



5.1 Roles and Responsibilities

The NSW Department of Health through the AIDS/Infectious Diseases Branch (AIDB) is responsible for providing the overall strategic direction for the public health response to hepatitis C. Area Health Services (AHSs) are responsible for the planning, coordination and provision of local HCV health promotion, treatment, care and support services. Several non-government organisations (including the Hepatitis C Council of NSW, NUAA, AH&MRC and ASHM) are funded to provide various hepatitis C services.

education and control. The Hepatitis C Education and Prevention Initiative (HCEP) is funded by the Australian Government and was launched in 1999/2000. Some 58% of the funding goes to States and Territories for hepatitis C education and prevention programs. The balance of the funding is applied to Australian Government own purpose projects, national non-government organisation funding and overheads.

5.2 Funding

The Australian Government does not provide specific funding to the States and Territories for hepatitis C treatment and care services. In NSW the bulk of the investment in hepatitis C treatment, care and support is from the AHSs' general Resource Distribution Formula (RDF) allocation. The NSW Department of Health provide additional funding to support that investment.

The NSW Department of Health provides a contribution to support access to hepatitis C treatment and care services through the hepatitis C component in the AIDS Program funding to AHSs as well as the AHSs' HCEP allocation. Further the NSW NSP is allocated about \$12 million annually for hepatitis C and other BBV prevention activities specifically for the population of people who inject drugs. In addition, about \$2.8 million from the Australian Government's COAG²⁶ funding is allocated annually to AHSs and several statewide services to support and improve the NSP. The amount of HCV funding from the AIDB to AHSs and to statewide services in 2006/07 as well as the HCEP funding is given in Table 2.

The main contribution from the Australian Government is for programs associated with hepatitis C prevention,

Table 2 HCV funding to AHSs and to statewide services from the AIDB, 2006/07

Agency	AIDS Program	Enhancement	HCEP	Total
NSCCAHS	\$142,122	\$85,462	\$43,084	\$270,668
SSWAHS	\$320,962	\$112,468	*\$180,527	\$613,957
GWAHS	\$74,269	\$104,502	\$49,684	\$228,455
HNEAHS	\$110,494	\$92,522	\$44,857	\$247,873
SESIAHS	\$280,186	\$106,311	\$50,991	\$437,488
NCAHS	\$144,862	\$74,041	\$43,384	\$262,287
GSAHS	\$68,088	\$74,280	\$37,500	\$179,868
SWAHS	\$219,056	\$97,081	\$47,067	\$363,204
Justice Health		\$53,333	\$25,857	\$79,190
Total	\$1,360,039	\$800,000	\$522,951	\$2,683,020
Statewide services				
HCCNSW	\$837,800	\$250,000	\$145,000	\$1,232,800
AH&MRC	23,850	29,000	\$29,000	\$29,000
ASHM	\$180,700			\$180,700
Total	\$1,018,500	\$250,000	\$203,000	\$1,471,500

Source: AIDB NSW Health

* HCEP allocation to SSW includes \$29,000 for MHAHS and \$97,000 for a Statewide Hepatitis C Project Officer with the AIDB.

26 Funding for supporting measures relating to Needle and Syringe Programs from the Council of Australian Governments Illicit Drugs Diversion Initiative.

Other organisations, such as Multicultural HIV/AIDS and Hepatitis C Service (MHAHS), NSW Users and AIDS Association (NUAA), Haemophilia Foundation, TRAIDS, provide services for people with HIV as well as HCV and their funding is from the AIDS Program budget and is not identified as specifically HCV funding. Organisations such as Australasian Society for HIV Medicine (ASHM) receive most of their NSW Health funding from the AIDS Program budget.

NSW Health has also funded Aboriginal sexual health projects since 1989/90. The Australian Government Office for Aboriginal and Torres Strait Islander Health (OATSIH) began contributing Special Funding for this purpose at the start of the National AIDS Strategy 1993/94 to 1995/96.

The key objectives of the Aboriginal sexual health projects are to work with sexual health services and Aboriginal Community Controlled Community Health Service (ACCCHS) to:

- assist in reducing the incidence of sexually transmitted infections (STI), HIV and HCV within local Aboriginal communities;
- minimise adverse impacts of HIV, HCV and STIs by providing culturally appropriate services, support and education to the different target groups within the local Aboriginal communities;
- improve the quality of life, life expectancy and reduce geographical isolation of HIV positive Aboriginal people through adequate treatment, care and support.

5.3 Current HCV Services in Area Health Services

A detailed description of the HCV services in AHSs is provided in Appendix C. HCV services are based on individual hospitals/health services in AHSs. There is no standard model of service delivery. Some services are primarily anti-viral therapy services for people with hepatitis C; others provide the range of inpatient and outpatient services for people with chronic liver disease as well as providing anti-viral therapy for people with both hepatitis B and hepatitis C.

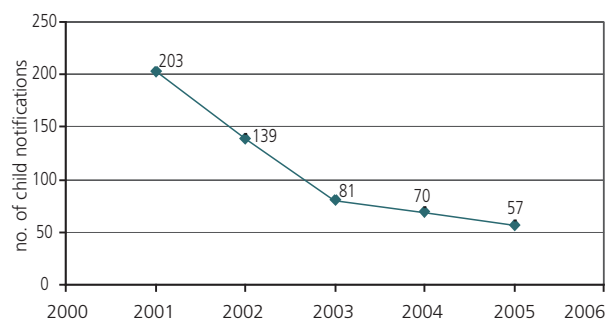
Table 3 (overleaf) shows the hospitals/health services where anti-viral therapy services for HCV are provided by AHS and gives some indication of the numbers of patients receiving anti-viral therapy.

5.4 Services for Children

Although only a small proportion (less than 3%) of the total number of HCV notifications, there is still a substantial number of children under the age of 18 notified each year with HCV. Figure 8 shows the number has dropped each year over the last five years from 203 in 2001 to 57 in 2005. Table 4 shows that the majority of cases each year are in the 15–17 year age group.

It is assumed that the majority of children acquire the HCV infection from mothers who are past or current people who inject drugs. The epidemiology and natural history of hepatitis C in Australian children are virtually unknown. There is currently no available data in NSW and the types of investigations which inform natural history such as liver biopsy have not been undertaken in any clinic to date. The international literature suggests that acquisition of HCV in childhood, conveys a better prognosis with 50% of patients approximately having spontaneous clearance of infection and cirrhosis developing in 2–4% after 20 years of infection.

Figure 8 Number of children under 18 years with HCV by year of notification



Source: NSW Health Notifiable Diseases Database

Table 4 Number of HCV notifications for children by age group as a proportion of total cases

Age	Year of notification									
	2001		2002		2003		2004		2005	
	N	%	N	%	N	%	N	%	N	%
0–4 yrs	32	0.4	29	0.4	17	0.3	18	0.4	6	0.1
5–9 yrs	1	0	2	0	4	0.1	5	0.1	4	0.1
10–14 yrs	13	0.2	6	0.1	4	0.1	4	0.1	3	0.1
15–17 yrs	157	1.8	102	1.5	56	1.1	43	0.9	44	1
18+ yrs	8447	97.7	6552	97.9	5167	98.5	4844	98.6	4301	98.7
Total	8650	100	6691	100	5248	100	4914	100	4358	100

Source: NSW Health Notifiable Diseases Database

Table 3 HCV anti-viral therapy services by AHS

Area Health Service/Hospital	No. of people receiving anti-viral treatment for HCV
South Eastern Sydney/Illawarra	
St Vincent's	60 patients receive treatment at any time; between 80 and 90 patients commence treatment each year
St George	Currently there are 96 patients on treatment
Prince of Wales	40-50 patients are on treatment at any one time
Illawarra	43 patients are currently on treatment in Wollongong; 8 in the Shoalhaven
Sydney South West	
Royal Prince Alfred	80-90 patients are treated each year and 120-130 are assessed. 10-20 patients are also treated through methadone outreach.
Concord/Canterbury	70-100 patients are treated each year at Concord Hospital, with Clinics at Canterbury offering anti-viral therapy in September 2007.
Liverpool/Bankstown	About 100 patients are treated per year and another 30 are treated at Bigge Park Centre (Sexual Health Service).
Sydney West	
Westmead	Between 150 and 200 people are treated each year.
Nepean/Blue Mountains	Between 70 and 80 people are treated each year
Northern Sydney/Central Coast	
Royal North Shore	25-30 patients receive treatment at any one time; last year 66 patients were treated.
Gosford/Wyong	Currently there are 30-40 patients on treatment; numbers have been as high as 50 at any one time
Hunter/New England	
John Hunter and Taree/Forster	Currently 120 patients are on treatment at John Hunter; at Taree and Forster 20 patients are on treatment or in the follow-up period
Tamworth	Currently there are 15 patients on treatment
North Coast	
Lismore	Currently over 100 patients are on treatment.
Coffs Harbour	There is a limit of 20 patients on treatment at any one time due to lack of resources
Greater Southern	
Canberra Hospital	Currently 30-40 people are on treatment; about one third of these patients are from NSW
Greater Western	
Dubbo	Currently 4 people are on treatment.
Orange	Currently 10 people are on treatment.
Broken Hill	Currently 2-3 people are receiving treatment.
Justice Health	In March 2007 80 people in custody were receiving treatment.

Services

Children with HCV are referred to gastroenterologists at the Children Hospital at Westmead (CHW), Sydney Children's Hospital (SCH) and John Hunter Children's Hospital (JHCH). Assessment includes serological testing, genotyping, viral load measurement and liver function testing. The PBS does not approve anti-viral therapy for patients less than 18 years of age so, to date, no child has received treatment despite randomised controlled

trials²⁷ that have demonstrated similar efficacy as that reported in the adult trials across all genotypes.

Number of patients

Currently CHW is following over 50 children, SCH is following 25 and less than 10 are being followed at JHCH.

27 Wirth S et al (2005) 'Peginterferon Alfa-2b plus Ribavirin Treatment in Children and Adolescents with Chronic Hepatitis C', *Hepatology* 41: 1013-1018.
Gonzalez-Peralta et al (2005) 'Interferon alfa-2b in Combination with Ribavirin for the Treatment of Chronic Hepatitis C in Children: Efficacy, Safety and Pharmacokinetics' *Hepatology* 42: 1010-1018.

5.5 General Practitioners

The review of HCV treatment and care services by NSW Health in 1999²⁸ revealed that many GPs only have a small caseload of patients which results in a lack of knowledge and skills about HCV and current anecdotal evidence suggests this situation has not changed. *C-Change*,²⁹ the report of the inquiry of the Anti-Discrimination Board of NSW found extensive discrimination against people with HCV especially from staff in health care settings including doctors, nurses and ancillary staff. This discrimination is often the result of stereotyped responses towards people on the basis of past, current or assumed injecting drug use and/or irrational fears about HCV infection.

However, improvements in the efficacy of combination therapy in the last five years and the widespread prevalence of HCV in the community means that it is becoming increasingly important for GPs to be more active in the treatment and care of people with HCV.

In September 2001, the NSW Ministerial Advisory Committee on Hepatitis (MACH) supported the development of a training and accreditation program to allow accredited GPs to prescribe s100 drugs for the treatment of hepatitis C. The *NSW Hepatitis C Strategy* also supports GP involvement in testing, assessment, treatment and support of people with hepatitis C.

ASHM worked with the NSW Department of Health to develop a proposal and model for a training and accreditation program. In 2002, NSW Health sought approval from the Highly Specialised Drugs Working Party³⁰ (HSDWP) to pilot a program of hepatitis C GP prescribing. The HSDWP and Australian Government Department of Health and Ageing agreed that the pilot may be beneficial in determining the advantages and disadvantages of community based medical practitioners prescribing highly specialised drugs for the treatment of people with chronic hepatitis. The Hepatitis C Community Prescribing Pilot was funded by the NSW Department of Health. GPs worked in a shared care arrangement with designated specialists in public hospitals. The GP would undertake the treatment workup, the specialist would initiate drug therapy and the GP would write the subsequent prescriptions and on-going patient management. The initial proposal was for an 18 month administrative pilot. The pilot was extended for a further 18 months till May 2007 and has again been extended (until the HSDWP has decided about a national shared care model).

The key goal of this pilot was to increase access to anti-viral treatment. The specific aims of the pilot were to determine:

1. Whether the mechanism in place for the training, accreditation and ongoing support of HIV s100 prescribers could be appropriately transferred to the HCV setting.
2. Whether arrangements could be established between public hospital based specialists and GPs to allow GPs to conduct the appropriate pre-tests necessary to precede biopsy.
3. In the case of patients going on to s100 therapy, provide the appropriate management to prescribe for, support and review them through their duration of therapy.

The evaluation of this pilot is discussed in section 7 of this report.

The NSW Department of Health is currently preparing a proposal for a pilot for trained and accredited general practitioners and other non-specialist medical practitioners to initiate treatment of chronic hepatitis C within the arrangements of the HSDP.

