Hepatitis C seroconversion: Using qualitative research to enhance surveillance, Phases 1 and 2 final report to NSW Health, December 2009

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National Centre in HIV Epidemiology and Clinical Research
and
National Centre in HIV Social Research

20 years
NCHSR

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Acronyms

AGDOHA	Australian Government Department of Health and Ageing
AHS	Area Health Service
AIVL	Australian Injecting & Drug Users League
ALT	Alanine transaminase
GP	General Practitioner
GSAHS	Greater Southern Area Health Service
GWAHS	Greater Western Area Health Service
HCCNSW	Hepatitis C Council of New South Wales
HCV	Hepatitis C virus
HCV ab	Hepatitis C antibody
HCV ab+ve	Hepatitis C antibody positive
HIV	Human immunodeficiency virus
HNEAHS	Hunter New England Area Health Service
HREC	Human Research Ethics Committee
INTERPOL	International Criminal Police Organisation
JH	Justice Health
LFT	Liver function test
MRN	Medical record number
NCAHS	North Coast Area Health Service
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NCHSR	National Centre in HIV Social Research
NDD	Notifiable Diseases Database
NNDSS	National Notifiable Diseases Surveillance System
NSCCAHS	North Sydney Central Coast Area Health Service
NSP	Needle and Syringe Program
NSW	New South Wales
NUAA	NSW Users & AIDS Association
OST	Opiate substitution treatment
PCR	Polymerase chain reaction
PHU	Public health units
PWID	People who inject drugs
RNA	Ribonucleic acid
SESIAHS	South Eastern Sydney and Illawarra Area Health Service
SSWAHS	Sydney South West Area Health Service
SWAHS	Sydney West Area Health Service
UNSW	The University of New South Wales
WHO	World Health Organisation

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Executive summary

In NSW, hepatitis C has been the subject of specific surveillance and prevention programs for many years. Despite this experience and significant investment, there remain challenges both in understanding the epidemiology of this virus and in implementing effective prevention programs. This study aimed to enhance the public health surveillance program and contribute to the evidence base for hepatitis C prevention in NSW.

Phase One

The aim of Phase One was to develop and trial a methodology for an ongoing program of enhanced surveillance of hepatitis C virus (HCV) in NSW.

Understanding the patterns of newly acquired infection is fundamental to understanding the progression of epidemics, particularly in assessing the impact of prevention interventions and initiatives to promote testing and treatment uptake. Accurate identification of newly acquired cases is a necessary first step towards improved understanding. However, identifying newly acquired HCV requires a documented recent negative HCV antibody test or clinical evidence of a seroconversion illness, making newly acquired cases difficult to identify.

Just over 4,000 cases of newly diagnosed HCV have been reported in NSW each year since 2004. Of these, 1.6% or less are identified as newly acquired cases using current surveillance methodologies. This is significantly less than the proportion of cases identified as newly acquired nationally.

A particular issue with the HCV surveillance system in NSW is that past HCV antibody negative test results held by laboratories for patients diagnosed with HCV are not usually passed to Public Health Units. It was hypothesized that systematic reporting of these past test results could potentially increase the number of newly acquired HCV cases identified.

To test the effectiveness of accessing past laboratory data, HCV test result data was obtained from two large laboratories in NSW. These data were analysed to identify cases which could be categorised as newly diagnosed and newly acquired in 2007, according to current NSW Health definitions.

Taken together the two laboratories selected for the trial accounted for approximately half of all newly diagnosed HCV notifications in NSW in 2007. Out of the 2,207 newly diagnosed cases found in the laboratory data, we identified a total of 21 newly acquired cases of HCV infection (1.0%).

In matching these 21 cases with the 65 newly acquired HCV cases identified by NSW Health for 2007, 18 cases had not previously identified by NSW Health as newly acquired, bringing the total number of newly acquired HCV cases for 2007 to 83. This increased the proportion of newly acquired to newly diagnosed HCV cases for 2007 from 65/4,192 (1.6%) to 83/4200 (2.0%), whilst increasing the yield by 28%. In addition, the number of newly acquired cases identified in laboratory data for some jurisdictions exceeded that reported by NSW Health.

The substantial increase in the number of newly acquired HCV cases identified by utilizing laboratory data indicates that, if used in addition to current reporting mechanisms, accessing laboratory data has the potential to increase both the proportion and yield of newly acquired cases in NSW.

Phase Two

The aim of Phase Two was to increase understanding of the practices, settings, networks and structures contributing to HCV infection.

This project represents the first published qualitative study of the experience of seroconversion to hepatitis C among people who inject drugs (PWID) in Australia. Understanding the factors which lead to a transmission event has the potential to inform prevention activities by, for example, changing the nature and content

of information provided to PWID, and/or changing the policies and programs, including structural interventions, designed to prevent hepatitis C infection.

In-depth qualitative interviews were conducted with 24 people who self-reported hepatitis C seroconversion within the two years prior to recruitment. Participants were recruited via a range of mechanisms from a variety of locations throughout Sydney (*n*=22) and regional NSW (*n*=2).

While participants typically could not identify specific events which led to seroconversion, all identified a number of possible practices and settings in which infection may have occurred including constraints on availability of sterile injecting equipment and vulnerability to unsafe injecting practices prompted by opiate withdrawal. Reuse and sharing of equipment was influenced by the physical and social environment in which injecting drug use took place, the people that were involved, the ability of individuals to be vigilant and challenge the practices of others and a lack of awareness of HCV risk posed by using injecting equipment other than needles and syringes.

Further, the diagnostic experiences of participants were sub-optimal according to national testing guidelines. These data indicate a need for changes to existing hepatitis C prevention programs and policies designed to support improved diagnosis experiences.

Recommendations

Phase One

Expanding the trial of methodology of enhanced surveillance of hepatitis C virus in NSW

We recommend continuing to assess the feasibility of using laboratory HCV testing data to increase the number of newly acquired HCV cases identified in NSW, but to enhance its scope in several ways. Including more years of data (prior to and after 2007) and/or obtaining test data from more laboratories would allow for evaluation against the larger pool of HCV notifications reported by NSW Health.

To enable identification of newly acquired cases with HCV antibody negative/PCR positive test results, all past HCV antibody negative tests for PCR positive cases, not only those conducted in the same year as the RNA test, should be obtained in future feasibility studies.

New surveillance system for newly acquired HCV in NSW

We recommend designing a new surveillance system for HCV in NSW which utilises a consistent methodology and combines current follow up of suspected or known newly acquired HCV cases (with doctors and patients) with follow up of unspecified HCV notifications with the notifying laboratory, to obtain data on past HCV test records.

Cross-matching between laboratories

As patients are often tested through different laboratories on different occasions (either by moving residence or by seeing a different doctor), linking data between laboratories as well as within single laboratories is an important goal to work towards. Cross-matching test data between two or three large laboratories may significantly increase identification of newly-acquired HCV. The feasibility of cross-matching between laboratories could be tested by obtaining identifiable data or codebooks from more than one laboratory and examining if the format of identifying information (date of birth, gender, and name or name codes) would allow linkage. The ability to link test results from different laboratories should be made a priority for the Healthelink electronic health record program currently being piloted by NSW Health.

Phase Two

Access to adequate volumes and type of injecting equipment

These findings highlight the need for increased access to greater volume and specific types of sterile injecting equipment. We recommend that NSW Health:

- Continue to enhance distribution of greater volumes of injecting equipment via NSP and pharmacy services
- Continue to explore ways to support peer distribution of injecting equipment
- Develop, in partnership with NUAA, education messages to inform clients that restrictions on amounts of equipment have been removed
- Consider providing sterile water in a range of volumes to facilitate client choice and safer practice (i.e. both 1ml and 5ml ampoules to avoid re-use/sharing of 5ml ampoules)
- Consider provision of winged infusion sets through NSPs

Adequate provision of pharmacotherapy in custodial settings

Our results highlight the vulnerability to infection produced by states of opiate withdrawal, including forced withdrawal from pharmacotherapy treatment as a result of detention in settings where continued access to prescribed pharmacotherapy is not provided.

We recommend that NSW Health, via MACH, instigate high level discussions with the Department of Corrective Services and the NSW Police Force regarding the right to access to pharmacotherapy as an essential medication for people in custodial settings.

Access of people in custodial settings to prevention programs of a standard equivalent to that available in the community

These findings highlight the seroconversion risk of injecting in prison. The C-Change report of the Anti-Discrimination Board enquiry into hepatitis C related discrimination noted that pressing concerns for people in prison was access to health care, health promotion and prevention programs at a standard equivalent to community programs.

We recommend that NSW Health consider means to support access to sterile injecting equipment for people in prison.

Messages and strategies to address transmission risk between couples who inject

These findings highlight that decisions of sexual partners to share injecting equipment may have lead to hepatitis C seroconversion. However, the evidence-base for health promotion for injecting couples is limited.

We recommend that NSW Health promote research and consultation on this topic to inform health promotion messages and strategies specifically targeted to men and women.

Development of guidelines for people who inject regarding appropriate testing frequency

The findings highlight that participants had difficulty identifying particular events which could have resulted in exposure and possible seroconversion. Rather, participants acknowledged a range of potential risk practices for hepatitis C infection.

We recommend that NSW Health, in partnership with NUAA, develop guidelines for seeking hepatitis C testing such as a self-assessment tool based on a range of risk practices.

Increasing awareness of National Hepatitis C Testing Policy key principles to improve diagnosis quality

This study demonstrated that few diagnosis experiences were adequate according to the principles of the National Hepatitis C Testing Strategy particularly with regard to the confidential and voluntary nature of testing with informed consent and pre-test and post-test discussion.

We recommend that NSW Health issue new policy directives to emphasise the testing policy recommendations including information about the Medicare rebate eligibility for hepatitis C RNA testing, and that this directive be circulated to all Area Health Services, including Justice Health.

Support for general practitioners providing hepatitis C diagnoses

It is acknowledged that only a small proportion of general practitioners will develop specialist skills in hepatitis C and most general practitioners will only deliver a small number of hepatitis C diagnoses in their careers.

We recommend that NSW Health consider opportunities to extend the ASHM mentoring program for GPs who have not previously given a HIV diagnosis, to support appropriate hepatitis C diagnosis experiences.

Further, we recommend that NSW Health consider liaison with diagnostic laboratory services to provide diagnosing doctors with a resource sheet delivered with pathology reports (via fax or electronically) which includes key information to be provided to the patient, including referral to community-based organisations.

Areas for future research

Findings from this qualitative data characterise the HCV diagnosis experience as sub-optimal. These findings support and extend earlier quantitative and qualitative research from NSW which established low levels of information provision and referral provided at diagnosis (and lower for people who inject drugs) (Hopwood et al., 2004). The impact of diagnosis experience on future care and treatment is unknown.

We recommend further research in this area to explore the impact of diagnosis experience on future engagement with treatment and care and other hepatitis C-related health outcomes.

Further, there is an emerging body of work examining the influence of social networks on injecting practice. Our findings extend this work to suggest ways in which people who inject are constrained in their decisions about and ability to use sterile injecting equipment. We recommend further research in this area to extend understandings of practice and explore implications for the measurement of injecting risk.

