Outcomes from the first two years of the Australian hepatitis C surveillance strategy

Jenean Spencer,[1] Gregory Dore,[2] Monica Robotin,[2] Patty Correll,[2] John Kaldor[2] on behalf of the Communicable Diseases Network Australia Viral Hepatitis Surveillance Committee

Abstract

The objectives of national hepatitis C surveillance are to identify those at risk in order to appropriately target prevention and care programs, and to evaluate the impact of these approaches. In 1998 the Communicable Diseases Network Australia New Zealand (CDNANZ) appointed the Hepatitis C Surveillance Committee to develop and implement approaches for improved hepatitis C surveillance in Australia. The Australian Hepatitis C Surveillance Strategy was endorsed in 1999 and provides a framework for improvements to national hepatitis C surveillance. The strategy covers two main surveillance activities: surveillance of incident and prevalent hepatitis C, and the long-term outcomes of hepatitis C. The committee (now the CDNA Viral Hepatitis Surveillance Committee) has continued to facilitate the implementation of the recommendations proposed. Progress towards improvement of hepatitis C surveillance in Australia includes the development of standard case reporting for hepatitis C, collation of data on incident and prevalent hepatitis C from a range of populations at lower and higher risk of hepatitis C, and collation of data from liver transplant registries. Advances in the implementation of the strategy are incremental. While there is enthusiastic commitment towards improving hepatitis C surveillance in Australia, the number of cases, the capacity and competing priorities of State and Territory health departments has meant that implementation has been challenging, highlighting the difficulties in introducing new systems into an already complex situation. *Commun Dis Intell* 2002;26:14-22.

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Introduction

Since 1989, when infection with the hepatitis C virus was identified as the main cause of non-A non-B viral hepatitis in most of the industrialised world, it has become the most frequently notified communicable disease in Australia. In 2000, just over 20,000 cases of hepatitis C infection were reported across the 8 public health jurisdictions. Surveys have found that the highest prevalence in Australia occurs in people with a history of injecting illicit drugs. Other groups with higher levels of hepatitis C are people with haemophilia, prisoners and people from countries with a high prevalence of hepatitis C.

In recognition of the public health importance of hepatitis C infection, the Communicable Diseases Network Australia (CDNA), formally CDNANZ, established the Hepatitis C Surveillance Committee in 1998. The committee was given the responsibility of improving the national capacity to monitor the occurrence of the infection and its consequences, through the development and implementation of a national surveillance strategy. This review reports on the outcome of this process to date.

Challenges presented by surveillance for hepatitis C

There are a number of aspects of hepatitis C infection that have presented challenges to surveillance activities. First, detection of incident cases of infection is difficult because less than 10 per cent of people who are exposed to the virus develop symptoms of acute hepatitis, and an even smaller proportion seek medical advice. New infection can also be detected serologically, but requires serial testing of individuals within a limited time period, to determine that antibodies have developed. Second, because hepatitis C infection in Australia is strongly associated with the illegal and socially stigmatised practice of injecting drug use, it is difficult to undertake monitoring of a large group of people who are at risk of infection. Finally, the long (over decades) and variable time course of chronic infection complicates the assessment of outcomes such as liver failure and hepatocellular carcinoma (HCC).

1. Surveillance and Epidemiology Section, Population Health Division, Commonwealth Department of Health and Ageing.
2. National Centre in HIV Epidemiology and Clinical Research, University of New South Wales.

Corresponding author: Professor John Kaldor, Deputy Director, National Centre in HIV Epidemiology and Clinical Research, Level 2, 376 Victoria Street, Darlinghurst, NSW 2010. Telephone: +61 2 9332 4648. Facsimile: +61 2 9332 1837. E-mail: jkaldor@nchecr.unsw.edu.au.

Development of the National Hepatitis C Surveillance Strategy

The Hepatitis C Surveillance Committee was established under the chairmanship of Dr Linda Selvey with a broad membership, including a representative with experience in hepatitis C surveillance from each State and Territory, and representatives from the Australian Hepatitis Council, the Australian National Council on AIDS, Hepatitis C and Related Diseases Hepatitis C Committee, the Macfarlane Burnet Centre for Medical Research, the National Centre in HIV Epidemiology and Clinical Research (NCHECR), the Public Health Laboratory Network, the Commonwealth Department of Health and Ageing and the NSW Users and AIDS Association.