5.6 Statewide services

5.6.1 Hepatitis C Council of NSW

The Hepatitis C Council of NSW (HCCNSW) is the independent, community-based non-government organisation funded by the NSW Health Department to provide information, support, referral, education, prevention and advocacy services for all people in NSW affected by hepatitis C. It employs a team of twelve paid staff, ten casual workers and involves 45 volunteer workers to carry out its day-to-day operations. A voluntary board of governance, drawn from the membership and other members of the community, has responsibility for overall strategic direction and policy.

Services include:

- Provision of detailed HCV information booklets, brochures and factsheets including *The Hep C Review*, a quarterly magazine, a **website** www.hepatitisc.org.au and a **library loan service**
- The *Hep C Helpline* — a statewide free and confidential telephone information, support and referral service for people affected by hepatitis C, health workers and the general community. The *Prisons Hep C Helpline* is an extension of the service for NSW prisoners, their families and corrections staff. Staffed by full time workers and supported by administration volunteers, the Helpline takes over 4,000 calls each year.
- *Hep Connect* — a project which began in 2007 as a 12-month pilot to provide peer support for people with hepatitis C who wish to talk with somebody

28 NSW Health (2002) *Review of NSW Hepatitis C Care and Treatment Services*, Sydney.

29 Anti-Discrimination Board of NSW (2001) *C-change: Report of the enquiry into hepatitis C related discrimination*. Anti-Discrimination Board of NSW, Sydney.

30 A non-statutory body established by the Australian Health Ministers Advisory Council in 1991 to oversee the policy and administrative aspects of the Highly Specialised Drugs Program

else with hepatitis C to discuss how they approached particular issues in their hepatitis C-related lives. The service has a specific focus on supporting people with hepatitis C who are either considering or undergoing treatment. In particular, *Hep Connect* serves to link trained volunteers with hepatitis C with the people calling in to the *Hep C Helplines* where the caller's requests extend beyond information or support provision. *Hep Connect* is a statewide, telephone based service with volunteers working from their homes or from the Council's Sydney office.

- **Hep C Australasia** is an Australian and New Zealand focused worldwide online support forum for people with hepatitis C. Hosted by the Hepatitis C Council of NSW, the forum is a community owned and led discussion forum with approximately 270 participants, community developed guidelines and a community-led moderation facility. Much of the discussion centres on treatment, its side effects and the social and practical management of issues connected with living with hepatitis C.
- Free **educational and workforce development** services to health care, community and youth workers, and others who work with people affected by or at risk of hepatitis C.
- **C-een & Heard** speakers serve as casual staff and share their experiences of hepatitis C with audiences of health care or other workers.
- Community members who have hepatitis C have been trained in working with media, be it television, radio or print.
- Input and feedback on hepatitis C strategic plans, submissions, resource development, and educational planning.
- **HepLink** — a statewide network comprised of various health care workers and others who address issues relating to hepatitis C in their work. The aim of **HepLink** is to share information, resources and support.
- Advocacy — at both a client and a community level.
- Council staff represent the Council and affected communities on a range of local, area, state and national committees.

5.6.2 Aboriginal Health and Medical Research Council of NSW

The Aboriginal Health and Medical Research Council of New South Wales (AH&MRC) is the peak body for Aboriginal health in NSW. The AH&MRC provides vital health and health related services, including blood borne virus and sexual health services, in association with its member organisations. The AH&MRC is comprised of over 50 Aboriginal Community Controlled Health Services (ACCHSs) and Health Related Services throughout the state. The AH&MRC supports the 40 or so Aboriginal Sexual Health Workers who are based in ACCHSs and AHSs across the state as well as other people working

with Aboriginal communities to address hepatitis C, by providing education and training, developing statewide resources and conducting other capacity building activities.

The AH&MRC has considerable experience in program delivery, advocacy and workforce development in the area of hepatitis C. In 2004 the AH&MRC published a report called *Increasing Access to Service in NSW for Aboriginal People at Risk of Contracting or Who Have Blood Borne Infections (BBI Report)*. This report was the result of extensive consultations across NSW with ACCHSs, Aboriginal community members, government health care services including health services in corrections, and relevant non-government organizations. Two new positions at the AH&MRC (Hepatitis C Workforce Development Project Officer, and the Harm Minimisation Policy Officer), were created as a result of this report. In addition to the BBI report, the AH&MRC has also:

- provided education sessions for ACCHSs & AHSs on hepatitis C and harm minimization
- developed resources including the *STI & BBI Manual* and *Hep C & Us Mob*
- continued the MOU with the Hepatitis C Council of NSW
- developed *Dr BBV* — an interactive game for young Aboriginal people about blood borne viruses.

The AH&MRC is also represented on the NSW Ministerial Advisory Committee for Hepatitis, and the NSW Aboriginal Sexual Health Advisory Committee.

5.6.3 Australasian Society for HIV Medicine

The Australasian Society for HIV Medicine (ASHM) conducts a broad Education Program in HIV and viral hepatitis for medical practitioners, health care providers and allied health workers and manages a program of continuing medical education in HIV and viral hepatitis. The Society receives support from the Australian Government Department of Health and Ageing, State and Territory Departments of Health and the pharmaceutical industry. In 2005/06 its total revenue was \$3.7m. NSW Health provided about 15% of this funding from the AIDS Program budget — 10% was for HIV related activities and 5% for HCV related activities.³¹

ASHM does not provide direct clinical services to people with HCV. Patient fact sheets (translated into 8 community languages) and general information are available from its website which patients can access. Generally, however, the fact sheets are promoted as resources to the doctor or health care worker who, in turn, provide them to their patient/client. These resources are also provided to ASHM's collaborators, including consumer organisations that may distribute them to their clients.

Primary Care Liaison Staff (clinical including general practitioners and nurses) provide advice to medical practitioners and other health care workers. From time

31 ASHM Annual Report, 2005–06.

to time they receive calls from people living with HCV and these are generally referred to a clinical service, or in regard to information calls responded to accordingly.

ASHM has produced a number of monographs on HCV including:

- *HIV/Viral hepatitis: a guide for primary care*
- *Coinfection — HIV & Viral Hepatitis: a guide for clinical management*
- *HIV and hepatitis C: policy, discrimination, legal and ethical issues*

In both 2006 and 2007 ASHM held a HCV Think Tank which explored ways of expanding access to HCV management in the community. Participants included representatives of clinical, policy, education, government and non-government sectors.

AHSM managed the NSW/ACT Hepatitis C Community Prescribing Pilot which allowed trained and accredited general practitioners in NSW and ACT, to prescribe section 100 drugs for the treatment of people with chronic hepatitis C. It was funded by the NSW Department of Health and ACT Department of Health.

5.6.4 Multicultural HIV/AIDS and Hepatitis C Service

The Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) receives funding from NSW Health to empower people with HIV/AIDS and/or HCV from culturally and linguistically diverse backgrounds to access better health care, support and information.

Specific HCV initiatives that MHAHS has provided are listed below:

- MHAHS worked in partnership over the last year with ASHM to deliver one-off HCV updates for GPs who have a significant caseload of clients from particular CALD groups.
- MHAHS worked in partnership over the last year with the Hepatitis C Council of NSW to deliver one-off HCV updates to multicultural health staff across NSW.
- Two HCV community development projects are undertaken each year targeted at a specific community.
- Every year the MHAHS ethnic media officer runs 2 HCV publicity campaigns, one of which is linked with the Australian Hepatitis Council (now Hepatitis Australia) national treatment awareness campaign, which targets CALD communities.
- Clinic HCV liaison workers (Chinese and Vietnamese) work one session a week at Westmead and St George Hospitals to facilitate patient throughput at the clinic by enhancing communication.
- MHAHS maintains a website which has a number of HCV resources available for download in a range of community languages (www.multiculturalhivhepc.net.au). It includes information about testing, support and treatment for HCV. The website is intended for use by both individuals and health workers, including GPs.

- One project is operating with additional funds from the Commonwealth: to update the Everybody's Business HCV video resource, which is a key national resource for trainers and educators to carry out HCV community education with priority CALD communities.

5.6.5 NSW Users and AIDS Association (NUAA)

NSW Users and AIDS Association (NUAA) is an independent community-based organisation funded by NSW Health. It was established in 1989, initially to provide preventative education about HIV/AIDS to drug users. NUAA's focus in relation to HCV is prevention through the provision of clean injecting equipment and the provision of information. NUAA currently employs 14.6 FTE permanent employees and has a budget of \$1.1m. per annum in addition to some COAG funding. There are no specific HCV positions and no separation of HCV issues.

In relation to HCV, NUAA's aim is to increase health literacy and help clients navigate the system. NUAA has a free information and referral line. People who are recently diagnosed with HCV regularly access the helpline. Its role primarily is interpreting results, re-explaining the basic information and facts, discussing transmission issues, and making referrals to GPs. Most callers are referred on to the HCCNSW for further information and support. As part of its outreach work NUAA provides opportunistic education and information about HCV. NUAA produces the quarterly magazine, *Users News*, which includes significant hepatitis C content and health promotion material.

5.6.6 Haemophilia Foundation

Haemophilia Foundation Australia (HFA) represents people with haemophilia, von Willebrand disorder and other related bleeding disorders and their families. HFA is committed to improving treatment and care through representation and advocacy, education and the promotion of research. HFA supports a network of State and Territory Foundations in Australia.

A current priority for HFA is to understand the needs of the bleeding disorders community affected by HCV and to develop and carry out a strategy to address those needs. HFA is currently working on a national strategy to understand the needs of the bleeding disorders community affected by HCV, to develop a plan to meet these needs and put the plan into action.

5.6.7 Transfusion Related AIDS and Infectious Diseases Service (TRAIDS)

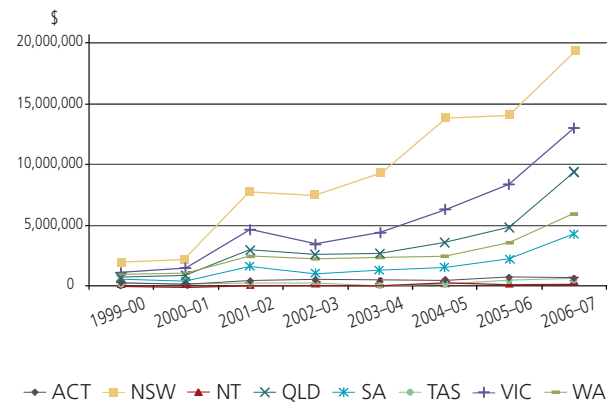
TRAIDS is a statewide service located within Western Sydney providing support, counselling and information to people with medically acquired HIV and hepatitis C and their families and friends. It was established in 1986 and extended its role to people who have medically acquired hepatitis C in 1994.

6.1 s100 Drug 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.

Table 5 and Figure 9 show the expenditure on s100 drugs for the treatment of HCV by State and Territory over the last 8 years from 1999/00 to 2006/07.³² The data for 2006/07 is only available for three consecutive quarters so an annual figure has been estimated on the basis of expenditure over the first three quarters.

Figure 9 Total expenditure by public and private hospitals on s100 drugs for the treatment of HCV by state and year



Source: Australian Government, Highly Specialised Drugs Program

Table 5 Total expenditure by public and private hospitals on s100 drugs for the treatment of HCV by state and financial year

	1999-00	2000-01	2001-02	2002-03	2003-04	2004-05	2005-06	2006-07*	% increase from 05/06 to 06/07
ACT	\$64,166	\$134,254	\$390,428	\$399,128	\$385,244	\$351,469	\$613,292	\$614,134	0.1%
NSW	\$1,710,085	\$2,053,233	\$8,084,718	\$7,411,916	\$9,371,231	\$13,844,252	\$14,161,573	\$19,416,141	37.1%
NT	\$13,544	\$36,064	\$87,300	\$15,538	\$215,519	\$269,497	\$162,107	\$312,289	92.6%
QLD	\$693,439	\$911,646	\$2,948,627	\$2,419,603	\$2,624,968	\$3,584,083	\$4,906,274	\$9,435,533	92.3%
SA	\$375,485	\$503,166	\$1,658,953	\$1,085,055	\$1,297,929	\$1,605,367	\$2,202,056	\$4,250,500	93.0%
TAS	\$80,245	\$85,649	\$154,344	\$132,838	\$255,690	\$250,064	\$368,896	\$582,828	58.0%
VIC	\$1,022,992	\$1,355,376	\$4,602,319	\$3,389,092	\$4,379,763	\$6,334,006	\$8,455,236	\$12,504,013	47.9%
WA	\$758,208	\$1,079,890	\$2,468,438	\$2,145,675	\$2,368,026	\$2,420,731	\$3,555,671	\$5,887,680	65.6%
Total	\$4,718,163	\$6,159,278	\$20,395,127	\$16,998,845	\$20,898,368	\$28,659,469	\$34,425,104	\$53,003,118	54.0%

* an annual estimate based on expenditure data for three quarters

Source: Australian Government, Highly Specialised Drugs Program

Expenditure increased dramatically between 2000/01 and 2001/02 from \$6.16m. to \$20.40m. It stabilised for a couple of years and took off again in 2004/05 from \$20.90m. in 2003/04 to \$28.66m. in 2004/05. There have been significant increases in the two years since 2004/05 to \$34.43m. in 2005/06 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 increase in expenditure on s100 drugs for HCV treatment in all States and Territories 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 and, in the case of Queensland, a significant injection of enhancement funds (in the order of \$1.46m. per year) into their HCV treatment services. The increased cost of drugs was responsible for the big expenditure increases in 2001/02 and 2004/05. However the big expenditure increase in 2006/07 was probably due to the removal of the requirement of people to have a liver biopsy before commencing therapy. Estimates from the NCHECR on the number of

³² The s100 drugs included in these expenditure data are: PEGINTERFERON ALFA-2a, PEGINTERFERON ALFA-2b, RIBAVIRIN & INTERFERON ALFA-2b, RIBAVIRIN & PEGINTERFERON ALFA-2a, RIBAVIRIN & PEGINTERFERON ALFA-2b.

people receiving treatment each year from 2002 to 2006 were 1458, 1142, 1847 and 2847 respectively.³³ The big increase in numbers in 2006 coincides with the relaxing of the liver biopsy requirement in April 2006.

