

## 1.1 Background and Approach to Project

### Background

Over the last decade hepatitis C has been the most commonly notified infectious disease in Australia. It has been estimated that 264,000 people were living with hepatitis C infection in Australia in 2005, including 154,000 with chronic hepatitis C and stage 0/1 liver disease, 38,000 with stage 2/3 liver disease and 5,300 with hepatitis C related cirrhosis. A further 67,000 had hepatitis C antibodies without chronic infection.

NSW accounts for around 40% of notifications in Australia. Up to the end of 2006, 97,844 people in NSW had been notified as carrying hepatitis C antibodies. Notifications in NSW reached a high of 8,632 in 2001, before falling to 4,478 in 2006.

The large population of people with hepatitis C, together with estimates of continued high hepatitis C incidence and the often long latency of hepatitis C related disease, will produce an escalating health burden for at least the next two decades. The already increasing incidence of hepatocellular carcinoma is thought to be related to the expanding hepatitis C epidemic, and cirrhosis due to chronic hepatitis C infection is already the most common underlying reason for liver transplantation.

The number of people living with hepatitis C related cirrhosis, incident cases of liver failure and hepatocellular carcinoma, and cumulative numbers of hepatitis C related deaths are all projected to double by 2020.

Significant improvements have been made in the treatment of hepatitis C. However, currently only a small proportion of people with chronic hepatitis C access anti-viral therapy.

People with hepatitis C have a range of treatment, care and support needs. Providing equitable access to treatment, care and support services and increasing treatment uptake among people with hepatitis C has been recognised as a major goal in the NSW Hepatitis C Strategy 2007–2009.

### Approach

This project consisted of the following key components:

- review of policy and planning documents and selected literature
- call for submissions
- survey of existing services
- consultations with key stakeholders (see list in Appendix A)

- one focus group with clients in metropolitan Sydney and another focus group with clients in the North Coast Area Health Service
- analysis of epidemiological and service utilisation data

## 1.2 Summary of Key Findings

### Epidemiology

In Australia the greatest source of risk for transmission of hepatitis C is through sharing or re-using needles, syringes and other drug injecting equipment which have been contaminated by infected blood. HCV prevalence in people who inject drugs has ranged from 50%–70% since the early 1970s. Of all people living with HCV antibodies in Australia, 82.3% are estimated to have been exposed through injecting drug use, 10.9% are migrants from countries of high prevalence, and 6.8% are recipients of contaminated blood or blood products or through other exposure routes such as unsterile tattooing or mother to child transmission.

In NSW in 2006, 4478 people were notified as having hepatitis C. The peak was in 2001 when there was 8632 notifications. The proportion of women notified each year with HCV are, on average (over the sixteen years between 1991 and 2006), 37% of the total. Most HCV notifications are in the 20–29, 30–39 age groups.

Between 1993 and 1997 South Eastern Sydney had the highest number of notifications. In 1998 and for the following two years Western Sydney had the most notifications and since 2001 South Western Sydney has had the highest number of HCV notifications per year. In 2006 South Western Sydney had the most HCV notifications with 581 cases, followed by South Eastern Sydney with 493 cases and Central Sydney with 450 cases.

The Northern Rivers has had the highest number of notifications among the rural Area Health Services since 1991 with the exception of one year, 2003, when the Illawarra had slightly more notifications. For the most part the Illawarra has had the second highest number of notifications per year. In 2006 the Mid North Coast had the third highest numbers of HCV notifications — a position it has maintained since 1998.

Central Sydney, South West Sydney, the Hunter and the Central Coast have the highest rates of age standardised notifications in the metropolitan Areas. In rural Areas the highest rates are in the Northern Rivers, the Mid West, Macquarie and the Far West. Rates in the Northern Rivers, the Mid West and Macquarie were higher in 2006 than rates in any metropolitan Area.

The HCV Projections Working Group estimates that if 2000 people with chronic HCV infection continue to be treated each year (i.e. the number treated in 2005), the number of people living with chronic HCV and more advanced stage F2/3 liver disease or cirrhosis are projected to increase by around 38% by 2015. It is estimated that more than 6000 people per year need to be treated to prevent the expected increases in people with advanced liver disease.

