission). The Committee fully supports this proposal.

The Committee wishes to see the Department assign dedicated, full time and permanent staff at appropriate senior levels to drive and implement the NSW Hepatitis C Policy Statement along with the NSW Hepatitis C Strategic Plan.

RECOMMENDATION 36:

That the Minister for Health ensure dedicated, adequate and appropriately graded full time and permanent staff are assigned within the AIDS and Infectious Diseases Branch of NSW Health to oversee the implementation of the NSW Hepatitis C Policy Statement proposed in Recommendation 28 and the NSW Hepatitis C Strategic Plan proposed in Recommendation 31.

5.4.3 ACTION AT THE REGIONAL LEVEL: THE AREA HEALTH SERVICES

- **Development of Regional Hepatitis C Strategic Plans**

Having argued for NSW Health to develop a Hepatitis C Policy Statement and associated Strategic Plan, the Committee considers the next step to be the development of strategic plans at the regional level to address local needs and issues.

Table Six demonstrated that Hepatitis C rates vary considerably across the state. Area Health Services such as South Eastern Sydney (18% of the NSW notifications), Central Sydney (13.4%), South Western Sydney (11.7%) and Western Sydney (10.2%) have Hepatitis C notification rates far exceeding those in, for example, rural Area Health Services such as Macquarie (0.7%), Far West (0.2%) and New England (1.8%). Figure Three showed that notifications in the Northern Rivers Area Health Service greatly exceed the Area's population on a percentage basis. Clearly it is imperative that those Area Health Services with high rates of Hepatitis C have strategic plans in place to address the issue and give direction to services. It is also essential that funding be available to these Area Health Services to implement their plans.

In considering the option of regional Hepatitis C strategic plans, the Committee is fully aware of the level of autonomy assigned to the state's Area Health Services. The Committee appreciates that the central agency of NSW Health is not able to direct Area Health Services to introduce measures either this Committee or the central agency consider necessary and appropriate. However, the Committee understands that contract performance agreements between NSW Health and the Area Health Services can be used to ensure minimum levels of services are achieved. As Kirketon Road Centre's Director suggested to the Committee:

> *I do think that if the [health] department were able to enter into more binding performance agreements . . . with the Area Health Services such that Area Health Services were required to reach a minimum level of service, and prevention services were tied into that agreement, that would be a positive thing* (van Beek evidence, 6 November 1997).

The Committee is also aware that some Area Health Services such as Central Sydney and Hunter Area Health Services have dedicated Hepatitis C strategies and that others are in the process of developing their strategic plans. The South Eastern Sydney Area Health Service has prepared a draft *Communicable Disease Strategic Directions Statement* that includes, amongst other diseases, Hepatitis C. The document identifies the broad directions of the Strategic Directions Statement and its guiding principles as well as a number of specific goals, which have been linked to objectives and strategies. According to the Statement, the implementation of the strategic goals and objectives will be undertaken by a formal, accountable and participatory process with defined lines of accountability and communication. According to the document, a Communicable Diseases Outcomes Advisory Committee will provide the mechanisms and structures

for the integration and co-ordination of communicable disease programs across the area and will enable area wide analysis of trends, patient flows and service utilisation (South Eastern Area Health Service, 1998:59).

The Committee was encouraged by the level of detail enunciated in the Statement. It would appear that considerable thought and effort has been given to the Statement's preparation. The Committee considers it regrettable that such thought and effort is not apparent at the state level. However, the Committee was concerned that Hepatitis C may become "buried" amongst the very large number of communicable diseases covered by this Strategic Directions Statement. The Committee would prefer to see a dedicated HCV strategic plan within the overall communicable disease strategic approach given the extremely large number of known HCV notifications in South Eastern Sydney Area Health Service.

The Committee would like to see those Area Health Services with the highest Hepatitis C notification rates - South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services - develop and implement regional and dedicated Hepatitis C strategic plans. Despite its communicable diseases strategic plan, the Committee has specifically included South Eastern Sydney in this list as it considers it essential that this area have a localised, dedicated Hepatitis C strategy.

RECOMMENDATION 37:

That the Minister for Health direct South Eastern Sydney, South Western Sydney, Western Sydney, Northern Sydney and Northern Rivers Area Health Services develop and implement Regional Hepatitis C Strategic Plans in line with the NSW Hepatitis C Policy Statement (as proposed in Recommendation 28) and the NSW Hepatitis C Strategic Plan (as proposed in Recommendation 31). This measure should be achieved through contract performance arrangements between NSW Health and the Area Health Services.

RECOMMENDATION 38:

That the Minister for Health ensure adequate and ongoing dedicated funding is provided for the full implementation of the regional Hepatitis C Strategic Plans proposed in Recommendation 37.

- **Adequate and Appropriate Staffing: Area Health Services**

The Department's submission noted that:

> *the majority of Area Health Services do not have staff specifically working on Hepatitis C. Rather Hepatitis C is one of a range of infectious diseases*

> *dealt with by a number of staff employed to work on HIV/AIDS and/or infectious diseases* (NSW Health submission).