The share of total expenditure on s100 drugs by State and Territory for 2005/06 and 2006/07 is shown in Figures 10 and 11. The share of total expenditure in Queensland increased from 14% in 2005/06 to 18% in 2006/07. NSW's share of total expenditure on s100 drugs fell from 42% to 36%. Share of total expenditure on s100 drugs needs to be viewed in the context of HCV prevalence by State and Territory. Table 6 shows that in 2005 it was estimated that NSW had 38% of HCV cases and Queensland had 15%.

Figure 10 Total s100 expenditure by State and Territory as a proportion of total expenditure, 2005/06

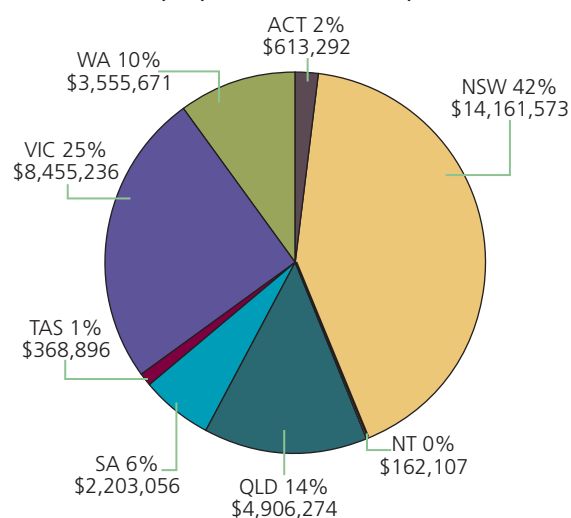


Figure 11 Total s100 expenditure by State and Territory as a proportion of total expenditure, 2006/07

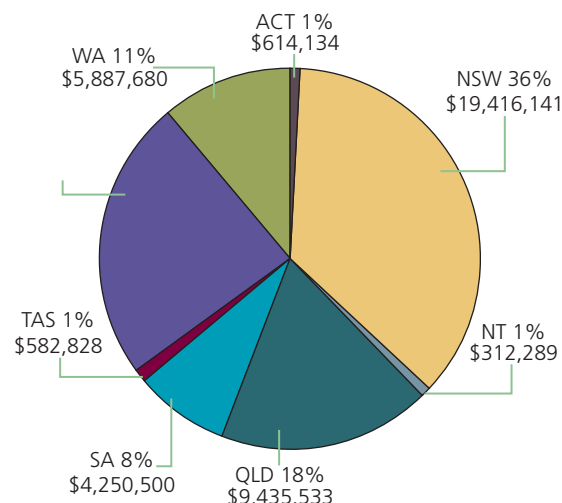


Table 6 HCV incidence and prevalence by State and Territory as a % of the total for Australia

State/Territory	%
ACT	1.3
NSW	38.0
NT	0.7
QLD	14.9
SA	6.5
TAS	1.3
VIC	28.1
WA	9.2
Total	100.0

Source: Hepatitis C Virus Projections Working Group

Tables 7 and 8 and Figures 12 and 13 show the breakdown of the s100 expenditure by public and private hospital. The bulk of expenditure on s100 drugs is through the public hospitals — \$45.81m. in 2006/07 compared to \$7.20m. In 2006/07 in the private system. The most significant increase in expenditure in the private system was in NSW where it increased by 94% from \$1.87m. in 2004/05 to \$3.64m. in 2006/07.³⁴

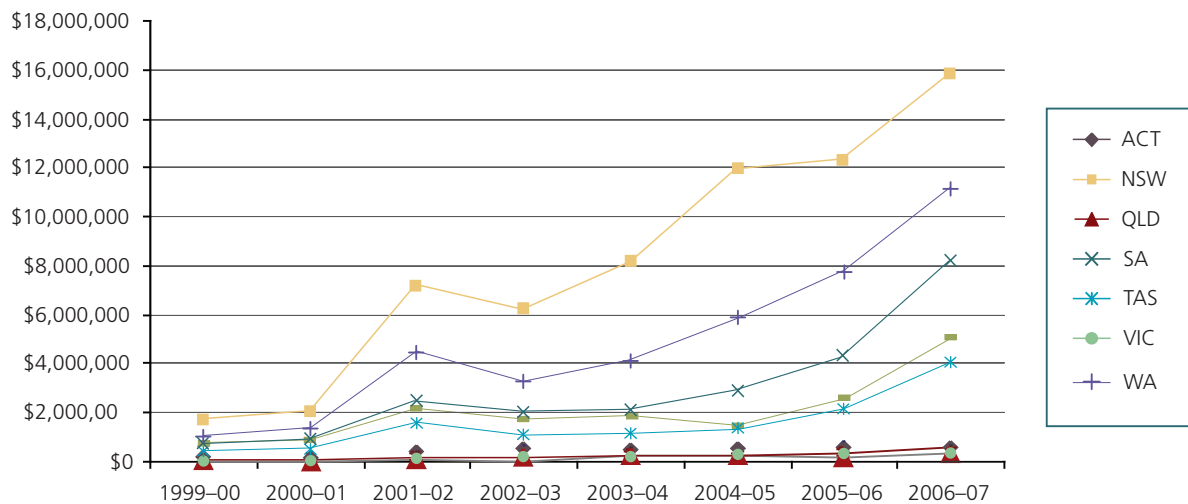
Table 7 Expenditure by public hospitals on s100 drugs for the treatment of HCV by state and year

	1999–00	2000–01	2001–02	2002–03	2003–04	2004–05	2005–06	2006–07*
ACT	\$64,166	\$134,254	\$390,428	\$399,128	\$385,244	\$351,469	\$602,459	\$611,363
NSW	\$1,710,085	\$2,051,485	\$7,109,229	\$6,219,208	\$8,194,095	\$11,907,656	\$12,288,333	\$15,779,654
NT	\$13,544	\$36,064	\$87,300	\$15,538	\$215,519	\$269,497	\$162,107	\$312,289
QLD	\$693,439	\$899,414	\$2,552,924	\$2,000,038	\$2,066,567	\$2,925,842	\$4,202,801	\$8,154,752
SA	\$375,485	\$495,148	\$1,576,335	\$1,053,577	\$1,209,234	\$1,492,611	\$2,186,908	\$4,122,700
TAS	\$80,245	\$85,649	\$154,344	\$132,838	\$255,690	\$250,064	\$368,896	\$574,928
VIC	\$1,022,992	\$1,341,299	\$4,441,995	\$3,238,702	\$4,122,279	\$5,876,695	\$7,764,854	\$11,205,497
WA	\$758,208	\$927,145	\$2,186,843	\$1,799,783	\$1,877,195	\$1,450,212	\$2,611,348	\$5,045,392
Total	\$4,718,163	\$5,970,458	\$18,499,399	\$14,858,812	\$18,325,823	\$24,524,046	\$30,187,705	\$45,806,575

* an annual estimate based on expenditure data for three quarters
Source: Australian Government, Highly Specialised Drugs Program

33 NCHECR (2007). *HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2007*. National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales, Sydney, NSW; Australian Institute of Health and Welfare, Canberra, ACT. p.134.

34 This probably relates to expenditure in Lismore where s100 drugs are obtained through the private system.

Figure 12 Expenditure by public hospitals on s100 drugs for the treatment of HCV by state and year

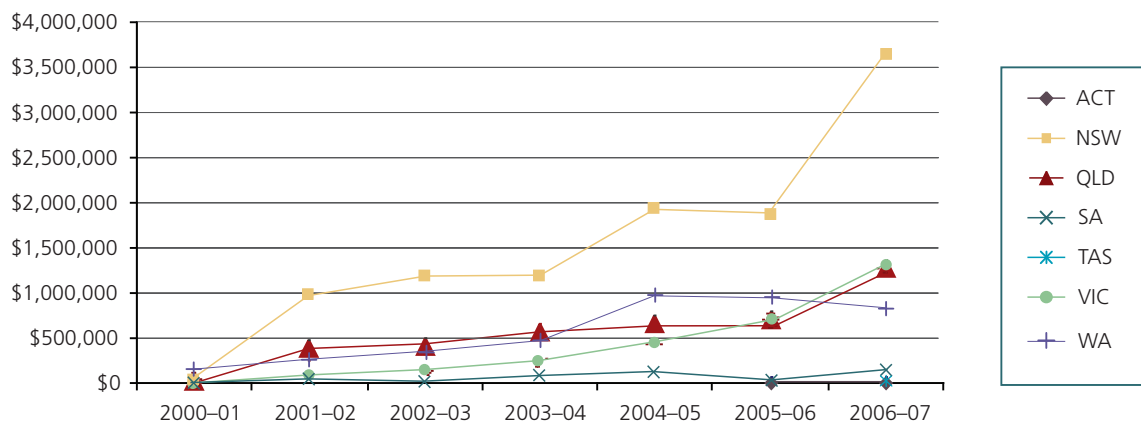
Source: Australian Government, Highly Specialised Drugs Program

Table 8 Expenditure in private system on s100 drugs for the treatment of HCV by state and year

	2000-01	2001-02	2002-03	2003-04	2004-05	2005-06	2006-07*
ACT						\$10,833	\$2,771
NSW	\$1,749	\$975,489	\$1,192,708	\$1,177,136	\$1,936,596	\$1,873,240	\$3,636,487
QLD	\$12,231	\$395,703	\$419,565	\$558,401	\$658,241	\$703,473	\$1,280,781
SA	\$8,018	\$82,618	\$31,478	\$88,695	\$112,756	\$15,148	\$127,800
TAS							\$7,900
VIC	\$14,077	\$160,323	\$150,390	\$257,483	\$457,311	\$690,382	\$1,298,516
WA	\$152,745	\$281,594	\$345,892	\$490,831	\$970,519	\$944,323	\$842,288
Total	\$188,820	\$1,895,728	\$2,140,033	\$2,572,545	\$4,135,423	\$4,237,399	\$7,196,543

* an annual estimate based on expenditure data for three quarters

Source: Australian Government, Highly Specialised Drugs Program

Figure 13 Expenditure by private hospitals on s100 drugs for the treatment of HCV by state and year

Source: Australian Government, Highly Specialised Drugs Program

Table 9 shows the expenditure by public hospitals on s100 drugs for HCV anti-viral treatment.³⁵ The total in Table 9 for NSW is \$14.791m, which is about one million dollars less than the figure estimated from the Commonwealth data for which only data for three quarters were available (Table 7). Also these data are the s100

expenditure data for public hospitals only and do not include the expenditure through the private system.

Figure 14 shows the proportion of this expenditure by AHS. Over half (52%) of this expenditure is by public hospitals in SSW (28%) and SESI (24%).

35 The s100 drugs included in these expenditure data are: PEGINTERFERON ALFA-2a, PEGINTERFERON ALFA-2b, RIBAVIRIN & PEGINTERFERON ALFA-2a, RIBAVIRIN & PEGINTERFERON ALFA-2b.

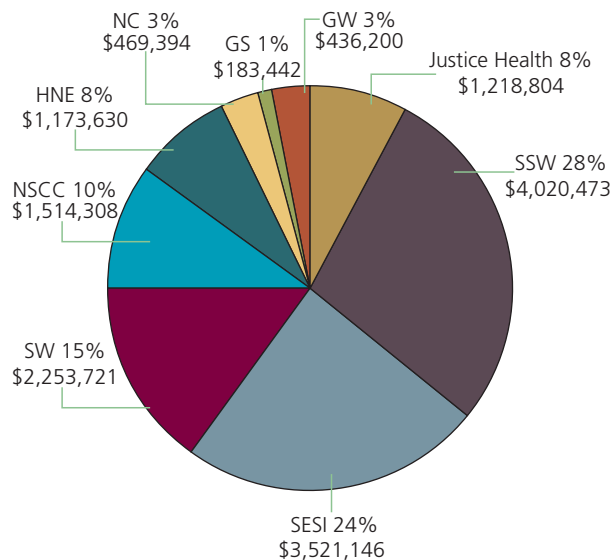
Table 9 shows expenditure on s100 anti-viral drugs for HCV by public hospital within each AHS. Data on expenditure for Lismore are not available as the anti-viral drugs prescribed at the Lismore clinic are through the private health system.