### Service Utilisation

In the absence of regular reporting on the number of people who have received/are receiving anti-viral therapy for HCV, expenditure on s100 drugs for HCV provides a proxy for treatment activity. There has been a substantial increase in expenditure on s100 drugs for HCV treatment over the last 8 years in all States and Territories. This increase is due to a number of factors including: improved drug efficacy, the increasing cost of therapy, removal of the requirement for all patients undergoing treatment to have a liver biopsy. There have been significant increases in the two years from 2004/05 to 2005/06 from \$28.66m to \$34.43m. and the estimated expenditure in 2006/07 is over \$53.0m. The overall increase across all States and Territories is estimated to be 54% between 2005/06 and 2006/07. However the increase in Queensland is estimated to be 92%, 93% in SA and 66% in WA. In NSW, it is 37%.

The cost of treatment of inpatients with conditions related to HCV is estimated to be around \$28 million per year. Hospitals with the highest caseload of people being treated for conditions related to HCV are Royal Prince Alfred, Westmead Hospital, St Vincent's, Prince of Wales Hospital, Liverpool and St George. The already increasing incidence of hepatocellular carcinoma is thought to be related to the expanding hepatitis C epidemic, and cirrhosis due to chronic hepatitis C infection is already the most common underlying reason for liver transplantation.

### Issues affecting future service delivery

- There is an increasing prevalence of HCV which has major implications for long term treatment costs.
- Most HCV services in all AHSs said that they had no spare capacity to increase the number of people on anti-viral therapy
- There is disparity in the extent of HCV service provision between Areas
- Funding for HCV non-inpatient services is from a variety of sources and most of it is non-recurrent.
- There is not a comprehensive service delivery framework for HCV that describes the key elements required for provision of best practice evidence-based care.
- The interest by GPs in the treatment and care of people with HCV is difficult to gauge and there are a number of barriers to successful shared care.
- Because of the high prevalence of HCV among AOD clients, there is scope to increase the involvement of

AOD services in providing HCV services.

- Sexual Health Services limit their role in the provision of services for people with HBV and HCV due to resource constraints yet if there is no specialist liver service (as in many rural areas), the Sexual Health Services provide an appropriate setting for HCV treatment.
- A number of population groups who are at risk of hepatitis C infection, may be disadvantaged in their access to HCV treatment and care services. These groups are:
  - people who inject drugs
  - people in custody
  - Aboriginal and Torres Strait Islander people
  - people from a culturally and linguistically diverse background. There are two sub-groups in this category:
    - those who have acquired the disease in their country of origin predominantly as a result of unsterile medical procedures or contaminated blood or blood products; and
    - those who have acquired the disease because they are current or past people who inject drugs who re-used or shared needles and syringes
- Clients have reported experiences of discrimination and misinformation/ inconsistency of information about anti-viral therapy; antenatal screening for HCV appears to be more widespread than recommended in the National Hepatitis C Testing Policy
- There are no identified hepatitis clinics or specific services for children infected with hepatitis C.
- The need to increase the number of people with HCV on anti-viral therapy as a means of reducing the number of people who go on to have chronic liver disease suggests that the HCV workforce will need to expand. However there are a number of factors that inhibit an easy expansion.
- There is no standardised reporting of the number of patients receiving anti-viral treatment for HCV. In addition, there is no systematic monitoring of the impact of HCV-related liver disease on inpatient services.

## 1.3 Recommendations

### Adopt the anti-viral treatment goals of the HCV Projections Working Group (see section 7.1)

The HCV Projections Working Group has estimated that the number of people on HCV anti-viral treatment will need to double if the number of people living with chronic HCV and more advanced stage F2/3 liver disease or cirrhosis is to be reduced.<sup>1</sup> Increasing the number of people treated will lead to better health outcomes for people with hepatitis C as well as a reduction in the long term burden on health services. To measure the success of this goal, careful monitoring of treatment numbers is required.

### Enhance current HCV treatment and care services as a matter of urgency (see sections

## 7.2, 7.3, 7.9)

If NSW is to double the number of people on anti-viral treatment, services in AHSs (including Justice Health) and in ACCHS will need to be enhanced. There is an urgency about achieving this recommendation as it is based on 2005 data. Currently there is no spare capacity in most of NSW's anti-viral treatment services and waiting lists are growing, so options to increase the capacity of services needs to be explored. Rural AHSs should not be seen as less of a priority in any enhancement program. Even though the number of notifications is less than metropolitan AHSs, their rates per 100,000 population are higher (see section 4.1.3). Enhanced HCV services should also emphasise the needs of priority populations — people who inject drugs, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, people in custody.