1 Phase One

1.1 Introduction

Hepatitis C (HCV) is a blood-borne infection which affects approximately three percent of the world's population and is a major cause of morbidity and mortality among people who inject drugs (PWID; Shepard et al. 2005; Sy and Jamal 2006). An estimated 271,000 people are living with HCV in Australia, of whom approximately 82% were exposed through injecting drug use (MACASHH 2006). Notifications data indicate that a total of 11,303 diagnoses of HCV infection were made in Australia in 2008 (NCHECR 2009)

Improved identification of newly acquired cases of HCV infection (those acquired in the last two years) and associated demographic characteristics and risk factors is important to better inform targeting of HCV prevention and treatment programs (Guy et al 2008; Robotin et al 2004; Spencer et al 2002). There is also evidence that treatment of acute HCV infection results in higher rates of clearance than treatment of longer-standing infections (Zekry et al 2005). However, identifying newly acquired HCV requires a documented recent negative HCV antibody test (in the past two years) or clinical evidence of a seroconversion illness (present only in a minority of cases), making newly acquired cases difficult to identify. For example, approximately 4,000 cases of newly diagnosed HCV have been reported in NSW each year since 2004. Of these, 1.6% or less (24/3,567 or 0.7% in 2008) are identified as newly acquired cases using current surveillance methodologies. This is significantly less than the proportion of cases identified as newly acquired nationally (381/11,303 or 3.4%; NCHECR 2009).

1.2 Phase One aim

The aim for Phase One of this study was to develop and trial a methodology for an ongoing program of enhanced surveillance of HCV in NSW.

1.3 Consultation and mapping

Consultation was carried out between January 2008 and October 2009 with a range of organisations and individuals including Communicable Diseases Branch and AIDS Infectious Diseases Branch, NSW Health; the Macfarlane Burnet Institute for Medical Research and Public Health (Burnet Institute); NCHECR surveillance staff; private and public laboratories; infectious diseases specialists; general practitioners; the Hepatitis C Council of NSW (HCCNSW) and the NSW Users and AIDS Association (NUAA).

Consultation was carried out in order to:

- confirm the definition of newly acquired HCV for the purposes of this study
- map the existing HCV surveillance system in NSW
- determine the methodology for the first phase of the study
- explore possible recruitment mechanisms for the second phase of the study.

1.4 Definition of newly acquired HCV

The National Notifiable Diseases Surveillance System (NNDSS) definition for newly acquired HCV has been adopted for this study. This definition is used by NSW Health and all Australian states and territories (NNDSS 2005). In summary, the requirements for newly acquired HCV are:

- Laboratory definitive evidence, or
- Laboratory suggestive evidence and clinical evidence.

Laboratory definitive evidence

- Detection of anti-HCV antibody from a person who has had a negative anti-HCV antibody test recorded within the past 24 months, or
- Detection of HCV by nucleic acid testing from a person who has had a

negative anti-HCV antibody test result within the past 24 months, or

- Detection of anti-HCV antibodies in a child aged 18 to 24 months, or
- Detection of HCV by nucleic acid testing, in a child aged 1 to 24 months.
- Laboratory suggestive evidence
- Detection of anti-HCV antibody or HCV by nucleic acid testing.

Clinical evidence

Clinical hepatitis within the past 24 months (where other causes of acute hepatitis have been excluded) defined as:

- Jaundice, or
- Bilirubin in urine, or
- Alanine transaminase (ALT) seven times upper normal limit.

1.5 NSW notification process

An understanding of the NSW HCV notification system was gained by reference to the Communicable Diseases Branch at NSW Health, NSW enhanced HCV notification forms and protocols, NCHECR surveillance staff, Communicable Disease Reports, and outcomes from an evaluation of enhanced surveillance conducted in 2002 (NSW Department of Health 2002), and is summarised in Figure 1.

As a notifiable disease, all cases of HCV (newly acquired or unspecified) are required to be reported to NSW Health via Area Health Service (AHS) Public Health Units (PHU). All laboratories in NSW report HCV antibody positive test results to the local PHU in the AHS the laboratory is located in (most laboratories report all positive results regardless of whether they have previously reported a positive result for that patient). Acute symptomatic HCV cases diagnosed by physicians are also reported to local

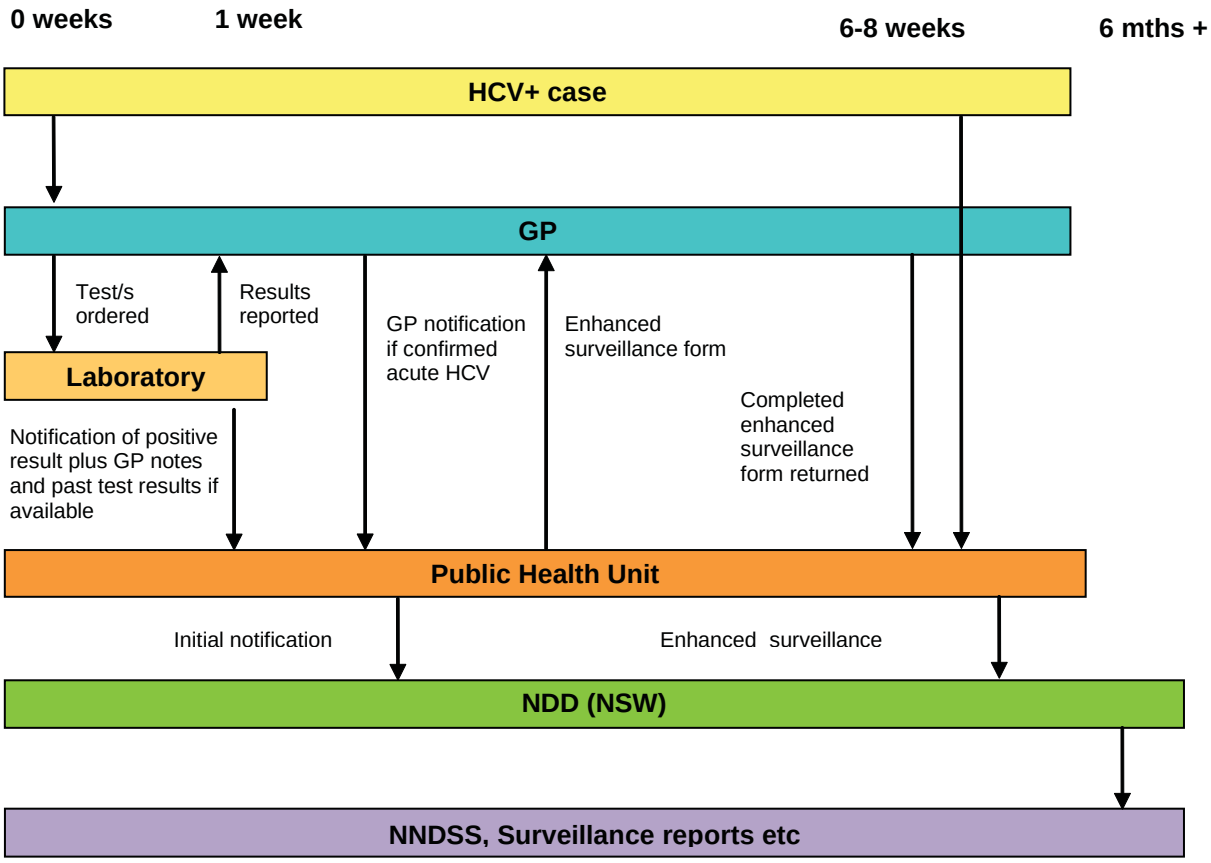

Figure 1: NSW HCV Notification Process

PHUs. PHU staff examine the notifications to remove cases not already included in the database at the PHU and remaining duplicates are removed by staff at the Communicable Diseases Branch, NSW Health in a twice yearly de-duplication process.

For each notification not previously reported to that PHU, staff enter the case's demographic and diagnosis details onto the NSW Notifiable Diseases Database (NDD). For cases identified as newly acquired, according to the definition in Section 2, enhanced HCV surveillance data consisting of the following fields is requested of notifying doctors, with permission sought to contact patients directly for risk factor information, and entered into the NDD when obtained. These data include:

- case details—sex, age, postcode, indigenous status, country of birth, language
- disease details—symptomatic in past 24 months (y/n), onset date, jaundice present (y/n), jaundice onset date, previous HCV test (y/n), date last negative, date first positive, notes, definition (suspect, presumptive, confirmed)
- laboratory—laboratory confirmed (y/n), specimen type, specimen date, genotype, ID method (serology/PCR), HCV antibody positive (y/n)
- notification—first notifier, notifier type (laboratory, doctor, hospital, other), notified date, received date, treating doctor
- outcome—hospitalised (y/n), admitted date, discharge date, hospital/s, medical record number, hospital doctor, deceased (y/n), death date, cause of death HCV (y/n/unknown)
- risk factors—y/n/u:
  A cluster (more than one case among patients of the same dental or health care provider, or tattooist or other skin penetration service provider), another notified case, possible case not notified, injecting drug use, born to HCV positive mother, needle stick at work, needle stick not at work, another's blood in eye/mouth, transfusion, dialysis, endoscopy, surgical procedures, dental procedures, tattooing, body piercing, acupuncture, other skin penetration, high risk sexual contact, residence in long term care, residence in prison, other risks, details of other risks, most likely source.
- Reason for test (symptomatic, patient request, source point in occupational exposure, exposed in occupation, prison entry, defence force, antenatal screen, drug and alcohol screen, blood donor screen, peri-operative screen, other)
- Contact management—case advised about reducing spread to others (y/n)
- Other notes about the case from the PHU or doctor.

Laboratory notifications generally reach PHUs within one to two weeks of the date of testing and the timeline for collection of enhanced surveillance data by PHU staff from patients and doctors is approximately six to eight weeks. Around 20-30% of all notifications on the NDD are duplicates due to cases being previously notified by another PHU (for example, where patients who have relocated are retested). These cases are removed from the NDD twice yearly by staff in the Communicable Diseases Branch, NSW Health and notifications can only be considered definitive after this point.

Enhanced surveillance for all HCV notifications in NSW was trialled from mid-2000, but was discontinued due to data quality issues and staffing constraints (NSW Department of Health 2002). As part of the trial, all notifications were followed up by PHU staff contacting the testing physicians to determine if they were newly acquired, then enhanced data was obtained from patients for the newly acquired cases. Follow-up of all notifications continued at Sydney South West AHS (SSWAHS) Camperdown PHU until 2008 and still continues at Greater West AHS (GWAHS) Broken Hill PHU but the majority of PHUs no longer follow up on new HCV notifications unless they are already confirmed by the laboratory or notifying physician as newly acquired. Unsurprisingly, the highest number of identified newly acquired HCV cases in 2007 was from one of the former jurisdictions. SSWAHS (Camperdown) identified 21 newly acquired cases out of 399 notified cases (5.3%; Communicable Diseases Branch, NSW Department of Health 2008) and approximately one-third of all newly acquired cases identified in NSW (21/65; 32%). However in 2008 SSWAHS discontinued follow-up of HCV cases due to resource constraints and did not report any newly acquired HCV cases for 2008 (Communicable Diseases Branch, NSW Department of Health 2009).