Table 9 Expenditure by public hospitals on s100 drugs for the treatment of HCV by AHS, 2006/07

AHS	\$
SSW	4,020,473
RPA	861,603
Concord	1,178,466
Canterbury	1,930
Liverpool	1,391,502
Bankstown	414,586
Campbelltown	137,064
Camden	35,322
SESI	3,521,146
STV	1,199,062
STG	750,139
POW	516,380
Illawarra	1,048,162
Sutherland	7,400
SW	2,253,721
Blacktown	132,324
Nepean	1,011,614
Westmead	1,083,959
Lithgow	25,824
NSCC	1,514,308
RNS	667,901
Gosford	772,165
Hornsby	74,242
HNE	1,173,630
JHH	866,666
Manning	176,128
Tamworth	130,836
NC	469,394
Coffs Harbour	343,912
Port Macquarie	96,855
Tweed	2,025
Kempsey	26,602
GS	183,442
Bega	63,570
Wagga	119,872
GW	436,200
Dubbo	79,557
Bathurst	119,957
Orange	220,542
Broken Hill	16,145
Justice Health	1,218,804
NSW	14,791,118

Source: NSW Health Finance Branch

Figure 14 Public hospital s100 expenditure by AHS as a proportion of total expenditure, 2006/07



6.2 Inpatient Utilisation

Data on the use of inpatient services is available from the database known as HOIST which records demographic and clinical details on all patients treated in NSW public and private hospitals.

In the previous HCV review undertaken in 1999,³⁶ an attempt was made to estimate the inpatient caseload with conditions related to HCV. Cases with a diagnosis of Hepatitis C and with either a diagnosis or procedure, which was identified as being related to the patient's HCV status, were selected from the statewide database of inpatient admissions. Staff at major specialist hepatology units who reviewed the data felt that it underestimated the true caseload of patients in hospital with disease related to their HCV. They suggested other diagnoses and procedures should have been included in the list to identify fully the HCV caseload. In other words, they felt that there were more conditions that people with HCV-related disease were admitted to hospital for. The analysis that follows is based on a revised, expanded list of diagnoses and procedures.

For this review, all cases with a diagnoses of Hepatitis C:

- B17.1 Acute Hepatitis C
- B18.2 Chronic Viral Hepatitis C
- O98.4 Viral Hepatitis complicating pregnancy, childbirth and the puerperium
- Z22.52 Carrier of viral hepatitis C

and with one or more of the diagnosis and procedures in the table below, were selected and their details analysed.

36 NSW Health (2002) *Review of NSW Hepatitis C Care and Treatment Services*, Sydney.

Table 10 Diagnoses and procedures identified as being a reason for being admitted to hospital as a consequence of being HCV positive

Procedure codes	CODES	BLOCK
Laparoscopy	30390-00	984
	30373-00	985
Insertion of Denver shunt	30408-00	983
Transjugular liver biopsy	90298-00	953
Insertion of transjugular intrahepatic portosystemic shunt (TIPPS)	9033400	1011
Biliary Interventions	See block range	957 – 973
ERCP	30484-00	957
Transplantation of liver	90317-00	954
Other repair of liver	90318-00	954
Percutaneous [closed] liver biopsy	30409-00	953
Intraoperative needle biopsy of liver (closed)	30412-00	953
Intraoperative biopsy of liver (wedge resection)(open)	30411-00	953
Abdominal paracentesis	30406-00	983
Diagnosis codes		
Spontaneous Bacterial Peritonitis	K65.0 – K65.9	
Septicaemia	A41.0 – A41.9	
Encephalopathy	G93.4	
Liver Failure	K72.0 – K72.9	
Renal Failure	N17.0 – N19	
Uncontrolled Blood Sugar	R73, E09.0 – E09.9, E10.65, E11.65, E12.65, E13.65, E14.65	
Cellulitis	L03.0 – L03.9	
CMV and other viral infections	B25.0 – B34.9	
Pleural effusions	J90 – J91	
Oesophageal varices with bleeding	I85.0	
Oesophageal varices without bleeding	I85.9	
Oesophageal varices in diseases classified elsewhere, without mention of bleeding	I98.20	
Oesophageal varices in diseases classified elsewhere, with bleeding	I98.21	
Liver cell carcinoma	C22.0	

A summary of the results of this analysis is provided in the tables below.

Table 11 shows that in each of the three financial years, 2003/04, 2004/05 and 2005/06 there were 2,443, 3,189 and 3,127 separations respectively from public and private hospitals in NSW whose reason for admission was related to their HCV positive status. These same separations represented 6,348, 7,660 and 7,548 cost weighted separations and 18,329, 23,483 and 24,304 beddays. The value of these separations in current dollar values are \$23.443m., \$28.288m. and \$27.875m. and they represent 59, 74 and 78 beds respectively. About 30% of these separations in each year were day only patients (Table 12). The average length of stay of patients (excluding day only) was 10.5 days, 10.2 days and 10.6 days respectively.

Table 11 HCV related separations, cost weighted separations and beddays in NSW public and private hospitals for three years, 2003/04 to 2005/06

	2003/04	2004/05	2005/06
separations	2443	3189	3127
cost weighted seps	6348	7660	7548
beddays	18329	23483	24304

Source: HOIST

Table 12 HCV related day only separations from NSW public and private hospitals for three years, 2003/04 to 2005/06

	2003/04	2004/05	2005/06
separations	762	982	929
cost weighted seps	629	781	768
beddays	762	982	929

Source: HOIST

In 2005/06 27% of all separations were from hospitals in SSWAHS; 20% were from hospitals in SESIAHS and 12% were from hospitals in SWAHS (Table 13). However the share of beddays was greater: in SSWAHS hospitals it was 35%, 23% in SESIAHS hospitals and 12% in SWAHS hospitals (Table 14).

Table 13 HCV related separations by AHS of treating hospitals

	2003/04		2004/05		2005/06	
	Number	Percentage	Number	Percentage	Number	Percentage
Greater Southern	74	3.0%	238	7.5%	224	7.2%
Greater Western	60	2.5%	62	1.9%	61	2.0%
Hunter / New England	234	9.6%	307	9.6%	357	11.4%
Justice Health	13	0.5%	3	0.1%	10	0.3%
North Coast	173	7.1%	306	9.6%	333	10.6%
Northern Sydney / Central Coast	222	9.1%	342	10.7%	314	10.0%
South Eastern Sydney / Illawarra	535	21.9%	623	19.5%	613	19.6%
Sydney South West	803	32.9%	877	27.5%	849	27.2%
Sydney West	329	13.5%	429	13.5%	365	11.7%
The Children's Hospital at Westmead	0	0.0%	2	0.1%	1	0.0%
Grand Total	2443	100.0%	3189	100.0%	3127	100.0%

Source: HOIST

Table 14 HCV related beddays by AHS of treating hospitals

	2003/04		2004/05		2005/06	
	Number	Percentage	Number	Percentage	Number	Percentage
Greater Southern	377	2.1%	733	3.1%	542	2.2%
Greater Western	338	1.8%	300	1.3%	208	0.9%
Hunter / New England	1427	7.8%	1815	7.7%	2281	9.4%
Justice Health	244	1.3%	86	0.4%	180	0.7%
North Coast	670	3.7%	1528	6.5%	1644	6.8%
Northern Sydney / Central Coast	1411	7.7%	3118	13.3%	2677	11.0%
South Eastern Sydney / Illawarra	4186	22.8%	6050	25.8%	5493	22.6%
Sydney South West	6416	35.0%	6905	29.4%	8485	34.9%
Sydney West	3260	17.8%	2945	12.5%	2793	11.5%
The Children's Hospital at Westmead	0	0.0%	3	0.0%	1	0.0%
Grand Total	18329	100.0%	23483	100.0%	24304	100.0%

Source: HOIST

The casemix of these HCV related separations identified through this analysis, defined as Australian Refined Diagnosis Related Groups (AR-DRGs) is shown in Appendix D. Most conditions are in the Major Diagnostic Category related to liver disease. However there are substantial numbers admitted for other conditions such as cellulitis and septicaemia.

Table 15 shows the separations and beddays of the treating hospitals with the largest caseloads. RPAH has the most cases, treating 466 patients with HCV related disease in 2005/06. These patients were in hospital for 4,437 days which is equivalent to 14.3 beds (assuming 85% occupancy rate). The longer length of stay relates to more complex cases at RPAH including liver transplantation. The hospital with the next highest caseload is JHH with 235 patients and 1,436 beddays in

2005/06 — the equivalent of 4.6 beds. In 2005/06 Wagga Wagga Hospital had the third highest caseload with 169 patients but only 267 beddays (0.86 beds) which suggests that there was possibly one patient admitted many times in that year for only a short period. The bed equivalents of other high caseloads hospitals are:

- Westmead Hospital — 4.4 beds
- St Vincent's Hospital — 3.7 beds
- Prince of Wales Hospital — 5.4 beds
- Liverpool Hospital — 4.9 beds
- St George Hospital — 3.0 beds

Table 15 HCV related separations and beddays by top 18 treating hospitals, 2005/06

Hospital	Separations	%	Beddays	%
Royal Prince Alfred Hospital	466	14.9%	4437	18.3%
John Hunter Hospital	235	7.5%	1436	5.9%
Wagga Wagga Base Hospital	169	5.4%	267	1.1%
Westmead Hospital (all units)	157	5.0%	1372	5.6%
St Vincent's Hospital, Darlinghurst	142	4.5%	1149	4.7%
Prince of Wales Hospital	127	4.1%	1694	7.0%
Liverpool Hospital	126	4.0%	1525	6.3%
St George Hospital	120	3.8%	924	3.8%
Lismore Base Hospital	110	3.5%	431	1.8%
Gosford Hospital	104	3.3%	867	3.6%
Concord Hospital	89	2.8%	763	3.1%
Blacktown Hospital	84	2.7%	597	2.5%
Royal North Shore Hospital	82	2.6%	793	3.3%
Bankstown / Lidcombe Hospital	71	2.3%	946	3.9%
The Tweed Hospital	66	2.1%	560	2.3%
Nepean Hospital	58	1.9%	477	2.0%
Wollongong Hospital	52	1.7%	595	2.4%
Coffs Harbour Base Hospital	50	1.6%	190	0.8%
All other hospitals	909	29.1%	5281	21.70%
Grand Total	3127	100.0%	24304	100.0%

Source: HOIST

Table 16 shows the hospitals with the highest number of day only cases — a similar but not identical list to the one in Table 15.

Table 16 HCV related day only separations from top 16 treating hospitals, 2005/06

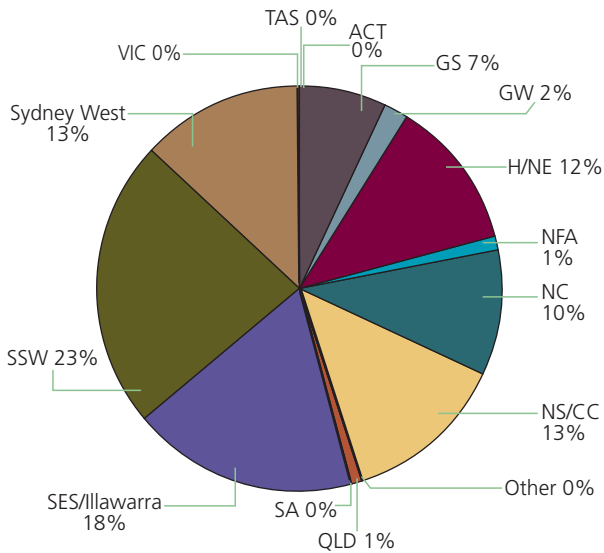
Hospital	Day only separations	D/o as a % of total separations
Royal Prince Alfred Hospital	163	34.9
Wagga Wagga Base Hospital	151	89.3
John Hunter Hospital	101	43.0
Lismore Base Hospital	67	60.9
Westmead Hospital (all units)	39	24.8
Kempsey Hospital	35	77.7
Royal North Shore Hospital	32	39.0
St George Hospital	32	26.7
De-identified private hospital South Eastern Sydney AHS	31	67.4
Concord Hospital	26	29.2
Coffs Harbour Base Hospital	21	42.0
Bankstown / Lidcombe Hospital	20	28.2
St Vincent's Hospital, Darlinghurst	18	12.7
Liverpool Hospital	13	10.3
Blacktown Hospital	12	14.3
Gosford Hospital	11	10.6
All other hosps	157	15.2
Grand Total	929	29.7

Source: HOIST



Figure 15 shows the AHS of residence of the people admitted to NSW public and private hospitals for HCV related disease in 2005/06. Residents of SSWAHS are the largest group (23%) followed by the residents of SESIAHS (18%), NSCCAHS (13%), SWAHS (13%), H/NEAHS (12%) and NCAHS (10%).