The terms of reference agreed for the committee were to:-

1. Develop a strategy for national hepatitis C surveillance in Australia, to incorporate routine case reporting of hepatitis C diagnoses as well as other methods of data collection.
2. Oversee the implementation of the strategy at a national level.
3. Consider mechanisms for integrating hepatitis C surveillance activities with the corresponding activities for HIV.

Following a series of meetings, the Australian Hepatitis C Surveillance Strategy was drafted by the committee and endorsed in 1999 by the CDNA. Since then the committee has continued to facilitate the implementation of the recommendations proposed in the Strategy. In 2001, its terms of reference were extended to include the development of national surveillance for hepatitis B infection, and the name was changed to CDNA Viral Hepatitis Surveillance Committee.

Specific elements of the strategy for the surveillance of hepatitis C are summarised in Table 1. In implementing the strategy, the committee recognised that finite resources and differing surveillance structures within jurisdictions would mean that not all of the agreed activities could be introduced at once, and that an incremental approach would be required. In the remainder of this review, we outline the developments that have taken place in key areas of the strategy.

Routine reporting of incident hepatitis C via NNDSS

In reviewing existing procedures in the course of developing the surveillance strategy, the committee identified the lack of standard case definitions across jurisdictions, and the absence of information on risk factors for hepatitis C as key weaknesses in the national surveillance system. The jurisdictions recognised that they would be likely to continue to use somewhat different procedures for identifying and reporting on incident and prevalent cases of hepatitis C infection, but they endorsed standard case definitions, and a set of risk categories that would be used to classify exposure for all cases determined to be incident (Table 2). Currently the case definitions are awaiting CDNA approval. The enhanced data collection for hepatitis C infection was incorporated in broader changes that were taking place in the reporting procedures of the National Notifiable Diseases Surveillance System.

Incident hepatitis C cases have been separately reported by all jurisdictions (except Queensland and Northern Territory) since 1997 (Table 3). The numbers of incident cases detected are likely to be affected by the mechanisms for detecting cases in these years (Table 4). In the largest jurisdictions, classification of incident cases is determined by passive reporting. In smaller jurisdictions, where all (or the majority) of hepatitis C notifications were actively investigated to determine if they were incident or prevalent during this time period, a much higher proportion of cases has been determined to have been incident. Changes in surveillance practices within jurisdictions (e.g. the introduction of enhanced surveillance in Western Australia and in some New South Wales Public Health Units) has contributed to an increased number of incident cases reported at various times between 1997 and 2000.

In 2001, the Australian Capital Territory, the Northern Territory, South Australia and Tasmania undertook enhanced surveillance on all HCV notifications. NSW Health had developed a procedure for enhanced hepatitis C surveillance which was implemented via the Public Health Units. Victoria chose to undertake enhanced surveillance on 10 per cent of all new notifications of hepatitis C infection. Western Australia developed new procedures to coincide with the introduction of the revised national system for reporting notifiable communicable diseases, including a review of 30 per cent of all notifications for the assessment of risk factors. All jurisdictions found that there was a considerable amount of extra work involved in processing cases under the strategy, both in order to identify incident cases and to collect risk factor information.