The approach in Queensland to enhance anti-viral treatment services was to increase the number of nurses and counsellors. Among many of the people consulted as part of this review, there was a consensus that the most effective way of increasing the number of people on anti-viral treatment is to increase the number of nurses in anti-viral treatment services.<sup>2</sup> Queensland's investment of \$1.46m. per year is mainly on 10 nurses and has resulted in the doubling of cases treated in less than a year. This cost is very modest when considered as a proportion of the cost of treating HCV related liver disease, which is estimated to be around \$28m in NSW.

The message that HCV is a very significant disease in terms of its potential impact on the utilisation of inpatient services unless numbers receiving anti-viral treatment are increased, needs to be widely promoted among politicians and Area Health Services executives. A mechanism is needed for re-allocation of resources from inpatient care to ambulatory care.

## Clarify levels of funding for HCV services and reduce dependence on non-recurrent funding (see section 7.4)

Funding available for HCV services needs to be clarified in terms of its type (general funds, HIV Program etc.) source, duration and specific purpose; consolidated as the total budget for HCV services; and identified as recurrent or non-recurrent. Steps should be taken to move towards recurrent funding from all sources and to reduce dependence on funding from pharmaceutical companies.

## Define an optimal service delivery framework for HCV treatment and care (see section 7.5, 7.9)

Some issues that need to be considered include:

- defining HCV as a chronic disease and having it recognised in the Chronic Disease Program (see detail of this program in section 7.5)
- describing the spectrum of care — prevention, early intervention, treatment, continuing care (including recognition of support and care from community based organisations)
- recognising that HCV services include inpatient and ambulatory services
- making the distinction between viral hepatitis (including HBV) service and HCV anti-viral treatment service
- assessing how metropolitan services can best support rural services
- determining how ACCHSs can be integrated into the treatment framework to improve access to services for Aboriginal and Torres Strait Islander people
- involving the Clinical Services Redesign Program<sup>3</sup> and the Greater Metropolitan Clinical Taskforce in developing a statewide approach.<sup>4</sup>

1 The Working Group actually estimated that there was a need to triple the number of people on anti-viral treatment if there is to be a reduction of people with advanced liver disease. This estimate was based on 2005 figures when around 2000 people received anti-viral treatment. In 2006 it is estimated that 3000 people received anti-viral treatment. So as the number needed to be treated to reduce the increase in people with advanced liver disease is around 6000 a year, the current number on treatment needs to double.

2 This could include the upskilling of practice nurses in GP surgeries.

3 The Clinical Services Redesign Program (CSRP) is an ambitious and important reform program established by NSW Health. Clinical service systems are being redesigned to improve patient journeys across multiple care centres in local health services. Each Area Health Service has been given funding and support to help redesign clinical services. A program office has been established within the NSW Department of Health to provide support and to lead the program at a statewide level. <http://www.health.nsw.gov.au/csrp/about.html>

4 The Greater Metropolitan Clinical Taskforce (GMCT) was established in 2004 to continue the work (which was begun by the Greater Metropolitan Transition Taskforce (GMITT) in implementing the recommendations of the Greater Metropolitan Services Implementation Group (GMSIG)) of engaging clinicians and consumers in planning and implementing improved health services. Some 24 Specialty Service Networks were developed during 2002–2007 with ongoing support from the GMCT Executive. These groups became cohesive multi-disciplinary teams from multiple facilities, with Chairs and Co-chairs elected to guide their work. Networks gather information, develop consensus documents to standardise and guide clinical practice —referral protocols, clinical practice guidelines, resources for patients, educational resources for staff, undertake research and coordinate clinical services and provide advice to the Department of Health. Most Networks devote resources to ensuring better access to pertinent clinical data. Minimum data sets and standardised data collection systems are being implemented. The collated clinical data from across the networks helps to identify trends and provide a more accurate picture of patient disease patterns and demand, which in turn drive improvements in clinical practice and the provision of services. Source: [http://www.health.nsw.gov.au/gmct/background/history\\_gmsig.html](http://www.health.nsw.gov.au/gmct/background/history_gmsig.html)

## Resolve issues around shared care by GPs and hospital based specialists in the provision of anti-viral treatment of people with HCV (see sections 7.6, 7.9)

Shared care of HCV anti-viral treatment by GPs and hospital based specialist services should be formally adopted as part of the service delivery framework because of its advantages including the fact that:

- it takes some of the anti-viral treatment load off the specialist services
- it facilitates access to services, especially in rural areas

The evaluation of the GP prescriber pilot in NSW and the ACT identified some issues that could enhance the effectiveness of shared care (see section 7.6). These include:

- provision for GPs to initiate treatment
- recognition of the pivotal role of nurses in the treatment process in terms of case management, facilitating communication between the specialist and the GP, maintaining the necessary paperwork and exploiting opportunities available through Medicare such as Enhanced Primary Care (EPC) and access to counselling (the nurse involved does not need to be from the specialist HCV service, he/she could be the GP practice nurse if given the appropriate training)
- the importance of psycho-social support
- the need for better access to hepatitis C treatment drugs (i.e. option to dispense via community pharmacy as well as the hospital pharmacy)

These issues should all be addressed in the proposed pilot of community prescriber initiation of hepatitis C anti-viral therapy (section 7.6).