Figure 15 Area of residence of HCV related separations who are treated in NSW public and private hospitals, 2005/06



Source: HOIST



7.1 Prevalence of HCV and implications for long term treatment costs

In section 4 above, it was revealed that the Hepatitis C Virus Projections Working Group estimated that 58,500 people in NSW are living with chronic HCV and early (stage F0/1) liver disease. Another 14,500 are living with chronic HCV and moderate (stage F2/3) liver disease and 2,000 people are living with cirrhosis.

The HCV Projections Working Group also estimated that if 2000 people with chronic HCV infection continue to be treated each year (i.e. the number treated nationally in 2005), the number of people living with chronic HCV and more advanced stage F2/3 liver disease or cirrhosis is projected to increase by around 38% by 2015. The Working Group argued that to reduce the number of people living with chronic HCV and stage F2/3 liver disease or cirrhosis, the number of people receiving treatment each year needs to be tripled. This means that the total number treated nationally each year should be around 6000.

The increase in the expenditure on s100 drugs for the treatment of chronic hepatitis C by 54% nationally between 2005/06 and 2006/07 (see section 6.1) suggests that there has been an increase in the number of people treated in Australia from 2000 to 3000. However this number needs to be doubled again to reduce the projected number of people living with chronic HCV and stage F2/3 liver disease or cirrhosis. The cost of s100 drugs under this scenario would be double the current cost of \$53m. to \$106m.

The analysis in section 6.2 suggests that there is a substantial HCV related caseload in NSW hospitals that is costing around \$28m. annually to treat. The expectation is that this burden of disease will only increase unless there is a doubling of cases treated with anti-viral therapy. Assuming an increase of 38% by 2015, as the HCV Projections Working Group has estimated, the cost of treating these people in NSW hospitals will be in the order of \$39m. (in current dollars).

7.2 No spare capacity in current HCV services

Most HCV services in all AHSs said that they had no spare capacity to increase the number of people on anti-viral therapy. In most services there are anywhere between 5 and 50 people waiting for anti-viral treatment. Waiting time can vary from one month to between six and twelve months. Some services commented on an increase in the number of people

interested in receiving anti-viral treatment since the liver biopsy requirement was removed in April 2006. The s100 expenditure data suggests that there has been a substantial increase in the number receiving anti-viral treatment in the last year which explains why most services say that they are at their limit.

7.3 Disparity in HCV service provision between Areas

Section 5 of this report describes the HCV services and the personnel available in each AHS. In some locations (e.g. Coffs Harbour, Central Coast) the HCV service is primarily an anti-viral treatment service. In other locations (e.g. RPA, St George, RNS), the service provides a broad range of viral hepatitis services and is responsible for people on anti-viral treatment for both HCV and HBV, their on-going follow-up and, in the case of some patients, their progression to end stage liver disease as both outpatients and inpatients. In most rural and regional areas, there is no identifiable HCV service; staff of the Sexual Health Service or Infection Control Service provide a range of services from education and testing to counselling, monitoring, referral and treatment, depending on their other commitments and the resources available.

There is no Area-wide hepatitis service in any AHS with the exception of Justice Health where the HCV services are centrally coordinated and managed for the State. Not even under the previous Area structure was there a coordinated hepatitis service for any Area. Services are usually based on a specific hospital/health service. The service that develops depends more on the individuals involved and the resources available than from a defined model of care.

The position of the hepatitis service within the organisational structure of the hospital/health service also varies. The hepatitis service may be closely integrated with HIV services and may share resources (e.g. STV, RNS) or be quite separate from them (e.g. Wollongong). In most metropolitan hospitals, the hepatitis services are within the Gastroenterology Department. In rural Areas such as GWAHS and GSAHS, and in Coffs Harbour (Northern Rivers AHS), HCV and HBV treatment services are part of the sexual health services. However in Lismore (also Northern Rivers AHS), the HCV service stands alone and is separate from SHAIDS, the Sexual Health Service.

The role of the HARP manager in relation to the hepatitis services varies from Area to Area. The influence of the HARP manager depends largely on the amount of funding or resources that the hepatitis service receives from the AIDS Program. The HARP managers and the

hepatitis services have different reporting lines, which is not conducive to good communication or planning. In most metropolitan Areas the hepatitis services usually report through the hospital's Division of Medicine, to the Area Director of Acute Care and, in turn, to the Area Director of Clinical Operations. The HARP manager, on the other hand, reports either to the Area Director of Policy, Planning and Performance or to the Area Director of Primary and Community Care. The involvement of HARP managers in service planning and development varies.

7.4 Funding

Section 5 identifies the funding source for each hepatitis service. Most services receive their funding from a variety of sources:

- Hepatitis C allocation within the AIDS Program budget
- HCEP Initiative
- HIV funding within the AIDS Program budget
- general Area Health Service budget
- AOD budget
- Medicare — for the payment of outpatient medical consultations
- pharmaceutical companies — direct funding and clinical trial income
- Highly Specialised Drugs Program

A description of each of these sources is provided below.

Hepatitis C allocation

The Department of Health provides a contribution to Area Health Services for the provision of education and prevention services for HCV. The recurrent amount allocated to each AHS from the AIDS Program budget and a non-recurrent enhancement grant for 2006/07 can be seen in Table 2. The total recurrent amount to AHSs in 2006/07 was \$1.36m. and \$800,000 in one-off enhancement funds. Another \$1.018m. was given in 2006/07 to the HCCNSW (\$837,800) and ASHM (\$180,700). HCCNSW also received an enhancement grant of \$250,000 in 2006/07.

HCEP Initiative

In 2006-07, the Department distributed \$522,951 in funding from the Australian Government's HCEP allocation to NSW to AHSs and Justice Health (see Table 2 in Section 5). This funding is for programs associated with hepatitis C prevention, education and control. Most Areas receive between \$40,000 and \$50,000.

HIV funding within the AIDS Program budget

Some hepatitis services share resources with HIV/AIDS services. For example, at STV the hepatitis service shares the same physical space, Immunology B Ambulatory Care (IBAC), as the HIV/AIDS service for the provision of

ambulatory care. As a result the hepatitis service shares resources with the HIV/AIDS service and has access to a range of allied health staff — social workers, dietician, psychologist, physiotherapists, pharmacist — that are funded from the HIV budget. Clinic 16 at RNS has the same arrangement.

Sexual health services in all AHSs receive funding from the AIDS Program. Most sexual health services provide education, testing, monitoring and sometimes counselling for people with HCV. They also provide vaccinations for HBV.

General Area Health Service budget

Section 6.2 estimates the cost of treating inpatients with liver disease as a consequence of HCV. The cost of inpatient care for these people is largely provided in public hospitals and is paid for out of the Area's general funds. In a few locations such as the Central Coast and the Illawarra, the ambulatory HCV treatment service is also paid for from general funds.

AOD budget

Some HCV services have a close relationship with the local AOD services. In a few health services, there is a gastroenterologist working in the AOD service who has a joint appointment in the Gastroenterology Department. They provide the assessment for treatment of patients in the AOD setting and either commence anti-viral treatment there or refer patients to HCV service for treatment (e.g. RPA, Westmead, Nepean).

Medicare

In most ambulatory settings where patients are receiving anti-viral treatment (with the exception of sexual health services), medical consultations are billed through Medicare.

Pharmaceutical companies

Two pharmaceutical companies manufacture the anti-viral drugs used to treat people with HCV — Roche and Schering-Plough. Both companies make a significant contribution to HCV treatment services in NSW public hospitals. For the calendar year 2007, Roche funded a number of nursing positions in seven, mostly metropolitan, hospitals at a cost of around \$270,000.³⁷ In 2007, Schering-Plough supported 5.5 CNC positions in five hospitals.³⁸ Funding is negotiated between the hospital and the AHS on an annual basis. The estimated annual contribution by pharmaceutical companies is around \$600,000.

Highly Specialised Drugs Program

The cost of anti-viral treatment for patients with HCV is paid for by the Australian Government through the Highly Specialised Drugs Program. Most of these costs are reimbursed through the public hospital system but some are billed privately through Medicare (see details in Section 6.1 of this report).

37 Personal communication from a representative from Roche, May 2007.

38 Personal communication from a representative from Schering-Plough, July 2007.

Some patients are not eligible for s100 funding because they do not meet the criteria for access to these drugs. In some instances one of the two main drug companies will pay for a patient's drug treatment under their compassionate access program. One of the drug companies revealed that in 2007 they paid for 20 patients' treatment under this program.

Comment

Table 17 summarises the many sources of funding for HCV services. HCV services are developed on the basis of an amalgamation of allocations to AHSs from these various sources.

Table 17 Summary of funding for HCV services by source, 2006/07

Funding source			Non-inpatient \$	Inpatient \$	Statewide service \$
Australian Government	NSW Government	Other			
Hepatitis C allocation within AIDS Program			1,360,039		1,018,000
	Hepatitis C enhancement within AIDS Program		800,000		250,000
HCEP			522,951		
HIV funding within AIDS Program			Amount undetermined		
	General AHS funds			Approx. \$28m.	
Medicare			Amount undetermined		
		Pharmaceutical companies	approx. 600,000		
S100 funding			19,416,141		

Most of the identified HCV funding for non-inpatient services is not recurrent. Consequently staff positions cannot be permanent and experienced personnel are often reluctant to apply. Furthermore non-inpatient funding is mostly not provided from general Area funds. This situation suggests that AHSs are unaware of the significance of the HCV epidemic and the importance of treating HCV with anti-viral therapy to reduce the long term burden of chronic liver disease. Moreover, as one clinician commented, AHSs are often reluctant to fund non-inpatient services they see them as the domain of the Australian Government.

There are interesting parallels between the treatment for diabetes and the treatment for HCV. Unlike HCV, both the State and Federal governments are aware of the efficacy and effectiveness of treating diabetes on an ambulatory basis to reduce the longer term impact of the disease. Consequently there are many initiatives, in Medicare and in the State public health system that are geared towards early treatment on an ambulatory basis.

This lack of awareness by AHSs of the significance of the potential impact of the long term effects of people with HCV on the health system, is understandable. There is no regular analysis performed that reveals the cost of inpatient services for people with chronic liver disease due to HCV compared to the relatively small investment that could be made in ambulatory care to reduce this inpatient burden and cost. Furthermore, even if AHSs were aware of this contradiction, there is no mechanism

that enables AHSs to reallocate inpatient services' funding to ambulatory services' funding without there being the provision of some enhancement funding, in the first instance, to enable this reallocation to occur.

Pharmaceutical company money is a significant component of HCV treatment service funding. It is also temporary and is reviewed and allocated on an annual basis. Not only is this funding non-recurrent but it also has the potential to create a conflict of interest for the staff working in the service.

The result is that most of the HCV ambulatory services are not permanently funded and even the short term existence of many services is threatened by the uncertainty of on-going temporary funding.

7.5 Model of care

Most AHSs refer to their HCV services as:

- the provision of information and education (NSPs, sexual health services, health promotion services)
- testing, counselling and monitoring (provided by sexual health services, some AOD services, some mental health services, some GPs)
- treatment with anti-viral therapy or for advanced liver disease (provided primarily by hospital liver services and gastroenterology departments)

There is a continuum of care and a continuum of disease but there is not a comprehensive service delivery

framework that describes the key elements required for provision of best practice evidence-based care.

HCV is a chronic disease and, as the NSW Chronic Disease Strategy states, services need to be integrated and coordinated across multiple providers and multiple settings.³⁹

The lack of a service delivery framework and inadequate funding has meant that HCV services have not developed in a coordinated way across the spectrum of care that includes prevention, health promotion, early detection, treatment and continuing care across primary, secondary and tertiary health services.

The description of HCV services in Section 5 shows there are variable levels of service in each Area. All metropolitan AHSs have specialised services in the major hospitals but these are not coordinated across the Area and the pattern of resourcing does not necessarily reflect local need.

There are best practice guidelines⁴⁰ for the clinical care of people with HCV. They provide information to medical practitioners, other health professionals and people with HCV about treatment and management options. They focus on treatment with anti-viral therapy and other issues such as the transmission of HCV from mother to child, co-infection with HIV, co-infection with HBV, diet, complementary medicine, lifestyle and support services. However they are not service planning guidelines — they do not identify the resources needed to ensure that the best practice standards can be reached or the role of the various providers in the provision of care. They do not provide a comprehensive framework of care that includes prevention, early detection, treatment (in terms of anti-viral therapy and liver disease) and continuing care.