Past negative results are not required to be reported to PHUs by laboratories and usually are not provided as part of routine notifications. Indeed, in NSW privacy legislation precludes the release of any patient information except as needed to fulfil surveillance requirements. There are also more fundamental barriers to improved identification of newly acquired cases, being that there is no specific test for newly acquired HCV and most cases are asymptomatic at infection; challenges that are beyond the scope of this study. An HCV antibody negative test in the past two years is generally required to confirm a case as newly acquired. Even where a patient has been previously tested in this time interval, this information may not be available to testing doctors due to patient mobility. Patient-reported results cannot be used to determine if a case is newly acquired. Past testing history can also only be reported by laboratories if previous tests were performed by the same laboratory.

Results from the consultation in relation to the NSW HCV notification process indicate that there is currently no systematic method of identifying newly acquired cases of HCV in NSW. One major and potentially correctable limitation identified relates to the fact that past negative HCV tests recorded by laboratories are not generally actively sourced by PHU staff or required to be reported to NSW Health. This limits the pool of data from which identifications of newly acquired cases can be made. Active follow up of laboratory data may help to increase identification of newly acquired HCV cases in NSW with less burden on PHU staff than current enhanced surveillance processes.

1.6 Utilisation of laboratory-held past HCV testing data: Victoria

A mechanism to increase the number of identified newly acquired HCV cases was trialled in Victoria in the first quarter of 2006 (January to March; Department of Human Services Victoria 2006). For all new HCV notifications, testing laboratories were followed-up by the Communicable Diseases Control Unit, Victorian Department of Human Services, for previous negative HCV antibody and liver function tests. Previously, only notifications with specific notification indicators[1], or if the case was aged between 16 and 19 years, were assessed as potentially newly acquired and followed up to determine if cases were truly newly acquired, and to collect further information on risk factors, demographics and testing history.

The Victorian trial found that numbers of identified newly acquired HCV cases were approximately doubled by utilising laboratory follow up. Fifty-six cases were confirmed to be newly acquired in the three month trial period out of 721 notifications (8%) with 32 of the 56 (57%) of these identified through intensive laboratory follow-up (Department of Human Services Victoria 2006). This is considerably higher than the same periods in 2004 and 2005 where 23/768 (3%) and 30/645 (5%) of notifications were identified as newly acquired respectively. (In the quarter immediately prior to the trial 55/779 (7%) newly acquired HCV cases were identified but this cannot be compared as informal laboratory follow up was already occurring at this time.) Intensive laboratory follow up for all HCV notifications where the person is aged less than 30 years has now been utilised in Victoria since June 2006. Combined with intensive follow up of cases with specific notification indicators, since 2006 approximately 50–200 HCV notifications annually (6–8% of all HCV notifications; Department of Human Services Victoria 2008) have been found to be newly acquired.

More than 20 laboratories in Victoria test for HCV and are routinely contacted for follow up of previous testing results.

1.7 Utilisation of laboratory-held past HCV testing data: NSW trial

Following the consultation process, it was decided to test if using HCV test records held by laboratories would increase the number of newly acquired HCV cases identified in NSW.

There are approximately 70 laboratories (public and private) in NSW which report to NSW Health on all notifiable diseases, with five or less laboratories accounting for approximately half of all notifications (Mark Bartlett, Communicable Diseases Branch, NSW Health, private communication April 2008).

We requested data for all new HCV positive test results processed by two large laboratories in NSW during the calendar year 2007. Providers consisted of a public laboratory which covers requests from specialists and tertiary clinics as well as general practitioners within a single PHU catchment area, and a large private laboratory which receives specimens from all over NSW, primarily from general practitioners. The laboratory data requested were for the same cases reported to NSW Health as part of standard laboratory notification procedures. However, in addition we requested data on previous negative test results for these cases in order to improve the identification of newly acquired cases and to compare cases identified by this methodology with those reported by NSW Health for 2007.

Data from 2007 was chosen to be examined in this study in order for notifications data to be finalised and offer a stable comparison.

1.8 Trial objectives

Primary

The primary objective of this study was to compare the proportion of new HCV positive cases identified by these two laboratories in 2007 which could be categorised as newly acquired using past data held by each, according to the current NSW Health definition, to the proportion of newly acquired HCV cases in relevant jurisdictions as reported by NSW Health.

[1] Diagnosing doctor or laboratory notified a case as acute; the date of disease onset was within the past 24 months; there was evidence of a previous negative test in the past 24 months; or if clinical symptoms noted were consistent with acute hepatitis (jaundice, bilirubin detected in urine or ALT levels seven times upper normal limit)

Secondary

The secondary objective was to compare the characteristics of newly acquired and newly diagnosed HCV cases identified by the two laboratories in 2007, and reported for relevant jurisdictions by NSW Health.

1.9 Methodology

NCHECR researchers (RD and LM) were responsible for designing and conducting the Phase One component of this study.

Records for individual patients were matched only to records from the same laboratory. Records were not attempted to be matched to the same individual between the two laboratories as insufficient identifying data were provided.

1.9.1 Public laboratory

For the public laboratory, identifiable data were required in order to match patient's names, sex and dates of birth. Identifiers were used solely for the purpose of matching records and were deleted after analysis. Ethics approval to access identified data was granted through the Northern Hospital Network, Prince of Wales Hospital HREC in April 2009 (HREC 08/163).

1.9.1.1 Data obtained

The public laboratory provided data on records as listed below. Data were mapped by the laboratory using both medical record numbers (MRN) and a combination of surname, given name, sex and date of birth.

- All HCV antibody testing records from 2007, with ALT on episode where available
- Mapped positive HCV antibody 2007 records to 2005 and 2006 HCV antibody testing records
- Mapped positive HCV antibody 2007 to 2005–2007 ALT testing records
- All HCV nucleic testing (polymerase chain reaction—PCR) testing records from 2007
- For each record, the following information was obtained.
- Episode: a unique code assigned by the laboratory to each test performed
- MRN
- Surname, given name
- Sex
- Date of birth
- Residential address
- Location and site: laboratory codes
- Requesting doctor details
- Date test received by laboratory

For HCV antibody and ALT test records:

- Hep C (1) antibody: Result of the first antibody test
- Hep C (2) antibody: Result of second/confirmatory antibody test where carried out
- ALT: where ALT was measured on the same episode, the result in units/L

For HCV PCR test records:

- Test set: type of test
- Test code: reporting codes
- Result
- Comment.

1.9.1.2 Data processing

In total, 11,300 HCV antibody test records (including 11,197 from 2007) were provided by the public laboratory in addition to 4,111 separate ALT and 1,625 PCR test records.

HCV antibody test data were cleaned to remove records where date of birth was not given (n=136), and records where test results were inconclusive (as per Table 11 in Appendix A) or not provided (n=157). A unique identifier (IDCONCAT) was generated for each antibody record, consisting of a combination of given name, family name, date of birth and sex. IDCONCATs were used to identify all records from the same person (these records may, but not necessarily, also have the same MRN). There were no cases where records which had identical MRNs did not have identical IDCONCATs.

In total, 9,758 individuals were tested for HCV antibodies at the public laboratory in 2007.

Figure 2 (see page 10) displays graphically the matching processes described in the following sections needed to identify newly acquired and newly diagnosed HCV cases in the public laboratory data.

1.9.1.3 Identification of newly diagnosed HCV in 2007

To identify which records represented a new diagnosis of HCV in 2007, records from the cleaned HCV antibody test results for 2005–2007 were combined into one file. The records were sorted in order of IDCONCAT then ascending order of date received. A flag was generated to indicate which records satisfied the following criteria:

- A single positive HCV antibody test result with date received in 2007 (no previous records held by laboratory), i.e. the previous record in the list did not match IDCONCAT, or

- A positive HCV antibody test from 2007 where the previous record matched IDCONCAT and had an HCV antibody negative result. For a patient with multiple positive HCV antibody results from 2007, the record indicating a new diagnosis was taken as the first positive test result in 2007.

In this way, 537 patients were identified as potentially newly diagnosed with HCV by this laboratory in 2007. AHS was assigned to each record, where possible, according to the suburb and/or postcode of residence. Four records from people not resident in NSW were removed, leaving 533 cases. The laboratory location code indicated 100 records originating from Justice Health. A significant number of records (*n*=116) had no address data and could not be assigned to an AHS; a small number of these records may originate from people residing outside of NSW.

Checks were performed to examine if any of these cases had combinations of test results that would invalidate the diagnosis, such as there being an inconclusive test prior to the positive test (with no negative test earlier); none were found.

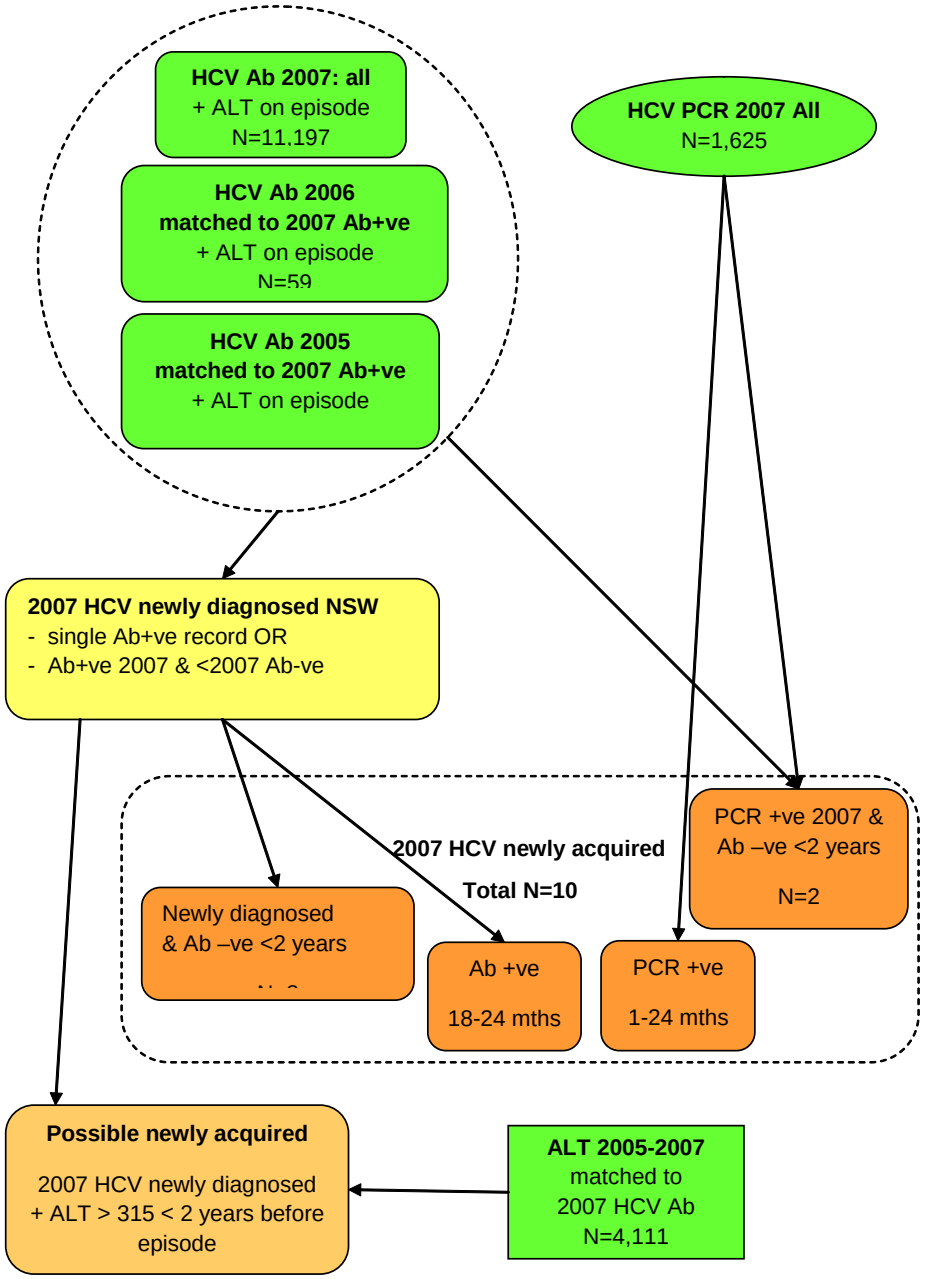

Figure 2: Public laboratory data-matching flow chart

1.9.1.4 Identification of newly acquired HCV in 2007

There were four sets of records to examine in order to identify newly acquired HCV as per the NSW Health definitions in Section 161.4.