The Committee is aware that a few Area Health Services have staff assigned to work on Hepatitis C. Wentworth and Central Coast Area Health Services have part time, temporary staff working under contract, while Illawarra has in the past had a Hepatitis C Manager. Other Area Health Services such as Central Sydney and Western Sydney have clinical nurse consultants working in the area of Hepatitis C - these positions are outside the scope of the current discussion.

The Committee is also aware that many, if not all, Area Health Services have dedicated Area HIV/AIDS Managers who carry out a range of duties such as:

- act as the Executive Officer for the Area HIV/AIDS services;
- consult with health services, hospitals and other relevant agencies to establish the needs and priorities of the Area;
- develop and implement HIV/AIDS treatment/care and prevention/education programs consistent with state HIV planning documents;
- develop, implement and evaluate Area plans, including HIV plans, develop service models, strategies, performance indicators and outcome measures; policies and programs for the treatment/care and education/prevention services;
- facilitate the co-ordination of the various HIV/AIDS services for which the Area Health Service is responsible; and
- consult with health services, hospitals and other relevant agencies to establish the changing needs and priorities of the Area in the development and implementation of HIV/AIDS treatment/care, prevention/education and management programs.

Many of these Managers are being asked to add Hepatitis C related issues to their already heavy workloads. The Duty Statement for the position of Manger - HIV/AIDS Services for the Central Sydney Area Health Service, for example states that "where appropriate facilitate the inclusion of Hepatitis C within existing programs and services" and includes Hepatitis C along with HIV/AIDS in several activities such as "facilitate the coordination of the various HIV/AIDS and Hepatitis C services for which the Area Health Service is responsible" (Central Sydney Area Health Service, undated). Similarly, the duties of the AIDS Coordinator in the New England Area Health Service include participation in the Infectious Diseases Team response to notifications of, amongst other diseases, Hepatitis C (New England Area Health Service, undated).

In terms of HIV/AIDS Managers taking on additional duties, Loveday noted that the Hepatitis C Council:

certainly welcomes the expansion of their duties to take on Hepatitis C. But, realistically, to have Hepatitis C just added to their job description on top of in many cases . . . a full HIV-related workload, does not bode well for the known 45,000 and estimated 90,000 people in NSW with Hepatitis C (Loveday evidence, 30 March 1998).

The Committee considers the practice of requiring Area HIV/AIDS Managers to take on Hepatitis C related issues to be inappropriate, particularly in those Area Health Services that have high rates of both HIV/AIDS and HCV such as South Western Sydney and Central Sydney. The Committee fully agrees with Loveday who proposed that:

it would make great sense to fund the appointment of hepatitis services co-ordinating staff in area health services who, with an appropriate budget, would assist in the localised provision of education, information and referral services (Loveday evidence, 30 March 19998).

However, given that the demand for Hepatitis C management will differ across the state in line with varying Hepatitis C rates, the Committee would like to see a full review conducted across all Area Health Services to determine the specific needs of each Area Health Service in terms of Hepatitis C management.

RECOMMENDATION 39:

That the Minister for Health review all Area Health Services to determine the needs of each Area Health Service for Area Hepatitis C Managers.

While proposing the introduction of Area Hepatitis C Managers, the Committee is fully aware that its recommendation will take some time to implement. It is concerned that in the interim access to Hepatitis C services, care and support will be limited. It therefore proposes Area Hepatitis C Managers be placed in those Area Health Services the Committee considers to be in greatest need, based on Hepatitis C notification rates: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Northern Rivers.

RECOMMENDATION 40:

That the Minister for Health instruct that, as a matter of priority, the position of dedicated Area Hepatitis C Manager be established and filled in the following Area Health Services: South Eastern Sydney; Western Sydney; South Western Sydney; Central Sydney and Northern Rivers. The Committee further recommends that the position of dedicated Area Hepatitis C Manager be in addition to existing positions of Area HIV/AIDS Managers which may currently exist in the identified Area Health Services.

RECOMMENDATION 41:
That the Minister for Health ensure dedicated funding is allocated to the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services for the establishment of Area Hepatitis C Manager positions.

RECOMMENDATION 42:
That the Minister for Health instruct that the positions of Area Hepatitis C Manager in the South Eastern Sydney, Western Sydney, South Western Sydney, Central Sydney and Northern Rivers Area Health Services be incorporated in the review of Hepatitis C staffing needs proposed in Recommendation 39. The Committee further recommends that, following this review, and where necessary additional staff dedicated to Hepatitis C management at the local Area Health Service level be appointed.

5.5 CONCLUSION

Despite the current Hepatitis C epidemic there are no policies at the state level giving overall direction to the control, treatment, management and prevention of this disease. To overcome the current inadequate situation, the Committee has forwarded a number of recommendations including upgrading the Hepatitis Advisory Committee to the Ministerial Advisory Committee on Hepatitis C; the design, development and implementation of a NSW Hepatitis C Policy Statement and a NSW Hepatitis C Strategic Plan; adequate and ongoing dedicated funding for the full implementation of the Policy Statement and Strategic Plan, dedicated, adequate and appropriately graded full time and permanent staff to oversee the implementation of the Hepatitis C Policy and Strategic Plan and, as a matter of priority, Area Hepatitis C Managers assigned to the five Area Health Services with exceptionally high levels of HCV notifications.