In addition there should be:

- flexibility of the model so that it accommodates GPs working in ACCHSs
- active encouragement of s100 prescribers in ACCHSs to facilitate an increase in number

## Develop strategies to involve AOD services in HCV anti-viral treatment (see section 7.7)

There is much potential and goodwill around the involvement of AOD services in provision of HCV anti-viral treatment. Priority areas for action include:

- discussions with the Mental Health and Drug and Alcohol Office of NSW Health
- assessment of the feasibility of public and private methadone prescribers providing HCV anti-viral treatment
- development of a detailed plan including resource, training and education requirements (of both staff and clients) to enable greater AOD involvement in HCV treatment and care

- close monitoring of the project being undertaken by NCHECR to pilot and evaluate the uptake of hepatitis C testing and treatment in drug dependency settings
- obtaining client perspectives including people from an Aboriginal and Torres Strait Islander and people with a culturally and linguistically diverse background in understanding how best to work with people with HCV in AOD settings

## Articulate optimal model of care for HCV anti-viral treatment (see sections 7.5, 7.6, 7.7, 7.8, 7.9, 7.10)

A key element of the HCV services is the provision of anti-viral treatment. An increase in numbers receiving anti-viral treatment is fundamental to reducing HCV related liver disease. The optimal model of treatment needs to:

- define the role of each of the providers — hospital specialists, private specialists, GPs, nurses, counsellors, SHSs, ACCHS, AOD services, support services (HCCNSW, NUAA) in metropolitan and rural AHSs
- define the key elements of the model — shared care with GPs, case management by nurses, importance of peer support groups, networks of metropolitan and rural services, referrals to community based organisations for support and information
- define the resource modules needed to treat a specific number of cases taking into account patient complexity (current research by Digiusto et al.<sup>5</sup> could assist in this process)
- confirm treatment protocols
- define patient complexity to facilitate definition of the relative roles of GPs and specialists
- explore opportunities that exist in Medicare to enhance the model — EPC, access to counselling
- review other opportunities that are currently in place for other chronic diseases e.g. diabetes education
- assess the potential role of the nurse practitioner in the provision of HCV anti-viral treatment

In defining this model of HCV anti-viral treatment services, the AIDB should seek the involvement of, and possible funding from, the Clinical Services Redesign Program.

## Create awareness of the impact of HCV on AHSs (section 7.4) and tighten organisational structures (section 7.3)

Area Chief Executives need to be made aware of the potential impact of people with chronic hepatitis C on their health services (see section 7.4 Comment). One way of achieving this may be to include HCV service performance measures in Chief Executives' performance contracts e.g. number of people who received anti-viral treatment, inpatient costs of treating HCV related illness etc.

5 Digiusto E, McPherson M, Ang, J (2007) 'The nature of services available to patients undertaking hepatitis C antiviral therapy in NSW' paper presented at the National Hepatitis C Health Promotion Conference, Melbourne, June.

The variation between AHSs of the organisational position of HCV services within AHS structures and the ambiguous role of HARP managers in the management and planning of services needs to be addressed. The pros and cons of coordinating HCV services at an AHS level — e.g. joint planning, monitoring and budgeting, shared protocols for treatment and patient management, education program for GPs — needs to be explored (see section 7.3).

### **Acknowledge and equitably address specific requirements of populations at risk**

Services need to be designed so that they are accessible for at risk populations. Specific needs of these groups are:

#### **People who inject drugs (see section 7.9)**

- non-discriminatory and empathetic staff in services
- good support services including social, peer, psychological and physical
- low threshold access (not too many eligibility criteria) to anti-viral treatment
- detailed information
- knowledgeable, supportive and caring GPs

#### **People in custody (see section 7.9)**

The high prevalence of HCV among the prison population and the potential for it to increase because of the high rates of injecting drug use and the non-availability of sterile injecting equipment, make accessible to treatment services very important. In their submission to this review, Justice Health lists and costs their priorities for enhancement. Justice Health needs to be included in the service enhancement proposed in section 8.1. Discussions also need to occur with the Department of Juvenile Justice to determine how best to ensure that young people in custody know about the signs and symptoms of HCV, future treatment options and liver care.