1. Detection of HCV antibody from a person with an HCV antibody negative test within the past 24 months:

These results were identified by taking the cleaned HCV antibody records and sorting in order of IDCONCAT followed by ascending order of date received. A flag was generated to indicate which records satisfied the following:

- Newly diagnosed HCV in 2007:
- Previous record in the list matched on IDCONCAT and reported an HCV antibody negative result.

In this way, nine cases were identified as potential newly acquired HCV cases. One record was removed as the preceding negative result dated more than two years previous to the positive test in 2007, leaving eight cases who fit the definition for newly acquired HCV.

2. Detection of HCV by PCR from a person with an HCV antibody negative test result within the past 24 months:

In rare instances, someone may return a PCR positive HCV test (ie, positive to HCV viral RNA) but have recently tested HCV antibody negative. This occurs when testing is carried out very soon after infection, before HCV antibodies have developed (up to approximately six months post-infection).

A total of 1,006 HCV PCR positive records were isolated from the datasheet, as per the test definitions listed in Table 12 in Appendix A. These were compared to HCV antibody negative records from 2005–2007 to identify any cases with HCV antibody negative results from up to 24 months prior to the positive HCV PCR result.

Two cases were found that had not already been identified as newly acquired in the previous section. One case had HCV PCR and antibody tests performed on same date and the other had tested HCV antibody negative six months prior. This brought the total number of newly acquired HCV cases to 10 for the public laboratory.

A limitation to identifying HCV antibody negative/PCR positive newly acquired cases with this dataset was that the only HCV antibody negative cases from 2005 and 2006 provided by the laboratory were from patients who tested HCV antibody positive in 2007. Therefore, HCV antibody negative/PCR positive cases where the HCV antibody negative result dated from 2006 or 2005 could not be identified in this dataset.

3. Detection of HCV antibodies in a child aged 18–24 months:

HCV antibody positive tests from 2007 were searched for cases which, on the test date, would have been aged between 18 and 24 months; none were found.

4. Detection of HCV by PCR in a child aged 1–24 months:

PCR positive tests were searched for cases which, on the test date, would have been aged less than 24 months; none were found.

1.9.1.5 Identification of possible HCV cases: ALT levels more than seven times upper normal limit

One piece of clinical evidence for newly acquired HCV, where other causes of acute hepatitis are excluded, is the presence of ALT levels seven times the upper normal limit. For the public laboratory, the normal adult ALT level was defined as 45 units/L, therefore only cases of newly diagnosed HCV which had ALT levels above 315 units/L on records up to two years earlier or on the same date of HCV diagnosis were included.

The data obtained from the public laboratory are not sufficient to rule out other causes of acute hepatitis such as long-term HCV infection, or hepatitis A or B infection. However, cases for which there is a new HCV antibody positive result coupled with high ALT levels should be flagged for intensive follow up to determine if they are newly acquired.

The number of such cases identified in the public laboratory dataset was 14, in addition to cases already identified as newly acquired on the basis of HCV PCR or antibody results.

1.9.2 Private laboratory

For the private laboratory, de-identified data only were supplied; individual records were identified by a patient ID. A limitation was that no PCR data were available in addition to HCV antibody and ALT results.

1.9.2.1 Data obtained

The private laboratory provided 3,380 records from the following:

- All HCV antibody positive test results from 2007.
- All HCV antibody test results for the same patients spanning 1991 to 2009.

For each record, the following variables were provided:

- Patient ID number;
- Age at test date;
- Sex;
- Postcode of residence;
- Test date;
- HCV antibody result; and
- ALT result (where available).

1.9.2.2 Data processing

Tests performed in 2008 and 2009 and prior to 2005 (*n*=786) were discarded. AHS was assigned to all records according to the postcode of residence. No records had the postcode omitted. A further 124 records from patients resident outside of NSW were discarded, leaving a total of 2,398 records for tests performed between 2005 and 2007.

Figure 3 displays graphically the matching methodology (described in the following sections) undertaken to identify newly acquired and newly diagnosed HCV cases in the private laboratory data.

1.9.2.3 Identification of newly diagnosed HCV in 2007

To identify which patients had a new diagnosis of HCV at the private laboratory in 2007, records were sorted in ascending order by patient ID number, then date of record (least to most recent). A flag was generated to identify records which potentially indicated a new HCV diagnosis using the criteria below.

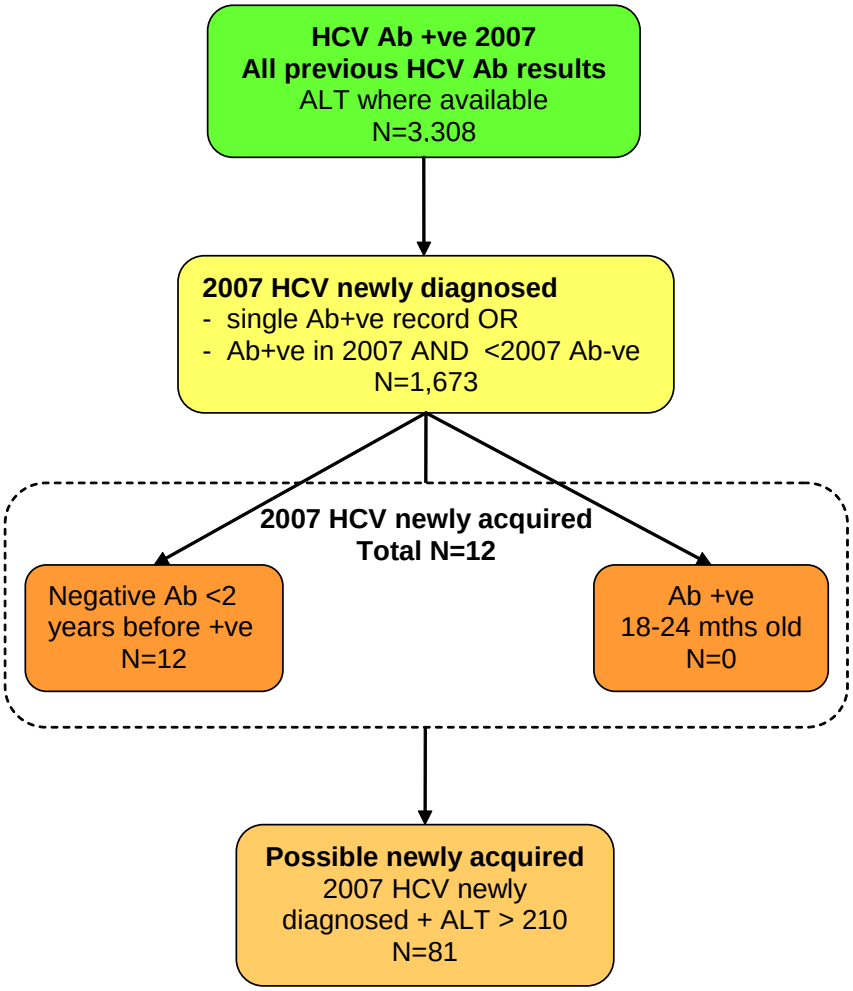

Figure 3: Private laboratory data matching flow chart

- A single HCV antibody positive test result with test date from 2007 (no previous records held by laboratory), i.e. the previous record in the list did not match on patient number, or
- A positive HCV antibody test from 2007 where the previous record matched on patient number and indicated HCV antibody negative result.

There were 1,673 individuals tested through this laboratory who were newly diagnosed with HCV in 2007.

1.9.2.4 Identification of newly acquired HCV in 2007

As PCR testing results were not able to be provided, there were only two sets of records to examine for newly acquired HCV as per the definitions in Section 2.

1. Detection of hepatitis C antibody from a person with an HCV antibody negative test within the past 24 months:

Cases of newly acquired HCV were identified by taking the cleaned HCV antibody records and sorting in order of patient ID followed by ascending order of test date. A flag was generated to indicate which records satisfied the following criteria:

- Newly diagnosed in 2007
- Previous record in the list matched on IDCONCAT and reported a negative HCV antibody result.

In this way, 12 cases of newly acquired HCV were identified.

2. Detection of HCV antibodies in a child aged 18 to 24 months:

There were no records of HCV antibody tests performed on children aged less than 24 months.

1.9.2.5 Identification of possible HCV cases: ALT levels more than seven times upper normal limit

As for the public laboratory, suggestive cases of newly acquired HCV were identified in the private laboratory data by searching for newly diagnosed HCV cases which reported ALT levels more than seven times the upper normal limit on the same or a record dated up to 2 years earlier. The upper normal limit for ALT for the private laboratory was 30 units/L; therefore records with ALT over 210 units/L were included.

The number of cases identified with newly diagnosed HCV and ALT in excess of 210 units/L, which had not already been identified as newly acquired, was 81.

1.9.3 Summary

Twenty-two newly acquired HCV cases were identified from the laboratory datasets. Comparison of individual age, gender and test dates of the cases from each laboratory found no matches, therefore cases identified by each laboratory were deemed unique.

1.10 Matching to newly acquired HCV cases reported by NSW Health

The newly acquired HCV cases identified from the laboratory datasets were compared to newly acquired HCV cases identified by NSW Health for 2007 from the NDD (Kate Ward, Communicable Diseases Branch, NSW Health, private communication December 2009), in order to confirm if the cases identified in this study had been identified by the existing NSW surveillance system. Cases were matched on the following details.

Public laboratory:

- Name code (first two letters first name, first two letters last name)
- Postcode
- Gender
- Date of birth
- Date of HCV diagnosis

Private laboratory:

- Postcode
- Gender
- Age
- Date of HCV diagnosis

One case was matched on age, sex and date of diagnosis but did not match on postcode. The two postcodes were within the same AHS and referred to localities approximately 50km from each other, therefore this case was taken as a definite match. A further case was found to have been first notified to NSW Health in 1999. This case was removed from the laboratory results and the number of newly acquired HCV cases identified in the laboratory data revised to 21.