Table 1. Recommendations from the Hepatitis C Surveillance Strategy

Focus of surveillance activities			Recommendation	Priority
1. Surveillance for HCV transmission	1.1 Incident HCV infections	1.1.1 Routine reports	Common data collection Enhanced surveillance and NIHCR	High
		1.1.2 Sentinel populations	Set up sites based on CDC model	High
		1.1.3 Serially tested populations	Collate data from • People who inject drugs • Blood donors	High
	1.2 Prevalent HCV infections	1.2.1 Routine reports	Common data collection	High
		1.2.2 Populations at higher risk	Collate data from • Needle-syringe program • Methadone clinics • Prison entrants	High
		1.2.3 Populations at lower risk	Collate data from • Blood donors • Pregnant women/newborns • ADF entrants • Primary care and STI clinics	High
2. Surveillance for the long termoutcomes of chronic HCV infection	2.1 Existing data sources	2.1.1 Cancer registries	Collate data from HCV positive registrants	Moderate
		2.1.2 National Liver Transplant Register	Collate data from HCV positive registrants	Moderate
		2.1.3 Hospital discharge data	Collate data from HCV positive admissions	Moderate
	2.2 Clinical networks		Build collaborative networks	Moderate
	2.3 Incident case register		Develop a national register	High
	2.4 Morbidity and mortality in research cohorts of people with advanced liver disease		Build collaborative networks with researchers who study advanced liver disease	Moderate-low
	2.5. HCV related ABS mortality data		Collate data from HCV related deaths	Moderate

Table 2. Risk categories for incident HCV infections

Associated with injecting drug use	Other risk factors
Injecting drug use only in the previous two years	Blood/blood products/tissues in Australia
Injecting drug use more than 2 years ago	Blood/blood products/tissues overseas
Injecting drug use unknown	Haemodialysis
Never injected drugs	Needlestick/biohazardous injury in healthcare worker
	Needlestick/biohazardous injury in non-healthcare worker
	Surgical work
	Major dental surgery
	Tattoos
	Acupuncture
	Ear or body piercing
	Perinatal transmission
	Sexual partner with HCV
	Imprisonment
	Health care worker with no documented exposure
	Household contact with HCV
	Non IDU remote risk (non IDU associated risk identified, but not in one/two years prior to diagnosis)
	Other risk (specify in other risk details)
	Risk unable to be determined
	Unknown (not recorded)

Table 3. Number of incident hepatitis C notifications reported to NNDSS in Australia, 1997-2000*

State or Territory of diagnosis	1997	1998	1999	2000
ACT	3	8	20	20
NSW	19	110	100	139
SA	48	67	80	89
Tas	2	18	18	31
Vic	9	21	70	87
WA	73	126	108	75
Total	**154**	**350**	**396**	**441**

* Analysis by onset date

Table 4. Summary of State and Territory HCV notification systems

State or territory	Source of HCV notifications	Passive or enhanced surveillance for incident cases
ACT	Doctor, laboratory, hospital	Enhanced
NSW	Laboratory, doctor notification possible, but rare	Passive
NT	Doctor, laboratory	Passive
Qld	Doctor, laboratory, hospital	No surveillance of incident cases
SA	Doctor, laboratory	Enhanced
Tas	Doctor, laboratory	Enhanced
Vic	Doctor, laboratory	Passive
WA	Doctor*	Enhanced system operational between 1995-1999

* No public health legislation requiring laboratories to report HCV notifications. Informal agreement with largest pathology laboratory to notify cases operational in recent years.

Assessment of HCV incidence via other surveillance mechanisms

The Commonwealth Department of Health and Ageing provides funding to NCHECR for HCV surveillance activities. A number of agencies responsible for HCV testing provide regular tabulations of testing results to the NCHECR. Methods and results are in turn made publicly available through the NCHECR Annual surveillance report.[1]

Incidence in serially tested populations

The surveillance strategy recognised that there are several population groups in Australia that undergo repeat or regular testing for hepatitis C infection and could be used to further monitor HCV transmission in Australia, particularly among people at higher risk. Possible sites for monitoring of this kind include primary care facilities that provide services to people who inject drugs, prison medical services, and blood transfusion services. So far, systematic information on repeat testing has been available only from the Kirketon Road Centre, a primary care clinical service in central Sydney (Table 5). The hepatitis C incidence rate among injecting drug users attending the Kirketon Road Centre between 1996 and 2000 varied between 12 and 21 per 100 person years, with higher rates among the younger age group (less than 20 years).[1] Monitoring of hepatitis C incidence among people at higher risk will assist in the development and evaluation of prevention strategies and identification of factors within these groups that are associated with an increased risk of infection.