As the provision of anti-viral treatment is so important in reducing the number of people with chronic liver disease, much focus has been placed on the resources needed to provide effective anti-viral treatment services. In most of these services, the nurses play a major role in the patient's treatment journey. They see the patient most often, schedule their appointments with medical specialists and refer the patient for counselling, if required. However there is some debate about this model of care and questions about other options such as whether there should be:

- greater doctor involvement — both specialists and GPs
- increased involvement of infectious diseases (ID) physicians (specialist care should not just be the domain of gastroenterologists)
- the role of other services such as sexual health services, AOD services and mental health services

- the role of nurse practitioners (there is currently one nurse practitioner operating in the provision of HCV services in NSW)
- the effectiveness of case management and by whom

In Queensland the role of the nurse has been seen as critical to the expansion of anti-viral treatment services. In July 2006, a commitment of \$1.46m. per year (recurrent) was made by Queensland Health to enhance HCV anti-viral treatment services. Ten hospitals across Queensland were provided with funding for a team of health professionals including a full time nurse, a part time psychologist, 0.2 FTE administration officer and some VMO sessions. The impact of this enhancement has already been seen in the rate of increase of expenditure on s100 drugs in the last year and, therefore, an increase in the number of people receiving treatment.

A similar investment in nurses has recently been announced by the Ontario provincial government in Canada. The government is providing AU\$2.5 million to employ up to 20 nurses who will provide support to approximately 1500 patients a year and help manage patient's treatment by ensuring they follow their treatment plans.⁴¹

7.6 Role of GPs

The interest by GPs in the treatment and care of people with HCV is difficult to gauge. Some GPs have a high caseload of people with HCV and many of them have a special interest in HCV treatment and care. GPs who are methadone prescribers would mostly fit this description. However GPs with only a few patients with HCV may not be very interested in providing HCV treatment and care. They may lack knowledge and skills and there may be variation in the frequency and nature of their monitoring of the disease. Calls by people with HCV to the HCCNSW Hepatitis C Helpline suggest that pre-test information and post test counselling are inconsistent and often poorly provided.⁴² The NSW Department of Health and the MACH requested public and private laboratories to include a referral to the Hepatitis C Council of NSW for patients and to ASHM for doctors on each hepatitis C antibody positive test result to facilitate the improvement of information provision for newly diagnosed people. It is unknown whether all laboratories comply with this request.

The two focus groups (one in Sydney and one in Lismore) of people with HCV saw advantages for GPs to be involved in their HCV treatment because of the convenience, especially if the GP is a methadone

39 NSW Health (2006) *NSW Chronic Care Program Phase Three:2006-2009*, NSW Chronic Disease Strategy, North Sydney.

40 ANCAHRD (2003) *A Model of Care for the Management of Hepatitis C Infection in Adults*, July.

41 HCCNSW (2007) 'Ontario investment in hep C treatment nurses' *The Hep C Review*, winter issue, 57:12

42 HCCNSW submission to this review.

prescriber and they are on the methadone program. However, there were also some disadvantages:

- discriminatory attitudes
- no bulk billing — especially in rural areas
- closed books — again in rural areas where there is a shortage of GPs

Specialist HCV services in AHS have had varying degrees of success in involving GPs in the shared care of people receiving anti-viral treatment. For the most part they report that the GPs were not interested and suggested that the reasons for this lack of interest were that they are too busy, they have other priorities, there are not the financial incentives. As part of this review, substantial effort was made to talk to GPs to ask them directly the reasons why they were not interested in participating in shared care and what were their needs in the management of people with HCV:

- 40 GPs were invited to a focus group in the early evening where food and beverages were to be supplied. No one replied to the invitation so the event was cancelled.
- the CEO of the Alliance of NSW Divisions of General Practice was asked what he thought would be the best way to elicit information from GPs. A letter was drafted for the CEO to forward to members, but no responses were received.
- 60 letters were sent to GP members of ASHM asking them directly how they would like to be consulted — phone call, short email survey, interview, focus group. Once again no one replied to this letter.

Unfortunately, despite these repeated attempts, it was not possible to ask GPs directly their views in treating and caring for people with HCV with the exception of the three GPs who were contacted in relation to the services they provide within ACCHSs (see section 7.9). However a good indication of their views comes from a recent national survey of a randomly selected group of Australian GPs by Gupta et al.⁴³ This study revealed the widespread prevalence of people with HCV. A total of 76% of respondents (346 out of 458) indicated that they had managed a patient with HCV in the last 12 months. The number of patients seen per year ranged from 1 to 200 patients. The majority of GPs referred the most recent patient that they had seen to a hospital or specialist. The GPs in this study ranked therapeutics, interpretation of tests and pre- and post-test counselling as topics for future skills development to assist them in their management of patients with HCV.

In addition in NSW and the ACT, a pilot of GP prescribers has recently been completed and the evaluation report⁴⁴ provides some insights into the views of the GPs involved.

The NSW/ACT Hepatitis C Community Prescribing Pilot

The NSW/ACT Hepatitis C Community Prescribing Pilot allowed trained and accredited general practitioners in NSW and ACT to prescribe section 100 drugs for the treatment of people with chronic hepatitis C.

The rationale for the pilot project was to increase access to hepatitis C treatment and to enable the health system to cope with an anticipated increased demand for treatment. In order to participate in the pilot, GPs had to undertake a training and accreditation program to become authorised prescribers for treatment of HCV. They would then enter into a shared care arrangement with a specialist at a HCV treatment centre to provide ongoing anti-viral treatment for people with HCV, after initiation by the specialist.

There were 35 collaborating specialists participating in the pilot, with a total of 19 tertiary facilities linked to the pilot. A total of 88 GPs completed their final assessment and indicated a preparedness to participate in hepatitis C management including prescribing (17 were from rural/regional areas). At the end of April 2007, there were 81 accredited GPs still participating in the project. Of these 81 prescribers, 38 had enrolled at least one patient.

As at 14 May 2007, 236 patients had enrolled in the pilot. Of these:

- 40 patients had been treated and had scripts written by community prescribers, and 22 of these had completed treatment.
- 110 patients had not commenced treatment for various reasons.
- 38 patients had been lost to follow-up (some of these may have ended up on clinical trials but cannot be identified at the clinic and they have not returned to their GPs).
- 48 referred patients had been treated for HCV by the liver clinics. A number of these patients are likely to have entered clinical trials. Some patients may have also chosen to be treated by the clinic.

Patient views and experience

ASHM developed, in collaboration with the National Centre in HIV Social Research, a survey that was forwarded to patients who were enrolled in the pilot. A total of 41 surveys were returned. Of these, 28 were surveys returned from patients of one community prescriber at a drug and alcohol practice. The other 13 respondents were attending various practice locations.

Twenty respondents were due to commence, were currently on or had completed treatment. Eight respondents reported that their hepatitis C treatment

43 Gupta L, Shah S and Ward JE (2006) 'Educational and health service needs of Australian general practitioners in managing hepatitis C' *Jnl of Gastroenterology and Hepatology* 21:694-699.

44 Spina A (2007) *NSW/ACT Hepatitis C Community Prescribing Pilot: Evaluation Report*, ASHM.

was managed by their GP. All eight respondents generally reported favourably on the care provided by their GP. Twelve respondents reported that their hepatitis C treatment was managed by their specialist.

Twenty-one respondents indicated that they were not having treatment. A range of factors influenced their decision not to be treated at this point in time. Most commonly respondents reported that they were concerned about the impact it would have on family and friends, and the impact it would have on their work.

Another 17 people participated in a telephone interview. Of these, 14 people had completed or were undergoing treatment and 10 had their HCV treatment managed by GPs. Overall these people were very positive about having their GP involved in their hepatitis C treatment.

Community prescribers' views and experiences

Community prescribers identified common barriers to the uptake of treatment by patients:

- not seen as a priority by patient
- psycho-social issues such as chaotic personal lives, poor support networks, accommodation and employment needed to be addressed before consideration of treatment
- patient not suitable for a variety of reasons — previous treatment failure, non-responsive genotype, HIV coinfection, depression, mental health issues

In February 2007, a focus group was held with 14 community prescribers who had participated in the pilot project. The evaluation report concluded that:

'Overall, focus group participants were critical of the model of shared care adopted for the pilot. Participants' criticism of the shared care model was that the model did not adequately facilitate shared care. There were some exceptions, but overall most participants reported very similar experiences regardless of the liver clinic to which they referred patients. Focus group participants reported that it was not uncommon for the diagnostic tests that were conducted by the community prescriber prior to patient referral to the clinic, to be repeated by the specialist at the clinic'.⁴⁵

Focus group participants also reported that frequently patients that were referred to specialist liver clinics as part of the pilot project ended up been treated by the liver clinic.

Although focus group participants supported community prescribing, they believed that the model needed to be reviewed so that accredited community prescribers could initiate treatment. Community prescribers believed that this would be the most effective way to increase access to HCV treatments, and reduce the burden on hospital

liver clinics. They were keen to highlight that even if GPs who are accredited prescribers can initiate treatment, they would not be managing the more complex cases receiving hepatitis C anti-viral treatment.

The main reason why they felt it was important for GPs to initiate treatment was the fact that most patients had to wait on average two to three months for a first appointment with a liver clinic. Participants reported that this delay in obtaining a first appointment acted as a significant impediment to patients commencing treatment, as patients often lost interest and motivation due to the time lag.

Specialists' views and experiences

All participating specialists were offered an opportunity to provide input into the evaluation. Input was received from five specialists. According to the evaluation report:

'Some of the specialists who supported the pilot indicated that they believed that for access to hepatitis C treatments to be increased, any future model of community prescribing would need to give consideration to supporting GPs being able to initiate patients on to treatment.

Other specialists who provided input into the evaluation expressed scepticism of the value of the model. They believed the shared care model had not been effective. They were critical of the level of care provided. They did not support the continuation of community prescribing.

Some questioned the model. They did not see any value in the model focussing on GPs being enabled to write scripts, when they believed the focus needed to be on ensuring appropriate support for patients considering treatment. They questioned whether GPs had the amount of time required, appropriate access to ancillary services and the skills required to offer patients the treatment support they required. They believed that specialist centres had more capacity to meet the needs of patients in this regard, particularly given the experience and skill of CNCs and particularly as ancillary support services required were often hospital-based. And, not unexpectedly, they reported that it was easier to work with liver clinic nursing staff than GPs in the community.⁴⁶

CNCs' views and experiences

A focus group was also held with eight clinical nurse consultants and/or clinical nurse specialists from liver clinics who participated in the pilot project. They reported that nurses play a pivotal role in supporting patients in undertaking treatment. They felt that the role of nurses was not well recognised and the initial implementation of the pilot failed to adequately engage them in the process. Although the issue was rectified during project implementation, focus group participants were keen to

45 Spina A (2007) *NSW/ACT Hepatitis C Community Prescribing Pilot: Evaluation Report*, ASHM p. 29

46 Spina A (2007) *NSW/ACT Hepatitis C Community Prescribing Pilot: Evaluation Report*, ASHM p. 31–32.

ensure any future shared care models recognise the important role nurses play within liver clinics in supporting patients, as well as the key role they can play in supporting and linking with community prescribers.

Proposed pilot of community prescriber initiation of hepatitis C anti-viral therapy

The NSW Department of Health is preparing a proposal for a 36-month pilot for accredited community prescribers — general practitioners and other non-specialist medical practitioners — to initiate treatment of chronic hepatitis C, within the arrangements of the HSDP. This would involve:

- A pilot of initiation of treatment of chronic hepatitis C by accredited community prescribers;
- Medical practitioners undertaking a training and accreditation program to become authorised prescribers; and
- Medical practitioners entering a shared care arrangement with a specialist at an authorised hepatitis C centre.

The project would be evaluated after 24 months, and the evaluation report would be provided to the Department of Health and Ageing for consideration. This arrangement would allow for a period of 12 months for the evaluation report to be considered, and to seek approval for the arrangements to be made permanent if found to be successful.

7.7 Role of AOD Services

HCV prevalence is particularly high in clients of AOD services (estimated to be as high as 75% among clients of methadone programs)⁴⁷, but to date the involvement of AOD services in providing HCV services has been limited. In some Areas the HCV nurses provide clinics in the public methadone dispensing settings where they provide information, undertake testing and provide referrals to the liver clinics. At RPA the AOD specialist is a gastroenterologist who provides a monthly treatment clinic at Clinic 36, one of the private methadone clinics in the Area. The HCV nurses from RPA also provide a weekly clinic at three private methadone clinics in the Area.

There is increasing support for greater involvement of AOD services in HCV treatment and care. The Mental Health and Drug and Alcohol Office of NSW Health stated in a phone interview for this review that it was committed to having HCV treatment available for all its pharmacotherapy (methadone and buprenorphine) clients.

However a survey of drug and alcohol agencies throughout Australia to identify the prevalence of BBVs testing, counselling and vaccination services for people who inject drugs revealed that even though three-quarters of agencies provided some access to HIV, HBV and HCV testing and HBV vaccinations, only a third offered these services routinely on site.⁴⁸ The authors of this study concluded that the restricted provision of BBV services represents missed opportunities to reduce individual and community morbidity to this marginalised and high risk group.