There were four laboratory identified cases which could not be matched with any NSW Health identified cases despite relaxing criteria for matching (dropping postcode and searching for different diagnosis dates).

1.10.1 Results from matching laboratory and NSW Health cases

Out of the 21 laboratory cases, 18 could not be matched to newly acquired HCV cases reported by NSW Health. Most of these cases (14/18) had been identified by NSW Health as new diagnoses but there were four cases which could not be matched. There was no pattern in the age, sex, diagnosing laboratory or postcode of residence for the 18 unmatched cases.

Table 1 summarises the number of newly acquired HCV cases identified from the laboratory data matched to NSW Health-identified newly acquired cases, and the number unmatched to any NSW Health cases. Matching the 21 laboratory cases with the 65 cases identified by NSW Health, most (18/21; 86%) cases identified by this study had not been identified by NSW Health as newly acquired and 4/21 (19%) had not been identified at all.

Taking into account the 18 newly acquired HCV cases not identified by NSW Health, examining data from two laboratories increased the proportion of newly acquired HCV cases for NSW in 2007 from 65/4,192 (1.6%) to 83/4,200 (2.0%).

Table 1: Number of cases identified with newly acquired HCV in 2007 from laboratory data matched to NSW Health newly acquired cases, and unmatched to any NSW Health cases

	Public (N)	Private (N)	Combined (N)
Laboratory-identified newly acquired HCV cases	9	12	21
Matched to NSW Health newly acquired cases?			
Yes	1	2	3 (14%)
No	8	10	18 (86%)
Unmatched to any NSW Health cases	*2*	*2*	*4 (19%)*

1.10.2 Implications for NDD

The NDD is expected to be complete for new HCV diagnoses. For 4/21 (19%) of newly acquired HCV cases identified from the laboratory datasets to be unmatched is concerning. It is possible these cases were diagnosed at another laboratory where name code and/or date of birth were recorded differently or erroneously, or details were mis-entered onto the NDD.

In addition, three cases from the public laboratory were found to have different diagnosis dates than their matches on the NDD, in one case the NDD being more than three months earlier. Although it is possible these cases were diagnosed with HCV through another laboratory prior to first testing positive at the public laboratory, one of the cases had a diagnosis date on the NDD one month later that from the public laboratory. There was no discernable pattern in the date differences and no explanation found. However, the date differences did not affect the year of diagnosis of the three cases, or their categorisation as newly acquired according to the laboratory data examined here.

1.11 Characteristics of laboratory identified HCV cases

The number of newly diagnosed, newly acquired and possible newly acquired HCV cases identified in the public and private laboratory datasets are summarised in Table 2. A total of 21 newly acquired cases of HCV infection were identified from 2,207 newly diagnosed cases (1.0%). These cases came from two laboratories which together accounted for approximately half (2,207/4,192; 53%) of the newly diagnosed HCV notifications in NSW in 2007.

The private laboratory had approximately twice the rate of possibly newly acquired cases than the public laboratory, which can be partially explained by the difference in the upper normal limits used by each (there is no standard upper normal limit for ALT).

Table 2 Number of cases identified with newly diagnosed, newly acquired and possible newly acquired HCV in 2007 from public and private laboratory data

HCV test status 2007	Public (N)	Private (N)
Newly diagnosed	534	1,673
Newly acquired		
Negative HCV antibody test in the 24 months before a HCV antibody positive test	7	12
PCR positive with HCV antibody test result within past 24 months	2	n/a
Detection of HCV antibodies in a child aged 18 to 24 months,	0	0
Detection of hepatitis C virus by nucleic acid testing, in a child aged 0 to 24 months	0	n/a
Total newly acquired (% of newly diagnosed)	9 (1.7)	12 (0.7)
Possible newly acquired		
ALT > 7x normal level (>315 units/L for public, >210 units/L for private)	13 (2.4%)	81 (4.8%)

The public laboratory diagnosed instances of newly acquired HCV over two times the rate of the private laboratory. This is probably due to the public laboratory receiving a large proportion of its samples from public health services and specialists servicing populations at higher risk of HCV compared with NSW overall.

1.11.1 Age and gender of newly acquired HCV cases

For both the laboratories and NSW Health, the median age of female patients with newly acquired HCV in 2007 (29 and 28 years respectively) was younger than for male patients (39 and 31 years respectively).

The overall median age for laboratory-identified cases (34 years) was older than for NSW Health-identified cases (28 years), and no cases aged less than 20 years were found. This may be due to older people who are potentially exposed to HCV being less mobile than young people and more likely to have repeat pathology tests performed through the same doctor and laboratory.

Table 3 summarises the number of males and females in each five year age group for both laboratories combined and NSW Health for 2007.

For both the laboratories and NSW Health, the median age of female patients with newly acquired HCV in 2007 (29 and 28 years respectively) was younger than for male patients (39 and 31 years respectively).

The overall median age for laboratory-identified cases (34 years) was older than for NSW Health-identified cases (28 years), and no cases aged less than 20 years were found. This may be due to older people who are potentially exposed to HCV being less mobile than young people and more likely to have repeat pathology tests performed through the same doctor and laboratory.

1.11.2 Newly acquired HCV cases by jurisdiction

Table 4 (see page 16) summarises results by AHS for the laboratories separately, combined, and in comparison with NSW Health . Italicised entries in the combined and NSW Health columns highlight the three AHSs where more newly acquired cases were identified by the current methodology than as reported by NSW Health. As none of these AHSs are ones where HCV notifications are routinely followed up for evidence of new acquisition, it is unsurprising that a review of laboratory data finds more cases in these AHSs.

1.12 Discussion

Taken together the two laboratories selected for the trial accounted for approximately half of all newly diagnosed HCV notifications in NSW in 2007. Out of the 2,207 newly diagnosed cases found in the laboratory data, we identified a total of 21 newly acquired cases of HCV infection (1.0%).

In matching these 21 cases with the 65 newly acquired HCV cases identified by NSW Health for 2007, 18 cases had not been previously identified by NSW Health as newly acquired, bringing the total number of newly acquired HCV cases for 2007 to 83. This increased the proportion of newly acquired to newly diagnosed HCV cases for 2007 from 65/4,192 (1.6%) to 83/4200 (2.0%),

Table 3: Number of males and females in five-year age groups, for laboratory and NSW Health newly acquired HCV cases from 2007

	Laboratories			NSW Health		
Age group	**Total (N)**	**Male (N)**	**Female (N)**	**Total (N)**	**Male (N)**	**Female (N)**
0-4	0	-	-	2	1	1
15-19	0	-	-	8	4	4
20-24	4	2	2	16	9	7
25-29	2	1	1	10	5	5
30-34	6	3	3	13	9	4
35-39	2	2	0	3	3	0
40-44	3	3	0	7	4	3
45-49	1	1	0	3	3	0
50-54	0	-	-	0	-	-
55-59	3	3	0	*1*	*1*	*0*
60-64	0	-	-	2	0	2
Total	21	15	6	65	39	26
Median age (range)	34 (21-58)	39 (23-58)	29 (21-34)	28 (0-64)	31 (0-58)	28 (2-64)

Table 4: Number of HCV newly diagnosed and newly acquired cases by laboratory and NSW Health

	Public laboratory		Private laboratory		Combined		NSW Health	
AHS	**Newly diagnosed (N)**	**Newly acquired (N)**	**Newly diagnosed (N)**	**Newly acquired (N)**	**Newly diagnosed (N)**	**Newly acquired (N)**	**Newly diagnosed (N)**	**Newly acquired (N)**
GSAHS	7	1	98	0	105	1 (1.0%)	217	4 (1.8%)
GWAHS	1	0	35	0	36	0	206	9 (4.4%)
HNEAHS	1	0	367	4	368	4 (1.1%)	417	7 (1.7%)
NCAHS	6	0	176	1	*182*	*1 (0.5%)*	*349*	*0 (0)*
NSCCAHS	11	1	225	0	*236*	*1 (0.4%)*	*385*	*0 (0)*
SESIAHS	234	1	257	4	*491*	*5 (1.0%)*	*572*	*2 (0.3%)*
SSWAHS	48	1	343	3	391	4 (1.0)	893	26 (2.9%)
SWAHS	11	0	172	0	183	0	540	1 (0.2%)
JH	99	2	0	0	99	2 (2.0%)	613	16 (2.6%)
Unknown	116	3	0	0	116	3 (2.6%)	0	0
Total	**534**	**9**	**1,673**	**12**	**2,207**	**21 (1.0%)**	**4,192**	**65 (1.6%)**

whilst increasing the yield by 28%. In addition, the number of newly acquired cases identified in laboratory data for some jurisdictions exceeded that reported by NSW Health.

The substantial increase in the number of newly acquired HCV cases identified in the laboratory data indicates that, if used in addition to current reporting mechanisms, utilising laboratory data has the potential to increase both the proportion and yield of newly acquired cases in NSW. Laboratory data is likely to identify an older set of newly acquired cases than those currently identified.

Recently released NSW HCV notification data for 2008 reveals that the number of newly acquired cases dropped to 24/3,916 (0.6%; Communicable Diseases Branch, NSW Department of Health, 2009). Examining 2008 laboratory data was beyond the scope of this study, but if the 2008 trend continues, the utilisation of past laboratory data could be considerably important in the identification of newly acquired HCV cases in NSW.

1.13 Limitations

A number of limitations to these data were identified.

RNA data

No RNA data were available from the private laboratory, therefore newly acquired cases where the evidence was an HCV antibody negative result coupled with a PCR positive result could not be identified. For the public laboratory, HCV antibody negative records prior to 2007 were not provided for patients not testing HCV antibody positive in 2007. This meant HCV antibody negative/PCR positive newly acquired cases where the antibody test was conducted in 2006 or 2005 could not be identified.

Name variations and data entry errors

Name variations such as omission of middle names and alternative spellings, and data entry errors were not taken into account when matching tests in the public laboratory data. The rationale for this was that a standard surveillance system is unlikely to be able to account for this level of detail.

Previous notification by other laboratories

It is unknown if any of the 2,207 cases identified in this study as newly diagnosed in 2007 were notified by another laboratory prior to being notified by the laboratories studied here. This would affect the date and possibly the year of diagnosis. For example, if a case had an HCV antibody negative test in April 2006 and an HCV antibody positive test in May 2007 at one of the laboratories examined here, this would have been counted by us as a newly acquired case for 2007. But it is possible that this case tested HCV antibody positive at a different laboratory (not examined in this trial) at a date in between, for example in November 2006. This would have been notified to NSW Health as a newly diagnosed case from the second laboratory and included in the NSW Health 2006 annual total. However, as most newly acquired HCV cases identified were matched to NSW Health cases (17/21) and the four unmatched cases had earlier notification dates searched for unsuccessfully, this limitation appears to be largely theoretical.

Location

One-fifth (111/534) of the newly diagnosed cases identified in the public laboratory data had insufficient address data therefore AHS could not be assigned. These included three cases identified as newly-acquired. A small number of unaddressed cases are likely to be from people resident outside NSW. For cases with sufficient address data, 1% (4/422) were found to be from people resident outside NSW. Therefore it is possible that a small number (one or two) of the laboratory identified newly diagnosed or acquired HCV cases are not from NSW. However this would not impact the conclusions of this report. Postcode data was complete for the private laboratory and an AHS could be assigned for every case.