#### **Aboriginal and Torres Strait Islander people (see section 7.9)**

Hepatitis C treatment and care services for Aboriginal populations need to be flexible, locationally specific and include Aboriginal health workers. Specific needs include:

- increased availability of HCV treatment from ACCHSs, by increasing number of s100 trained GPs
- further involvement of ACCHS and other Aboriginal services in hepatitis C care and treatment service delivery planning and implementation
- partnerships between liver clinic specialists and ACCHSs so that treating staff in ACCHSs are supported
- better access to mainstream services by developing good partnerships with the local ACCHS and ensuring all staff undertake cultural awareness training, to create a number of options for obtaining treatment

- more outreach services, especially in rural areas
- local access to anti-viral drugs
- case management for Aboriginal people during treatment
- involvement of peers assisting in raising awareness of treatment, explaining the issues around treatment (side effects, cure rates, support available)
- counselling and support for Aboriginal people during treatment
- consideration of transport issues when planning treatment for Aboriginal people
- culturally appropriate information about HCV for the wider Aboriginal community

#### **People from a culturally and linguistically diverse background (see section 7.9)**

- culturally and linguistically appropriate information about treatment services
- greater use of bi-lingual/bi-cultural co-workers in liver clinics
- better informed GPs from culturally and linguistically diverse backgrounds
- peer support and targeted outreach clinics within the geographic areas in which specific culturally and linguistically diverse communities reside

#### **Children (see section 7.11)**

Currently there are no identified HCV services for children. However there are a substantial number of notifications each year with over 500 notifications in the last five years — most of these in the 15–17 age group. The international literature suggests a similar response rate to anti-viral therapy as seen in adults. A statewide children's service along the lines proposed by the submission from the three children's hospitals seems to be the most cost effective and efficient approach to service provision. Funding for such a service appears warranted and is recommended to avoid the development of advanced liver disease in an estimated 2–4% of children who acquire the disease.<sup>6</sup> To enable this recommendation to be implemented the HSDP of the Australian Government will need to be convinced that s100 drugs should be made available to children less than 18 years of age.

#### **Pregnant women (see section 7.10)**

The extent of antenatal screening for HCV varies throughout Australia and there appears to be much more testing than would be expected if the National Testing Policy recommendations were being adhered to. The extent of antenatal screening should be monitored to ensure adherence to National Testing Policy guidelines.

6 Joint submission from the three NSW children's hospitals

## Develop workforce strategies (see sections 7.12, 7.10, 7.9, 7.6)

Priority areas of action include:

- supporting the work of the Australasian Hepatology Association in developing national standards in hepatology nursing
- facilitating negotiations with the relevant medical College about increasing hepatology component in advanced gastroenterology training
- working with universities and colleges to enhance medical, nursing and allied health undergraduate programs so that they include relevant issues in relation to HCV (access and equity, stigma and discrimination)
- reviewing all aspects of HCV in GP education in conjunction with relevant education organisations and develop a comprehensive education plan that covers all aspects of GP treatment and care (not just prescribing). GP education strategies should include a focus on changing health professionals' attitudes towards people with hepatitis C and people who inject drugs (see section 7.10) and on the advantages of referring to community based organisations for information and support
- working with AHSs to integrate HCV treatment and care issues into relevant health worker training programs
- working with AH&MRC to improve the knowledge of Aboriginal sexual health workers, ACCHS GPs and RNs about HCV treatment and care
- developing resource and training requirements to facilitate greater AOD involvement in HCV treatment and care
- supporting specific hepatitis C workforce development for the Aboriginal health workforce

## Develop a system for monitoring the use of HCV inpatient and ambulatory services (see section 7.13)

This review has demonstrated that there is no standardised data on the utilisation of HCV inpatient and ambulatory services. This information is essential to monitor the number of patients on anti-viral treatment and the impact of HCV related liver disease on the use of inpatient services.

Priority areas of action include:

- close scrutiny by clinicians of the method used in section 6.2 to describe and cost the use of inpatient services by people with HCV related illness, to determine its adequacy.
- development of a standardised reporting system with standard data definitions, especially the term 'Aboriginality', and data collection methods.
- assessment of the feasibility of developing an HCV ambulatory data system as part of the HIV/AIDS Minimum Data Set.
- investigation of the possibility of creating HCV DRGs, similar to the HIV DRGs.