It seems that there is huge potential to involve the AOD services more in the provision of HCV services. Byrne, Hallinan and Dore⁴⁹ describe the role of methadone prescribers in particular. At the Redfern clinic (Byrne surgery), a medical practice specialising in addiction treatment, they provide HCV testing at the commencement of opioid pharmacotherapy and six monthly thereafter as well as post test counselling. HCV seropositive patients are tested for HCV-RNA and, if positive, assessed for risk of progressive disease. The Redfern clinic participated in the recent prescribers' pilot and 25 patients were successfully started on anti-viral treatment at the Redfern clinic in conjunction with a specialist hepatitis treatment clinic. Byrne et al. believe that there is a great opportunity to reduce the burden of HCV disease through the integration of HCV services within existing opioid pharmacotherapy settings because:

- about 38,000 people are currently receiving opioid pharmacotherapies in Australia (the majority of whom would have HCV)
- many aspects of a HCV-specific clinical work-up are already incorporated in the routine assessment and monitoring of a person on opioid pharmacotherapy
- a drug treatment service is ideally placed to assist people reduce alcohol related harms — a priority for people with genotypes 1 and 4 who may be considering treatment

Another reason, often cited by people interviewed for this review, is the fact that methadone clients are coming regularly to methadone clinics to receive their methadone dose so it should be very convenient to receive treatment for HCV at the same time.

There is other evidence that supports the provision of treatment for HCV in methadone maintenance settings. Digiusto et al. are currently writing up the findings of a study on hepatitis C related treatment activity in the context of methadone treatment in NSW. Preliminary findings suggest that more clients on methadone treatment programs would undertake anti-viral treatment for HCV if methadone treatment providers 'encouraged

47 Hallinan R, Byrne A, Amin J, Dore G (2005) 'Hepatitis C virus prevalence and outcomes among IDUs on opioid replacement therapy', *Jnl of Gastroenterology and Hepatology* 20: 1082–1086.

48 Winstock AR, Anderson CM and Sheriden J (2006) 'National survey of HIV and hepatitis testing and vaccination services provided by drug and alcohol agencies in Australia' *MJA* 184 (11): 560–562.

49 Byrne A, Hallinan R and Dore G 'Harm reduction, hepatitis C and opioid pharmacotherapy: an opportunity for integrated HCV-specific harm reduction, *Harm Reduction Digest*, (in press).

and supported them as actively as possible.⁵⁰ Moreover, most of the 37 surveyed treatment providers in this study are interested in being involved in providing anti-viral therapy.

Despite all these possible advantages, only a small minority of opioid pharmacotherapy clinics integrate HCV treatment with drug treatment services. Byrne et al. conclude by saying:

'Establishment of integrated HCV prevention and treatment services within the setting of opioid pharmacotherapy provides the opportunity to reduce this burden [of HCV-related liver disease], may improve overall patient management, and simply makes sense.'

Treloar and Holt (2007)⁵¹ emphasise the need to educate consumers of drug treatment services if they are to be convinced of the need for hepatitis C treatment, together with a concerted effort to address the complex and continuing needs of those with drug and mental health problems.⁵² Brener and Treloar's current research⁵³ also shows differences in the ways in which people with and without HCV report being treated by health care workers, with those with HCV believing that it is related to their history of injecting. They conclude that these experiences might be a barrier to HCV treatment uptake in AOD treatment facilities and they highlight the need to take into account the client or user perspectives in understanding how best to work with people with HCV.

The latest development in the the effort to take advantage of the opportunity to provide HCV services in the drug treatment sector has been the awarding of Commonwealth and State (NSW Health) funding to the National Centre in HIV Epidemiology and Clinical Research (NCHECR) to pilot and evaluate the uptake of hepatitis C testing and treatment in drug dependency treatment settings. The key objectives of the project are:

- to assess the barriers and enablers to enhanced uptake of hepatitis C diagnosis and treatment in drug dependency treatment settings
- to develop and deliver an education and training program for drug dependency practitioners
- to establish pilot hepatitis C treatment services within drug dependency treatment settings

NCHECR has sub-contracted ASHM to provide the workforce development in hepatitis C to medical staff and other health professionals involved in the provision of pharmacotherapy treatment, with a view to supporting

the implementation of HCV services in the drug treatment sector. This research was announced in May 2007, so planning for the study has only just begun.

7.8 Role of Sexual Health Services

Most sexual health services (SHS) are involved in the provision of information about HCV, testing and pre- and post- test counselling. However in both metropolitan and rural and regional areas, SHS limit their role in the provision of services for people with HBV and HCV due to resource constraints.

In metropolitan settings, SHSs may assess and refer patients for HCV treatment to a liver clinic. In rural and regional settings there may not be a specialist liver service. Some patients are reluctant to go to their GP about their HCV if they are unwilling to disclose current or previous injecting drug use. Or they may not be able to see a GP for some of the reasons discussed in the previous section on the role of GPs in relation to HCV:

- GP's books are closed
- GP does not bulk bill
- GP not interested in becoming a community prescriber

If there is no specialist liver service, the SHSs provide an appropriate setting for HCV treatment. They are often familiar to the clientele who may have used the SHS for other purposes and often their HCV is diagnosed in the context of a sexual health screen. They also may be co-located with AOD services, which mean they could provide the convenience described in the section above, for patients on a methadone program. However SHSs are not funded to provide a HCV anti-viral treatment service i.e. there is not specific HCV funding for nurse, counsellor and doctor sessions — the resources necessary to enable anti-viral treatment to occur.

The service operating in Coffs Harbour operates from the SHS: visiting specialists provide a clinic every month and a nurse and counsellor support the patient in between. Shared care is encouraged between the clinic and the surrounding GPs. However the limited resources mean that the numbers on treatment have to be capped at 20, despite the fact that there are people waiting for treatment. If SHSs are to play a greater role in the provision of viral hepatitis treatment in rural and regional areas, they must be funded accordingly.

50 Digiusto E, McPherson M and Leist T (2006) *Hepatitis-related prevention and treatment activity in the context of methadone treatment in NSW*, presented at the 5th Australasian Viral Hepatitis Conference, Sydney, February.

51 Treloar C, Holt M (2007) Drug treatment clients' readiness for hepatitis C treatment: implications for expanding treatment services in drug and alcohol settings. *Australian Health Review*. Manuscript submitted.

52 Treloar C, Holt M. (2007) Complex vulnerabilities as barriers to treatment for illicit drug users with high prevalence mental health comorbidities. *Mental Health and Substance Use: Dual Diagnosis*. In press.

53 Brener L, Treloar C (2007) Alcohol and other drug treatment experiences of hepatitis C positive and hepatitis C negative clients: Implications for the roll out of hepatitis C treatment. *Australian Health Review*. Manuscript submitted.

7.9 Access to services by populations at risk

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.

People who inject drugs

In their submission to this review, NUAA stated that the main barrier to treatment is that many people who use drugs illicitly believe that current injecting drug use will be a barrier to treatment. There is also a perception that some treatment services are not user-friendly. Many are not flexible and have, in some cases, removed people from treatment for not attending treatment appointments. Another barrier is the lack of information on treatment in circulation and a lack of training and information available to GPs. NUAA lists other related concerns:

- patients' previous negative experiences of the health care system.
- negative responses by health care workers to the primary health care needs of users.
- pervasive views about 'deservingness' [of people who inject drugs] to access scarce resources.
- limitations of current treatment options — e.g. not all genotypes are as responsive to treatment as others; previous treatment exposure restricts future access.
- poor side effect management that leads to widespread negative views of treatment.

NUAA would like services for people who inject drugs with the following characteristics:

- low threshold (not too many eligibility criteria) and easy access to treatment
- social, psychological and physical support — to cope with side effects, children and families, work stresses, disclosure to family, friends and workplace about treatment

- peer (as in drug user peer) support mechanisms
- detailed information about treatment and support resources
- empathetic staff
- involvement by knowledgeable GPs
- flexible service models including the involvement of nurse practitioners in rural and regional areas where services are limited

People in custody

The full time inmate population in NSW correctional centres is approximately 9500, 93% male and 7% female. There is a high turnover and mobility, with approximately 18,000 people moving through the correctional system each year. The majority of inmates are imprisoned for periods of between three and six months. In May 2007, 20% of the male population and 28% of the female population were from an Aboriginal and Torres Strait Islander background — a much higher proportion than in the general population. The country of birth of inmates broadly reflects the general population with 74% Australian born and 17% born overseas in a non-English speaking country. The average daily number of young people in custody is 375, 47% of whom are Aboriginal or Torres Strait Islander and 8% of whom are female.

The rate of hepatitis C infection is high: approximately 40% of men and 64% of women are hepatitis C positive.⁵⁴ The combined rate for males and females in custody is estimated to be 43%.⁵⁵ The Young People in Custody Health Survey⁵⁶ indicates HCV prevalence of 8% for males and 18% for females.

With the prison population expected to rise, the numbers of inmates with HCV is also expected to rise. By 2011/12 it is estimated that 4,724 of the projected custody population of 10,985 will have been exposed to HCV (assuming that the prevalence of the disease in the prison population remains at 43%). Fifty percent of these people will have stage F/01 disease, 22.5% will have stage F2/3 disease and 2.5% will have cirrhosis.⁵⁷ Justice Health expects 2 deaths per year from 2007 directly related to advanced HCV liver disease.

The growing demand for services, including increasing numbers with HCV liver disease, necessitates a whole of organisation response with collaborative partnerships in the planning and delivery of services, particularly Drug and Alcohol services within Justice Health.

An important part of future planning is the development of discharge planning (for release) and continuity of care pathways with AHSs. Often the stay in prison provides the opportunity for the hepatitis C positive person to

54 Corrections Health Service (2003) *Hepatitis C: the challenges, the response, Strategic Directions 2003–2006*, A continuum of care for prevention and management of Hepatitis C in the NSW Correctional System, Sydney.

55 Justice Health submission to this review.

56 NSW Department of Juvenile Justice, *NSW Young People in Custody Health Survey 2003, Key Findings Report*, NSW Department of Juvenile Justice, Sydney, 2004.

57 Justice Health submission to this review.

obtain anti-viral treatment and it is vital that treatment is continued after release from prison.⁵⁸ As the AH&MRC noted in their submission to this review, 'Anecdotal evidence suggests that prisons are one of the few places that Aboriginal people living with hepatitis C are able to access and complete hepatitis C treatment'. In fact, a wide range of marginalised population groups, who have difficulty accessing health care in the general community, are given this window of opportunity during incarceration.

Other significant issues include:

- the need for more acute hospital beds for people with advanced liver disease
- non-acute rehabilitation / hostel type beds will also be required to house patients who are symptomatic and for whom general custodial accommodation is inadequate.

Justice Health identified the following service delivery priorities for the next five years:

- Expansion of adult medical hepatitis services at Long Bay Hospital 2 (LBH2) outpatients department, particularly for co-infected and complex management cases and advanced liver disease.
- Maintenance and support of local and regional adult Justice Health Hepatitis Clinics.
- Expansion of regional specialist hepatitis services.
- Establishment of public / sexual health and specialist hepatitis services for young people in custody.
- Improved access to specialist hepatitis C nursing and medical services for patients who have hepatitis C.

Aboriginal and Torres Strait Islander people

The Hepatitis C Virus Projections Working Group⁵⁹ estimated that there are 22,000 Aboriginal and Torres Strait Islander people with HCV antibodies, and 16,000 Aboriginal and Torres Strait Islander people living with chronic hepatitis C. This is approximately 8% of all the people living with HCV in Australia. This is a significant overrepresentation as Aboriginal and Torres Strait Islander people comprise approximately 2.4% of the total Australian population. The Projections Working Group also suggested that the progression of HCV-associated liver disease among Aboriginal and Torres Strait Islander people may be faster than in other populations due to their higher morbidity and mortality rates and the general disadvantage of this population in terms of access to health services and a range of social determinants such as education and housing.⁶⁰

There is no accurate data on the prevalence of hepatitis C in Aboriginal communities in NSW. Nor is there any data on the number of Aboriginal people living with

hepatitis C who have or are currently accessing anti-viral treatment.

Barriers to accessing services for HCV treatment in NSW identified in the consultations and in the submission to this review by the AH&MRC include:

- Low numbers of hepatitis C prescribers within Aboriginal Community Controlled Health Services (ACCHSs) — there are currently less than five ACCHS based GPs who are hepatitis C s100 prescribers.
- Rural isolation. Many ACCHSs are based in rural locations where there is limited specialist support and caseloads of hepatitis C patients are inadequate for maintaining prescriber status.
- case complexity — Aboriginal communities have high rates of other diseases which affect hepatitis C prognosis such as diabetes, obesity and smoking, as well as other comorbidities.
- the complexity of the referral pathway for assessment and initiation onto treatment may be a barrier for some Aboriginal people living with hepatitis C.
- knowledge about hepatitis C and its treatment is generally low in Aboriginal communities.
- hepatitis C may not be discussed openly in some Aboriginal communities because of perceived shame.