1.14 Phase One recommendations

Expansion of current study

We recommend continuing to assess the feasibility of using laboratory HCV testing data to increase the number of newly acquired HCV cases identified in NSW, but to enhance its scope in several ways. Including more years of data (prior to and after 2007) and/or obtaining test data from more laboratories would allow for evaluation against the larger pool of HCV notifications reported by NSW Health. We recommend following a consistent methodology for current follow up and for identifying past newly-acquired cases with follow up with the notifying laboratory for cases diagnosed over the previous five years.

To enable identification of newly-acquired cases with HCV antibody negative/PCR positive test results, all past HCV antibody negative tests for PCR positive cases, not only those conducted in the same year as the RNA test, should be obtained in future feasibility studies

A new surveillance system for newly acquired HCV in NSW

We recommend designing a new surveillance system for HCV in NSW which utilises a consistent methodology and combines current follow up of suspected or known newly acquired HCV cases (with doctors and patients) with follow up of unspecified HCV notifications with the notifying laboratory, to obtain data on past HCV test records.

Cross-matching between laboratories

As patients are often tested through different laboratories on different occasions (either by moving residence or by seeing a different doctor), linking data between laboratories as well as within single laboratories is an important goal to work towards. Cross-matching test data between two or three large laboratories may significantly increase identification of newly-acquired HCV. The feasibility of cross-matching between laboratories could be tested by obtaining identifiable data or code books from more than one laboratory and examining if the format of identifying information (date of birth, gender, and name or name codes) would allow linkage. The ability to link test results from different laboratories should be made a priority for the Healthelink electronic health record program currently being piloted by NSW Health.

2 Phase Two

2.1 Participant narratives of seroconversion

This section of the report presents the findings from Phase Two involving in-depth qualitative interviews conducted with people reporting HCV seroconversion within the previous two years. The aim of Phase Two was to increase understanding of the practices, settings, networks and structures contributing to HCV infection to inform hepatitis C prevention activities and recommendations for enhanced HCV surveillance systems. Further, the data collected allow examination of the hepatitis C testing and diagnosis experience of the study sample. These results will be structured in three sections.

Section 2.2 presents the results focusing on participants' analysis of the HCV seroconversion event. It details the experience of participants who believed that they could identify the actual event that resulted in their HCV seroconversion. It also documents the possible route of infection for those participants who were unable to identify a particular seroconversion event. In all examples, participants identified that the reuse and sharing of injecting equipment (needles and syringes including winged infusion sets, spoons and water) was the reason for their HCV seroconversion. However, this reuse and sharing was influenced by the physical and social environments in which drug use took place, the people that were involved, the ability of individuals to be vigilant and challenge the practices of others and a lack of awareness to HCV risk posed by injecting equipment other than needles and syringes.

Section 2.3 presents the results of participants' experiences of HCV testing and diagnosis. The results from this section highlight that the study participants had been tested for HCV a number of times prior to their positive HCV diagnosis, they had been given a number of negative HCV test results. The site and reason for participants' HCV testing is detailed. This section also assesses the test types used for participants' positive HCV diagnosis, including liver function, antibody tests and PCR testing. With a median time since testing of 15 months, concerns were raised about the quality of testing to confirm chronic HCV infection. The section concludes with an analysis of issues of informed consent related to testing drawing upon participants' lack of awareness regarding test types and the implications of different test findings.

Participants' experiences of receiving a positive HCV diagnosis were assessed by identifying, coding and analysing participants' experiences according to the information, counselling and referrals components of the National Hepatitis C Testing Policy (2007). The experience of the minority of participants met the standard of some components of the National Testing Policy (2007), including provision of written information and assistance with emotional and psychological needs. The majority of participants experienced a positive HCV diagnosis that did not meet the standards of National Hepatitis C Testing Policy, including absence of pre-test and post-test discussions, inappropriate timing of diagnosis, inappropriate tests used for positive diagnosis and a lack of emotional sensitivity whilst providing a positive diagnosis. The section also reports on the implications of not meeting people's emotional and psychological needs when a positive HCV diagnosis is given, the utility of community and user-based organisations in providing support to people and the extent of specialist referrals made after diagnosis.

2.1.1 Risk factors for HCV seroconversion

A recent review outlined the risk factors for HCV infection among PWID classifying risk factors in one of two groups: (1) more strongly established factors (principally pertaining to the injecting episode) and (2) potentially important and modifiable risk factors (including individual factors and those influenced by the environment and factors in the background of PWID, and possibly related in complex ways; Griew et al., 2008). A summary of these factors is presented below.

2.1.1.1 More strongly established risk factors

1. **Receptive needle and syringe sharing:** Strong evidence exists to link HCV infection with the reuse of needles and syringes.

2. **Sharing other injecting equipment:** This category includes filters and 'cookers'. The sharing of needles and syringes and other equipment has been linked to the social context (such as within sexual relationships and where money is pooled to purchase drugs).

3. **Being injected by someone else:** Being injected by some-one else may lead to inadvertent contamination of equipment.

4. **Injecting cocaine use:** This factor is related to the higher frequency of use of cocaine than other drugs which may also produce poor venous access enhanced by the vasoconstrictive properties of cocaine.

5. **Not receiving treatment for drug dependence:** This factor influences HCV infection risk by reducing the frequency of injecting.

6. **Being female:** This may be related to dynamics in sexual relationships and being injected by someone else.

7. **Injecting for a shorter duration of time:** The incidence of HCV infection decreases with length of time injecting.

2.1.1.2 Potentially important and modifiable risk factors

8. **Daily or more frequent injection**.

9. **Injecting in public/rushing to inject:** This factor influences HCV infection risk by potentially producing a greater presence of blood (from hurried and unsuccessful attempts to inject) and/or inadvertent reuse of potentially contaminated equipment. Rushing injecting may be related to the fear of being detected by others, especially police.

10. **Incarceration**: There is no regulated access to injecting equipment in any Australian prison: needles and syringes are contraband in these environments. Although the frequency of injecting in prison is reduced, the risk for each injection is potentially higher than in the community as the injecting equipment may be used by many people.

11. **Psychosocial issues that make health preservation harder:** A range of factors were described including:

- impact of stigma on choice of access to equipment;
- Perception of the inevitability of hepatitis C among PWID;
- prioritisation of health and well-being;
- mental health; and
- homelessness.

2.1.2 Methodology

A qualitative approach was deemed most appropriate for this study because of the complex and sensitive issues that were addressed and as such, necessitating a sensitive approach to facilitate the collection of detailed and accurate data (Patton, 2002; Pope et al., 1995). Semi-structured interviews were used to allow for consistency of interviewing while also permitting the interviewer to respond to the range of issues, perspectives and approaches that emerged in open-ended conversation.

During 2009, participants with newly acquired HCV were recruited using a range of mechanisms including advertisements placed in publications produced by the Hepatitis C Council of NSW (HCCNSW) and the NSW Users & AIDS Association (NUAA). Participants were also recruited via referral from the HITS-c study, a longitudinal study of people who inject drugs and are hepatitis C negative at baseline. A screening interview was conducted by telephone with people who responded to the study advertisement. Twenty-four in-depth qualitative interviews were conducted: two by telephone and 22 face-to-face (RD-12; MH-11; JE-1). Each interview took between 25 minutes and 140 minutes and participants were reimbursed with $30 cash for their time and/or travel expenses. Ethical approval for the study was obtained from the University of New South Wales (UNSW) Human Research Ethics Committee (HREC REF 08063).

The interview used a semi-structured interview schedule that explored participant's understandings of HCV, HCV seroconversion (including the identification of the seroconversion event or the risk environment in which HCV could have been transmitted); HCV testing processes (including timing of test, reason for HCV testing, HCV test types undertaken, participant understanding of HCV test types); HCV diagnosis (including diagnosis experience, explanation at diagnosis and referrals made); and HCV post diagnosis (including attitudes, awareness, readiness and willingness to undertake HCV treatment; care, HCV awareness and changing risk practices). The interview guide is included in Appendix B.

During data analysis, interview transcripts were checked for accuracy against audio recordings and de-identified by removal (or replacement) of identifying information. A list of codes emerging from the interviews was independently generated by three researchers (JN, MH and RD). The code lists were compared and discussed until a consensus was reached. Computer software (nVivo 8) was used to manage the data and retrieve like-coded sections of data for close reading. Close reading of the data was conducted to elaborate on emerging themes from the data and to extract quotes from participants that illustrated those themes. Data analysis involved coding and classifying participant's narratives about their acquisition of HCV (practices, settings, networks and structures contributing to HCV infection), testing (reasons for testing, types of tests undertaken, experience of testing process) and diagnosis.

In examining, analysing and presenting the data regarding seroconversion, we note the tensions between the epidemiological notions of risk with regard to HCV infection and the participant experience as explored in the social research literature. We have attempted to draw these two areas together. For example, the reuse of injecting equipment has been established as a risk factor for HCV infection (Maher et al., 2006; Thorpe et al., 2002; Hahn et al., 2002; Miller et al., 2002). Further, some contexts of injecting, such as injecting in prison, have also been established as independent risk factors for HCV infection. Further analysis of why reuse of injecting equipment happens has been influenced by three broad approaches. First, analyses of behaviour based in individual level factors such as models of health decision making, psychological motivations and risk calculus (Gagnon and Godin, 2009). Second, approaches that criticise the individual level approach and draw attention to the broader structural influences on practice (see Rhodes, 2009 for detailed analysis). Third, an emerging body of work examining social network structure and function (Amirkhanian et al., 2005; Katz et al., 2004; Latikin et al., 2003; Neaigus et al., 2001; Wizbel, 1996; Cook and Whitmeyer, 1992; Neaigus, 1998; Bourdieu, 1995). We have attempted to draw these areas together to examine the interconnections between these influences on HCV seroconversion.

Further, some practices and context outlined below may not directly relate to HCV seroconversion risk. However, for people who inject the notion of "safe" in injecting practice is broad and includes strong motivations for hygienic practice and to protect venous access (Treloar et al., 2008). In this sense, it was difficult to extract from participants' narratives only those practices which involved biological or epidemiological logics in relation to HCV seroconversion. Participants' narratives of HCV seroconversion risk bound together many aspects of knowledge, perception, practices, social setting and structural context. We have attempted to provide analysis of both aspects: that is, examining the interview data in relation to known epidemiological risk factors as well as preserving the integrity of the participant narrative with regard to risk.

2.1.3 Demographic characteristics of participants

In total, 24 participants were interviewed during the study. Participants' detailed demographic characteristics are contained in Appendix C. All research participants (*n*=24) self-reported medically diagnosed HCV and had received a positive hepatitis C diagnosis between 2006 and 2009, that is, within two years of recruitment into the study. The mean time elapsed since the positive diagnosis was 15 months. All participants self-reported receiving at least one negative HCV result prior to seroconversion.

The mean age of participants was 35 years, with a range of 21–49 years. Over half of the study participants were male (*n*=14), 9 were female and 1 was transgender (male to female). The majority of participants were born in Australia (*n*=21). Twenty-nine per cent of participants (*n*=7) identified as Aboriginal or Torres Strait Islander. All participants identified English as their main language.