Incidence in other populations

Detailed scrutiny of incident cases detected through blood donor screening or other testing in people at lower risk could lead to insight into the sources of HCV transmission through modes other than injecting drug use in Australia. Although the number of such cases is likely to be very small, they may have significant implications for public health practice. In particular, any cases that may be healthcare associated will require a very thorough investigation of possible breaches in infection control that may have occurred.

Table 5. Hepatitis C incidence among clients of Kirketon Road Centre, Sydney

Age	1996		1997		1998		1999		2000	
Under 20	5	(31)[1]	6	(42)	8	(74)	4	(67)	0	(0)
20-29	8	(11)	11	(19)	10	(21)	6	(20)	4	(27)
Over 30	2	(6)	3	(7)	2	(5)	2	(6)	2	(11)
Total	**15**	**(12)**	**20**	**(18)**	**20**	**(21)**	**12**	**(17)**	**6**	**(17)**

1. Numbers in brackets represent incidence per 100 person years

Monitoring of hepatitis C prevalence

Prevalence is a less effective indicator of HCV transmission patterns than incidence, but it has considerable value as an indicator of the extent of infection in the population, the current burden to the health care system and the levels of risk in different populations.

Prevalence data are available from a number of specific lower risk populations that are routinely tested for hepatitis C. Mandatory screening takes place for all blood donors through the Australian Red Cross Blood Service (Table 6) and Australian Defence Force (ADF) entrants (Table 7). A survey conducted by the NCHECR in 2001 found that many antenatal clinics in Australia routinely offer hepatitis C testing to pregnant women,[2] but it is difficult to derive prevalence information from these clinics in a comprehensive way. Development of a national network of antenatal clinics for hepatitis C (and hepatitis B) surveillance will commence in 2002.

Sexual health clinic attenders represent another population that is routinely offered hepatitis C testing, often as a result of self reported risk behaviours such as injecting drug use. A national network of sexual health clinics currently provide information on HIV testing,[1] and could provide additional data on the extent and outcomes of hepatitis C testing. Development of a national network of sexual health clinics for hepatitis C is a goal for 2002.

Monitoring of hepatitis C prevalence among people who inject drugs has been undertaken through surveys of attenders at needle and syringe programs that have been undertaken annually at a number of sites in Australia over a one week period since 1995.[3,4] The survey includes a questionnaire to ascertain demographic and behavioural information, and collects finger prick blood samples for analysis of anti-HCV antibody (Table 8). Monitoring of hepatitis C prevalence in survey participants who have recently commenced injecting (e.g. less than 3 years duration) provides a measure of recent HCV transmission levels among injecting drug users in Australia (Table 9).

Table 6. Hepatitis C prevalence among blood donors,* by State or Territory, 2000

State or Territory	Number screened for HCV antibody	Number positive for HCV antibody	Prevalence per 100 000 donations
ACT and NSW	307,690	40	13
NT	8,715	6	69
Qld	195,940	41	21
SA	87,828	7	8
Tas	-	-	-
Vic	258,014	39	15
WA	99,718	19	19
Total	**955,984**	**152**	**16**

* First time or repeat donors

Table 7. Hepatitis C prevalence among Australian Defence Force entrants, 1997 to 2000

	Jun to Dec 1997	Jan to Dec 1998	Jan to Dec 1999	Apr[1] to Mar 2001	Total
Number of entrants tested	1,676	3,352	4,379	4,384	13,791
Number positive for HCV antibody	1	2	9	4	16
HCV prevalence per 100 000 entrants	60	60	205	91	116

1 Data not available for first quarter of 2000

Table 8. Hepatitis C prevalence data from the 2000 Needle and Syringe Survey, according to sex and State or Territory of participating needle and syringe program

State or Territory	Percentage of anti-HCV antibody positive (number tested)		
	Males	Females	Total
ACT	54 (120)	64 (42)	57 (162)
NSW	65 (535)	69 (325)	66 (865)
NT	46 (70)	32 (19)	42 (90)
Qld	37 (464)	44 (249)	39 (719)
SA	48 (200)	46 (92)	47 (294)
Tas	53 (17)	13 (8)	40 (25)
Vic	64 (177)	59 (115)	62 (293)
WA	46 (56)	26 (19)	41 (75)
Total	**52 (1,639)**	**55 (869)**	**53 (2,523)**