As part of this review, three GPs working in ACCHSs in NSW were consulted. They identified barriers for Aboriginal people to accessing services including:

- complex social and economic factors that may impact upon a client's ability to access services
- a range of social, physical, economic and cultural factors that may affect a client's ability to complete treatment
- lack of knowledge about HCV and its treatment
- lack of treatment services locally
- transport to get to treatment centres
- financial, transport and other health priorities as well as cultural and family obligations that may impact on clients' ability to comply with treatment

The AH&MRC identified the following priorities in the development of HCV services for Aboriginal and Torres Strait Islander people:

- partnerships between liver clinic specialists in taking services to community members (eg partnership with ACCHSs)
- training for ACCHS GPs which focuses specifically on the unique context of providing hepatitis C treatment and care for Aboriginal clients

58 Anecdotal evidence suggests that the treatment dropout rate following release from prison is exceptionally high.

59 Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis: Hepatitis C Sub-Committee (2006) *Hepatitis C Virus Projections Working Group: Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006*, National Centre in HIV Epidemiology and Clinical Research (NCHECR), Sydney.

60 *ibid.* p 30.

- flexibility in the model of service delivery, including exploring outreach models and nurse practitioner models
- acknowledgment that a variety of models of service delivery may be necessary, depending on the locality of the service
- provision of resources to inform the Aboriginal community about hepatitis C, and the availability of hepatitis C treatment
- improved surveillance data on Aboriginal status of hepatitis C notifications in NSW
- improved data on Aboriginal people accessing treatment in NSW

The three ACCHS GPs also identified other key elements:

- the importance of Aboriginal Sexual Health workers in the provision of HCV treatment
- the importance of counselling and support during treatment
- case management by nurses
- locally available medication

Aboriginal people attend the mainstream services in Coffs Harbour where about a third of the caseload of the anti-viral treatment clinic at any time in the last year is Aboriginal. The staff of the service estimate that this high attendance by Aboriginal people is related to the good relationship the service has with the ACCHS and the fact that all staff have undertaken cultural awareness training so are aware of the needs of Aboriginal people.

The National Centre in HIV Social Research, in their submission to this review, advocates the involvement of peers assisting in raising awareness of treatment, explaining the issues around treatment (side effects, cure rates, support available) in potentially increasing the uptake of treatment.

People from a culturally and linguistically diverse background

The Hepatitis C Virus Projections Working Group estimated that at the end of 2005 there were 264,000 people living with HCV antibodies in Australia, of which 10.9% were migrants from countries of high HCV prevalence (Asia, Africa and South America).⁶¹

The Multicultural HIV/AIDS and Hepatitis C Service (MHAHS), in their submission to this review, argue that the poorer health literacy of people from culturally and linguistically diverse (CALD) backgrounds in relation of hepatitis C is a substantial barrier to accessing hepatitis C diagnostic and treatment services. There are cultural and linguistic barriers in accessing hepatitis C treatment

services, especially for older CALD individuals, who may have poor English skills and limited mobility.

The MHAHS has developed a model to reduce these cultural and linguistic barriers in treatment services, which utilises a bi-lingual/bi-cultural co-worker who is available to assist patients in administrative and procedural tasks on-site at the clinic. This model enables patients to effectively negotiate the treatment service with minimal disruption to their care and assist clinic staff with communication issues and tasks which interpreters are unable to carry out. This current service is available in Mandarin/Cantonese and Vietnamese at the St George and Westmead hepatitis C treatment centres. An expansion of this model to support Arabic-speaking patients and some other priority languages may be of benefit in increasing throughput, and reducing barriers, at key hepatitis C treatment centres.

Other suggested strategies to improve services for people from a CALD background include:

- regular promotion of information relating to hepatitis C needs to be carried out through ethnic media and through community-based agencies
- improved referral pathways to the Transcultural Mental Health Centre (TMHC) is important in a hepatitis C context for people from CALD backgrounds experiencing mental health issues as a result of hepatitis C treatment
- enhanced and systematic GP education needs to be implemented through accredited CME point initiatives, especially for CALD GPs
- peer support and targeted outreach clinics within the geographic areas in which communities reside

7.10 Client issues

Two focus groups were held with people with HCV — one in Sydney and one in Lismore. Fourteen people attended the Sydney group and 12 attended the Lismore group. Two written submissions were received from people with HCV.

Some common experiences included:

- **discrimination**⁶² from GPs and specialists e.g. one GP refused to prescribe sleeping tablets saying that he could not prescribe them to a person with a drug history; the same GP, when he had difficulty taking blood said 'you must be used to this'; another GP said that the only people who had side effects [of anti-viral therapy] were 'junkies' and that was because they were neurotic and found everything difficult.

61 Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis: Hepatitis C Sub-Committee (2006) *Hepatitis C Virus Projections Working Group: Estimates and Projections of the Hepatitis C Virus Epidemic in Australia 2006*, National Centre in HIV Epidemiology and Clinical Research (NCHECR), Sydney, p 24.

62 There is an emerging body of literature focusing on the discrimination against people with hepatitis C: Crofts N, Louie R, & Loff B (1997) 'The next plague: stigmatization and discrimination related to hepatitis C virus infection in Australia', *Health and Human Rights* 2: 86–97.

- **lack of knowledge** about HCV and its treatment among both GPs and specialists⁶³
- some **misinformation and inconsistency in information**, e.g. two very different views on treatment were expounded — some doctors would say there are no, or minimal, side effects from anti-viral treatment while at the other extreme one client was told by a specialist that ‘she would be crazy to go on the interferon’ — that ‘interferon can kill you’ and that he had had two patients — one who hung herself on treatment, and another who ended up in a locked psychiatric ward.

The key elements of anti-viral treatment identified by clients include:

- thorough psychosocial needs assessment prior to the commencement of treatment. (Recent research by Digiusto et al. on services available to patients undergoing HCV anti-viral treatment in NSW found that ‘all respondents said that their clinics assess patients’ mental health [status] as part of the anti-viral treatment assessment, but 93% did so using verbal questioning only, i.e. without using validated questionnaires.’)⁶⁴
- psychological support throughout treatment. Again this need was confirmed by the service providers in the research by Digiusto et al.
- peer and carer support⁶⁵ including mentoring
- stable home environment including tenure of accommodation, reliable transport to attend treatment
- after hours contact with the service providing treatment
- nurse as case manager
- shared care with GPs, especially in rural areas
- better access to dental services
- more information about HCV and its treatment
- on-going follow-up after treatment is completed

An issue raised by the HCCNSW is the appropriateness of the extent of antenatal HCV testing. The recently updated National Hepatitis C Testing Policy⁶⁶ recommends that:

‘Hepatitis C screening for pregnant women should be confined only to those women who provide a history of risk factors or request screening when counselled about relevant risk factors.’

It goes on to say that:

‘Testing should always be associated with specific informed consent, the provision of information about the meaning of the results (particularly in relation to the pregnancy) and post-test discussion.’

The HCCNSW have received calls on the NSW Hep C Helpline that suggest this policy is not observed and that antenatal screening is more widespread than recommended. This is confirmed by Spencer et al. (2003)⁶⁷ whose survey of private obstetricians, GPs affiliated with the RANZCOG and directors of obstetric units in public hospitals showed antenatal testing policy and practice varies in Australia and is reflective of individual policy. They estimated that 37% of pregnant women were tested for HCV in 1999 when prevalence rates for HCV were estimated at 13 per 1,000.

7.11 Services for Children

The joint submission to this review from the three children’s hospitals in NSW states that there are currently no HCV services for children. It says that case ascertainment and follow-up is ad hoc at best and treatment is nonexistent. It goes on to argue that the extent of the problem is completely unknown but it is thought that the number seen at the three children’s hospitals is just the ‘tip of the iceberg’. Moreover there are no identified hepatitis clinics or specific services for infected children and in the absence of an identifiable place to refer children to and a lack of any guidelines for follow-up and management there is a belief that many children may be ‘falling through the cracks’.

The submission proposes a single statewide service incorporating stakeholders from all three tertiary paediatric centres (i.e. CHW, SCH and Kaleidoscope (John Hunter Children’s Hospital)). The aims of the service would be to develop guidelines for screening, follow-up and therapy for infected children, to promote

63 A recent article by researchers in Melbourne explored the inter-relationship among health professionals’ hepatitis C knowledge and attitudes towards treating people with hepatitis C and their self reported clinical behaviour. They concluded, ‘The results suggest that focusing education strategies on changing health professionals’ attitudes toward people with hepatitis C, people who inject drugs, and infection control guidelines rather than concentrating solely on medical information might ultimately improve patient care.’ Richmond JA, Dunning TL, Desmond PV (2007) *Health Professionals’ Attitudes toward Caring for People with Hepatitis C*. *Journal of Viral Hepatitis* 14(9): 624-632. September.

64 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.

65 The submission to this review from the National Centre in HIV Social Research emphasised the importance of peer support to hepatitis C treatment programs as evidenced by the patient support groups in some treatment centres and the success of Hep Connect, the treatment support program run by the HCCNSW. The National Centre’s submission also stressed the importance of a treatment peer support program in AOD settings as is provided by Turning Point, an AOD clinic providing outreach hepatitis treatment.

66 Australian Government Department of Health and Ageing (2007) *National Hepatitis C Testing Policy*, Hepatitis C Subcommittee of the Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis; the Blood Borne Virus and Sexually Transmissible Infections Subcommittee of the Australian Population Health Development Committee, Canberra.

67 Spencer JD, Tibbits D, Tippet C, Mead C, Kaldor JM and Dore GJ (2003) ‘Review of antenatal testing policies and practice for HIV and hepatitis C infection’, *Australian and New Zealand Journal of Public Health*: 27(6): 614–619.

the service in a way to capture all the infected children in the state and by use of outreach clinics, to establish regular monitoring and to help develop treatment plans in conjunction with local paediatricians or family doctors. There is also a need to develop health information to inform local practitioners. Such a model would also concentrate expertise, provide data about natural history and allow for recruitment of meaningful numbers of patients into clinical trials.

The proposed core service would consist of 1.0 FTE nurse coordinator, 0.5 FTE staff specialist, 0.3 FTE psychologist, a part time data manager, a travel and pathology budget.

7.12 Workforce issues

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 liver disease suggests that the HCV workforce will need to expand. However there are a number of factors that inhibit an easy expansion.

It was noted in section 7.4 that the temporary nature of much of the funding has meant that often the best people are not attracted to the HCV jobs because positions are not permanent and often experienced personnel are reluctant to apply. The temporary nature of positions also means that there is no career structure. There are no hepatology nurse training courses⁶⁸ so most of the nurses come to the field of practice with varying backgrounds and attain their seniority through experience. The lack of a national nurse hepatology training program has resulted in the Australasian Hepatology Association developing competencies for advanced practice nurses working in the area of liver disease. These competencies have just been developed and are about to be focus tested. The plan is then to develop an education course, to be endorsed by the Royal College of Nursing. All this work in producing these competencies has been done by dedicated nurses on a voluntary basis with some financial assistance from pharmaceutical companies. More support from State and Federal governments is needed to enable the development of these national courses and standards.

Allied health staff, especially psychologists and social workers, are key members of the HCV treatment service in terms undertaking the pre-treatment assessment, providing support during treatment and helping to manage the side effects of treatment. Recent work from the National Centre in HIV Research⁶⁹ has highlighted the usefulness of concepts and tools from the psychological literature in assisting with readying patients for and supporting patients in treatment.

On the medical side, hepatology is less frequently chosen by gastroenterologists as a field of specialisation. One of the reasons for this, it has been suggested, is that hepatology is not a major part of gastroenterology speciality training. This situation needs to be rectified if there are to be enough specialists in liver disease to cope with the increasing numbers of patients with HCV requiring treatment.

7.13 Data

There is no standardised reporting of the number of patients receiving anti-viral treatment for HCV. This information has to be gleaned from s100 expenditure data and it is not routinely reviewed. It is difficult to estimate the actual number who have received treatment because it is not possible to know who is on 6-monthly treatment and who is on 12-monthly treatment. Moreover this expenditure data does not include the number of people on clinical trials or those receiving therapy under compassionate access schemes.

In addition there is no systematic monitoring of the impact of HCV-related liver disease on inpatient services. As part of this review an attempt has been made to estimate the HCV-related caseload in NSW hospitals but the methodology and results need to be closely scrutinised by treating clinicians to assess whether this approach is the best way to identify the number of inpatients with HCV-related liver disease.

There needs to be regular reporting and monitoring of people receiving anti-viral therapy for HCV (number of people on treatment, location of treatment, treatment outcome, Aboriginal status, country of birth/fluency in English etc.) and an agreed approach to determine the extent of HCV related liver disease in inpatient settings if there is to be a systematic way of measuring the impact of anti-viral treatment on the reduction in chronic liver disease.

68 Justice Health does offer an annual hepatology nurse training course which is currently being considered for eligibility for credit points towards a post graduate nursing degree with the University of Technology, Sydney.

69 Hopwood M, Treloar C and Redsull L (2006) *Experiences of hepatitis C treatment and its management: What some patients and health professionals say (Monograph 4/2006)*, National Centre in HIV Research, UNSW, Sydney.

Eleven main recommendations, based on the issues identified in section 7, are proposed. Section 8 should be read in conjunction with section 7 to fully appreciate the detail implied in the recommendations.

8.1 Adopt the anti-viral treatment goals of 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.⁷⁰ 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.

8.2 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.⁷¹ 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.

8.3 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.

8.4 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

70 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.

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