Most participants resided in Sydney (*n*= 22) and two in regional NSW. When participants were asked where they had lived in the last two years, the majority had lived in public housing (*n*=9) and private rentals (*n*=7).

Half of the study participants had ever been in prison (*n*=12) and of these participants 58% (*n*=7) had been in prison in the last two years. The main source of income for study participants was government allowances, including 46% receiving unemployment benefits (*n*=11) and 29% receiving pensions (*N*=7). The main drug injected by participants was heroin (*n*=18). However, poly drug use was reported by all participants. A summary of participant demographics is contained in Table 5.

Table 5: Summary of participant demographics

Participants (*N*=24)	*n*	%
Gender		
Male	14	59
Female	9	37
Transgender MTF	1	4
Age		
20–29 years	4	17
30–39 years	15	62
40–49 years	5	21
Country of birth		
Australia	21	88
UK	2	8
Greece	1	4
Aboriginal or Torres Strait Islander		
Yes	7	29
AHS residential location		
SESIAHS	17	70
SSWAHS	4	16
SWAHS	1	4
HNEAHS	1	4
NCASH	1	4
Main type of residence in last two years		
Public housing	9	38
Home ownership	2	8
Private rental	7	29
Emergency accommodation	2	8
Prison*	1	4
Residential rehabilitation	1	4
Unknown	2	8
Prison – ever		
Yes	12	58
Prison – last two years		
Yes	7	29
Main source of income		
Government benefits	18	75
Wages	5	21
Unknown	1	4
Main drug injected		
Heroin	18	75
Methamphetamine	5	21
Cocaine	1	4

*this participant had been recently released from prison.

2.1.1 Seroconversion event

The focus of the qualitative component of the study was to identify the event that resulted in participant's hepatitis C virus (HCV) seroconversion. In analysis of HCV seroconversion events, two groups of participants emerged. The first group were able to identify particular episodes that they attributed as the seroconversion event. The second group could not identify particular events. What was common to both groups, however, was the wide range of practices and settings in which HCV infection risk was identified.

The risks involved in seroconversion events identified by participants included the sharing or reusing of needles and syringes, as well as a spoon in one case and a bottle of methadone syrup believed to be contaminated with blood in another case (the methadone was injected).

While HCV infection as a result of reuse of injecting equipment has been previously established (Griew et al., 2008), these data are further examined to highlight the influence of the physical and social settings on injecting practices and the interconnections of these influences.

Although researchers, practitioners and policy makers are focused on understanding HCV infection through studies like this, the need to identify the seroconversion event was questioned by some participants. Some participants were generally curious about the event and wanted to know how it had occurred. One participant explained:

> I'd like to know exactly where [I came into contact with hepatitis C] … I don't know exactly where it happened but yeah, I'd love to know exactly when it did happen (Michael, 38 years).

Conversely, for one participant, the need to identify the immediate event that led to seroconversion could result in the allocation of blame. She explained:

> I'd be, I'm curious. Like I'm curious like but I guess, in the bigger picture, it's not really that important. Like … I can see how it is important for some people because like in terms of sort of like 'laying the blame' so to speak, you know, like I just, I guess to assess how much, how much of it is actually sort of your, your fault like … yeah. Or how much is kind of circumstantial. Yeah. But yeah, no I guess it's not really, it's not really important I guess (Naomi, 30 years).

2.1.2 Identified seroconversion events

Eight participants identified the immediate event that they believed resulted in their HCV seroconversion. However, it needs to be highlighted that these same participants also identified other instances that could have resulted in exposure to HCV. The identified contexts of seroconversion included sharing needles and syringes while in prison, sharing equipment in an intimate relationship, deliberately sharing blood, sharing a syringe with a partner who was hepatitis C positive, sharing a spoon and reusing needle and syringe, including winged vein infusion sets (WVIS) or "butterflies", as a result of "hanging out" including one case of enforced withdrawal from methadone during detention. These events are summarised in Table 6 (see page 22).

Table 6 Seroconversion event identified summary (*n*=8)

Event	Participant Explanation
Sharing a syringe while in prison (Narelle, 31 years)	Okay, yep, certainly. Okay, well I have, I've been in prison and I shared, stupidly shared a needle in prison. I was promised that, you know, the person I was sharing with didn't have anything and, of course, you know, at the time I believed it, you know. And yeah, I just, that's … I know that's exactly where I got it, you know. That's exactly where I got it.
Deliberately shared blood in a syringe in a group of 3 gay men as form of intimacy, attributed to methamphetamine use (George, 42 years)	I know exactly. I know, I know exactly how I acquired it. Three guys, including me, crystal meth, we all knew what each other had in terms of illnesses and we deliberately exchanged blood … Because of the, because of crystal it seemed a very intimate time and I wanted to be connected to these people … And sex was really, well you've heard 'crystal dick' no doubt. So sex wasn't really gonna happen. So this was our form of intimacy. And, and I was stoked after it, you know ... I felt pretty fucking stupid the next day.
Sharing syringe with partner as a form of intimacy (Anthony, 44 years)	From sharing a fit … With my girlfriend … She's the only person I've ever shared with … It wasn't a one-off … no, we used to share regularly. Yeah. A bit silly I suppose … It was, it was … I suppose it was a form of intimacy between us. It was one way that we were close, that you don't get with other people.
Injecting from a bottle of methadone supplied by partner after withdrawing from OST while in "lock up" (Jasmine, 29 years).	I received it from an ex-partner of mine…Going into details of how I got it, I spent some time in, in lock-up. A three-day weekend … And I was on a methadone program and I'd had no methadone over that period. And that makes you very sick … And silly me, I was in a very like bad relationship where she was the one that put me in, and this, that and the other. And very, not, not very good, basically. Anyway, she met me as soon as I got out. And I wasn't really doing anything but I actually, she bought me a bottle of methadone with her. Little did I realise. And after I'd said, you know, You haven't been using it yourself or anything? she said, No. I don't know whether it was spite or whether she … probably because at that point she was very much a user, a junkie. She was very bad with a lot of things. She had been using it and I actually injected it myself. And she'd been doing the same. So it had blood in it. And that's how I got it.
Reusing a syringe while "hanging out" (Steven, 42 years)	I was on heroin and I was hanging out. And we got some heroin. And we didn't have any new fits. So we just opened one of the boxes. And one of my fits was in the box but I grabbed the wrong one. So I knew the person was hep C positive. But I knew they were HIV negative, so I took the risk. And it, and it failed, you know, so … Then I recontracted it and I've been pretty crook since. Because I've recontracted a different strain than the first one ... It was late at night and there was no, no rooms where we could get fits, you know, clean stuff … Yeah. So yeah, I just, you know, cracked the box open and cleaned the fit out best I could.
Sharing a spoon with a partner (Teagan, 29 years)	I … the only way I can think of is when I was using with my partner, we ended up sharing the same spoon. And obviously she, she's got hepatitis C, and she obviously used it before me, and I didn't realise. Silly. And that's the only way I can think … that's the only way. Because I don't share needles. I don't share anything like that, and I won't.
Sharing a syringe with a partner (Wilson, 37 years)	My boyfriend: I shared a fit with him and he's hep C positive.
Accidental needle stick while disposing of friends syringe (Michael, 38 years)	I actually pretty much know how I got it ... I was trying to dispose of a friend's syringe and injected myself with it, right here on the knuckle. And I knew he had it [hepatitis C] so that's virtually pretty much, I'm pretty sure that I got it that way, by accident ... I pretty much think it was from that accident. But I, I don't know for sure, you know. Like I said, it could have been sort of, you know, sharing sort of a spoon with someone else, somewhere along the line. Because like I said, most other people that we injected with did have it.

Although these events were identified by participants as seroconversion events, these participants also identified other risks for HCV infection. These were, in turn, similar to the possible scenarios for HCV infection identified by those participants who could not specify a particular seroconversion event.

2.1.3 Other potential exposures to seroconversion risk

The majority of research participants (n=16) could not identify the exact time or specific event that resulted in their HCV seroconversion. The inability to identify particular events suggests ongoing and repeated risk incidents, which occurred within social situations and environments over a period of time. This was explained by one participant who identified that:

> You can't be one hundred percent sure because there's nothing, no definitive test to say exactly, you know, how you got it. You've just gotta try and think back to all the risk, types of risk behaviour, you know, that you partook in around that particular time. You know, around that window that you have contracted it. And try and work out where it stemmed from. Especially if there were a few different possibilities (Trina, 39 years).

The main risk factors identified by participants in relation to the means of HCV seroconversion was the reuse of injecting equipment. Reuse of equipment was in turn influenced by the physical and social environments in which drug use took place. A summary of the effects and influences of sharing and reusing equipment is contained in Table 7 and an analysis of the interconnections of influence follows.

Table 7 Summary of seroconversion risk

	Risk factor	Specific details
Seroconversion Risk	Reusing or sharing drug equipment	• Receptive sharing (borrowing syringes) • Reusing butterflies • Sharing spoons • Reusing 5ml water or sharing water from cups • Limited access to swabs
	Accidents	• Accidental needlestick

2.1.3.1 Reuse and sharing of injecting equipment

Although participants identified that access to sterile equipment had increased during business hours in inner city areas, reuse or sharing of drug preparation and injecting equipment still occurred and was identified as a potential means for HCV seroconversion. Sharing and reuse of equipment was not contained to needles and syringes used for injecting but extended to all equipment. The examples of reuse and sharing by participants were not always mutually exclusive, for example the sharing of both spoons and water could occur in one episode of injecting.

Needles and syringes

Receptive sharing of syringes was reported by over half of the research participants. Situations were this occurred included use with a partner and when people where "hanging out". Participants identified that they sometimes used strategies to reduce HCV infection risk when engaging in receptive sharing. This included cleaning the used syringe with bleach and water, and attempting to ensure that those who were not infected injected first. Participants also identified a practice of keeping used syringes for times when there were no others available. These strategies did not always work and will be discussed later in this section.

Similar to other needles and syringes, the reuse of butterflies was identified by one participant as a risk because people may not have been aware that had been used before. Butterflies are not available at NSW NSPs and not all pharmacies stock these for sale. Difficulty in accessing and the cost of butterflies may impact on decisions to re-use equipment or rely on others for the provision of equipment.

> Yeah, there was like a couple of times. Like this chick once said that she had a butterfly, and said that it wasn't used. And, you know, I used it and … you know, instead of just like slicing a neat hole, because they're very sharp, through, like forced my skin in and then popped through. So obviously it wasn't exactly sharp, so … Maybe. I don't know (Dylan, 37 years).

Spoons

The sharing and reuse of spoons was reported even by those who said "they would never use someone else's fit" and who perceived themselves to be "careful" and "cautious". The sharing of spoons was described as an occurrence that happens when groups of people pool resources to buy drugs and the drugs are then mixed in a common spoon with everyone drawing up from their own syringes. Spoons were generally taken from people's kitchens and reused without knowledge of previous use or evidence of adequate cleaning. These findings highlight that HCV infection risk from a spoon may be unknown, underestimated or undervalued. For example, one participant explained:

> I mean four or five blokes in my room … we all got new fits but the same spoon that I've used six or seven times. No-one said, 'Shit the spoon' … Well I didn't, I didn't think it was contagious. But it wasn't until later on that I'd found out that it was contagious; by then

> it's too late. It's already done. Not a day or two later: I mean when I got into rehab and that and, you know, we did harm minimisation. I found out that spoons (could transmit HCV) … shit (Caleb, 41 years).