Table 9. Hepatitis C prevalence data in injecting drug users reporting less than three years injecting from the Needle and Syringe Survey, 1995-2000

	Percentage of anti-HCV antibody positive (number tested)		
	Males	Females	Total
1995	18 (77)	28 (53)	22 (131)
1996	11 (162)	16 (74)	13 (238)
1997	12 (193)	16 (126)	13 (320)
1998	15 (273)	20 (182)	17 (457)
1999	16 (238)	28 (155)	20 (393)
2000	25 (207)	28 (127)	26 (334)

Surveillance of therapy uptake in people with chronic hepatitis C

Antiviral therapy for chronic hepatitis C has improved markedly in recent years, with combination interferon and ribavirin therapy producing a sustained response (indeed, a probable cure) in approximately 40 per cent of treated patients. Currently people with chronic hepatitis C who have progressed to moderate-severe hepatic fibrosis or cirrhosis are eligible for government funded combination interferon and ribavirin therapy through the Highly Specialised Drugs program. From 2002, information will be collated on the number of people in Australia receiving government funded antiviral therapy for chronic hepatitis C. If the current treatment criteria are maintained, these data may provide some information on trends in people with chronic hepatitis C and progressive liver disease.

Surveillance of the long-term outcomes of chronic hepatitis C

Progress towards the recommended activities in relation to the long term outcomes of hepatitis C include an analysis of liver transplant register data and cancer data. Morbidity and mortality data remain as other possible data sources, which could be used to further examine the long term outcomes of HCV infection. While all of these data sources may have biases, taken together, they do serve to provide some understanding of the long term burden of HCV.

Although the majority of people who acquire HCV infection develop chronic hepatitis C, a minority will progress to advanced complications, including liver failure and hepatocellular carcinoma. Estimates and projections of the hepatitis C epidemic in Australia indicate that the incidence of these disease complications is likely to double over the next decade.[5] In order to monitor long-term outcomes of chronic hepatitis C, data are being collected from the Australian and New Zealand Liver Transplant Registry on the incidence of liver transplantation in Australia and its underlying causes, including hepatitis B and hepatitis C. In 2002, data will also be collected on the number of people with liver failure who are awaiting (as opposed to undergoing) liver transplantation.

Analyses of trends in HCC mortality in Australia have recently been performed, with evidence of increasing mortality, in particular among overseas-born men.[6] Although these trends almost certainly represent increased incidence of long-term complications of chronic viral hepatitis (hepatitis B and C), no information on causation was available from the Australian Institute of Health and Welfare data source used for the analyses. In order to assess the incidence of HCC among people with hepatitis C infection, a proposal is under development to cross-match de-identified hepatitis C notifications with national death and cancer registries. Matching of this kind has previously been undertaken between the HIV/AIDS and cancer registration systems nationally.

In people with chronic hepatitis C who obtain a sustained response to antiviral therapy the risk of advanced liver disease complications is markedly reduced. However, for people with chronic hepatitis C and progressive disease, risk of advanced liver disease complications will be maintained in three distinct population groups: those with undiagnosed hepatitis C; those unable or not willing to access therapy; and those who fail antiviral therapy. A hepatitis C observational database with input from a collaborative network of hospital and primary care sites will be established in 2002. One of the objectives of the observational database will be to monitor progression to advanced liver disease complications among people who fail antiviral therapy.

Discussion

Despite clear commitment towards improving hepatitis C surveillance in Australia, the capacity and competing priorities of State and Territory health departments has inevitably led to lower levels of implementation than had been initially envisaged. Implementation of new policies and procedures to coordinate national hepatitis C surveillance in Australia is dependent on reaching a high level of agreement between the jurisdictions and recognition of the differing capacities, responsibilities and priorities of the States, Territories and the Commonwealth. Progress has highlighted the difficulties in introducing new systems into an already complex situation. The challenge for the Hepatitis C Surveillance Strategy is to recommend improvements to national HCV surveillance that are both feasible and sustainable, and to support the implementation of these recommendations. Consultation and continued communication with all stakeholders is essential for this process.

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