Water

Water was also identified by participants with respect to the risk of HCV seroconversion because participants explained that they "usually have my own equipment but often not my water" (Dylan, 37 years). The risk that water posed was expressed in two different situations. Two participants identified that people they knew were reusing the 5ml water ampoule contained in Fitpacks (Russell, 32 years; Dylan, 37 years). The reuse of water ampoules occurred because there was more water contained in the 5ml ampoule than required for one injection. One participant explained:

> Because the thing with those waters are that, like some of them contain five ml of water and it's tempting to a lot of people for it to retain … I mean I don't and I wouldn't, but there are some people that re-use it (Russell, 32 years).

Four participants also identified the need to use tap water due to a lack of water ampoules. Tap water was collected and contained in a cup that could have been used for drawing up water to prepare and inject and for rinsing a syringe after injection (Michael, 38 years; Helen, 23 years; Dylan, 37 years; Matthew, 34 years). This posed a significant seroconversion risk if the cup was contaminated through prior use, although people were sometimes not aware of HCV infection risk.

When water ampoules are not available, participants also identified obtaining water from where ever they could:

> I used to use rainwater, you know, to get water, you know. If I didn't have any water I used to go to a puddle and suck up the water from a puddle, you know (Wilson, 37 years).

Although the use of water in the environment does not constitute an HCV seroconversion risk, the scenario above illustrates the interconnection of risks. That is, to avoid using water from puddles, decisions may be made to share other available water such as used (previously) sterile water ampoules.

Swabs

International evaluations have been undertaken to assess the efficacy of swabs protective effect against HCV, although their results have not been published (Sopwith et al. 2002; Flynn et al. 1994). It is believed that the alcohol contained in swabs will not "kill" hepatitis C on surfaces, such as fingers or spoons (NCHECR, 2008). This is because the processes of swabbing disinfects the site rather than sterilise. However, the use of swabs is widely promoted in health promotion literature for "safe injecting". However, video-based research has shown the poor understanding and practice related to swabs (Treloar et al., 2008) including a high reliance on swabs as part of post-injection "cleaning". This has the potential to increase bleeding from the injection site theoretically increasing the presence of blood in the injecting context.

In these data, participants were concerned about the lack of access to swabs:

> Yeah, and you know, you never ever have enough swabs to, you know, at the time (Trina, 39 years).

> Unfortunately, we don't swab our skin 99 percent of the time. I mean if I have swabs I'll use them. But you usually don't and so, yeah, I don't swab (Michael, 38 years).

We are not presenting the use (or not or reuse) of swabs as a seroconversion risk. However, we are presenting the issues participants spoke of when discussing the possible way/s in which they acquired HCV infection. Given the concerns expressed about swabbing, the previous literature which linked motivations for hygiene and safe injecting with the practice of swabbing, and the inclusion of swabbing in health promotion materials targeted to people who inject drugs, swabs need to be considered as part of the equipment and knowledge environment in which prevention programs operate.

2.1.3.2 Accidental needlestick injury

One participant identified an accidental needlestick injury as the means of HCV infection (see Table 7). A further two participants identified an accidental needlestick injury as the possible means of HCV seroconversion. In these examples participants identified that the needlestick injury was an accidental means of HCV infection and occurred because of "bad luck". One participant further attributed his needlestick injury to being homeless and "out of it". He explained:

> And then there was a time I stood on, when I was homeless … Did I sit on it? Yeah, I sat on a syringe in the park when I was homeless. Because I was really out of it. And I just went tonk! And woke up, and there was a syringe hanging out of my butt (Wilson, 37 years).

The social research literature highlight the importance of people who inject drugs positioning themselves as

responsible users to maintain a desired self-identity (Rhodes and Treloar, 2008; Fraser, 2004; Vitellone, 2003). In these data, accidental needlestick injury was raised by participants as possible other means of HCV infection along with sharing and reuse of other injecting equipment. The inclusion of accidental needlestick injury in HCV seroconversion narratives may be a means for participants to maintain their self-image as a responsible injector.

2.1.4 Interconnecting influences on HCV seroconversion risk

Results suggest that irrespective of whether people could identify the actual event that led to their HCV seroconversion, a number of influences were operating on the sharing and reuse of equipment. These issues may not be mutually exclusive and a combination of environmental and structural influences, drug preparation practices, specifics effects of drugs and alcohol, and vigilance and social setting effects could occur during any one injecting episode. A summary of these influences is contained in Table 8.

2.1.4.1 Environmental and structural influences

Lack of access to sterile injecting equipment in prison

Over half of the research participants (*n*=12) had ever been in prison and of these a quarter identified that they had injected drugs whilst in prison (*n*=8). As there are no Needle and Syringe Programs in Australian prisons, people did not have access to new injection equipment and resorted to 'renting' injection equipment. This equipment may have "been used up to 40 or 50 times" (Teagan, 29 years) and "sharpened on a matchbox" (Luke, 33 years).

Outbreaks of HCV infection in Australian prisons have been documented since the 1990's (Haber et al., 1997; O'Sullivan et al., 2003) and these outbreaks were the direct result of the inability to acquire sterile injecting equipment (Molloy et al., 2008). Australian and international research has highlighted that needle and syringe sharing in prison-based settings is extensive and prevalence of this behaviour is estimated between 60–90% among people who inject in prison (Rutter et al., 1995; Dolan and Wodak, 1999; Kevin, 2000; Martin et al., 2005; Small et al., 2005; Allwright et al., 2000).

Table 8: Summary of HCV seroconversion influences

	HCV risk influence	Details
Interdependent effects and influences	Environment/Structural	• Prison • Public injecting • Policing practices • Service access • Stigma • Changing drug markets and supply
	Drug preparation & practices	• Not being able to inject oneself • Blocked syringes • Missing a vein
	Vigilance and social settings	• Not always 'in charge' of equipment or preparation • Drug affected and/or hanging out • Not able to challenge established practice • Relationships and intimacy • Economy of sharing finances to purchase drugs • Influence of stigma as a HCV infection risk
	Awareness of risk	• Needles, spoons and water
	Why people continue to share equipment	• Cost (Butterflies) • Lack of awareness of risk re spoons and water • Poor equipment access to equipment out of business hours especially for water and spoons • Unintentional reuse of others' equipment (systems to identify own equipment fail) • Relying on people to disclosure HCV status • Relying on cleaning and bleaching of equipment • Changing drug availability (need for metal spoons)

Needle and Syringe Programs in prisons currently operate in nine countries including Switzerland, Germany, Spain, Luxemburg, Belarus, Armenia, Iran, Moldavia, Kyrgyzstan (AIVL, 2008). The appropriateness of prison-based NSPs is because they are feasible and they are effective in reducing needle and syringe sharing (Jürgens et al., 2009; WHO, 2007; Rutter et al., 1995). The effectiveness of NSPs in prison-based settings has been demonstrated in an evaluation of 17 pilot programs in Switzerland, Germany and Spain. "The most important lesson emerging from the international evidence on prison needle exchange is that these programmes are very effective in reducing needle sharing and therefore in preventing the transmission of HIV and HCV" (Lines et al., 2005).

There is extensive evidence related to the ability of NSPs in the community to reduce the transmission of blood-borne viruses such as hepatitis C, with investment in such programs resulting in an "estimated 96,667 HCV infections averted between 2000–2009…and for every dollar spent on the activities of NSP, more than four dollars will be returned" (NCHECR, 2009; 9). There is widespread support from non-government and professional organisations for provision of prison-based NSPs (Hepatitis Australia, 2005; AIVL, 2008; NUAA, 2008; The Royal Australian College of Physicians, 2008). Further, the NSW Anti-Discrimination Board enquiry into hepatitis C related discrimination identified as a "pressing need" access of prisoners to "health care services and programs of a standard equivalent to that available in the community" (Anti-Discrimination Board of NSW, 2001; 15), including hepatitis C prevention programs such as Needle and Syringe Programs.

Lack of opiate substitution treatment in custodial or remand sentences

There is a risk of producing unsafe injecting practice resulting from the lack or withholding of, opiate substitution treatment (OST) while people are in remand or held in custody. As OST averts opiate withdrawal, the vulnerability experienced when OST is withheld can lead to impairment in decision making and this impairment can result in engaging in risky behaviour, such as reuse of injecting equipment (Mateu-Gelabert, et al., in press; Bruce and Schleifer, 2008; Theide et al., 2000; Jamner et al., 1996).

This example of a structural risk was identified by one of the study participants as the source of her seroconversion (see Jasmine, Table 2). The withholding of OST in detention created a withdrawal-associated vulnerability in that safety of injecting was comprised in the urgency to alleviate the withdrawal experience. In this case, the participant relied on another person to bring drugs and injecting equipment for use immediately upon her release from detention.

Injecting in public places

Injecting in public places may increase injecting-related risks, including HCV and other health risks (Griew et al., 2008; NCHECR, 2008). The inability to wash hands prior to injecting, not having access to water (Koester et al., 1990), mixing up in non-hygienic areas such as toilets and the need to rush because of the fear of being detected (Cooper et al., 2005; Maher and Dixon 1999), all resulted in an environment which reduced participant's ability to be vigilant around safe injection practices. For example, one participant noted:

> Yeah. I mean a lot of people, including myself, would have their own preferences and practices. And you'd be trying to ensure all of this happens. But in the chaotic situation of being in a park, especially for some of the people who are paranoid or, you know, want to get out of there as quickly as possible, it's not a relaxed, calm atmosphere (Russell, 32 years).

Although this scenario is not an example of immediate HCV seroconversion risk, it highlights that participant concerns relating to public injecting "distract attention from the practices of injecting and focus attention on the environments of injecting" (Small et al., 2007; 32). When attention is refocused on the environment of injecting, concerns related to hygiene and reusing or sharing practices may become secondary, especially where people who inject drugs rush their injecting practice to avoid detection (Small et al., 2007; Rhodes et al., 2007; Rhodes et al., 2006; Rhodes et al., 2005; Darke et al., 2001; Singer et al., 2000; Maher and Dixon 1999).

Policing practices

Another issue repeatedly reported by participants was the concern about being stopped and searched by police. Although participants were aware that is it legal to collect and carry sterile injecting equipment, the possibility of being stopped and searched by the police created a structural barrier to new equipment access, or acquiring sufficient equipment, so as to be prepared for future injections. As one participant explained:

> I understand that you are allowed to carry, you know, sealed needles around with you and you're not going to be charged with it. But if they (the police) do (and) were to find needles on you they're much more likely to strip, want to strip-search you or give you a much harder time. Do a warrant check or whatever else it may be. And so that's a disincentive in carrying around needles. And so, speaking for myself, I seldom, if ever, did for that reason (Russell, 32 years).

This finding that actual, or perceived, police searches significantly impacts on willingness to carry sterile injection equipment is also replicated in other studies (Cooper et al., 2005; Aitken et al., 2002; Maher and Dixon, 1999; Dixon and Maher 2001).

Shifts in the availability of heroin

Shifts in the availability of illicit drugs, specifically heroin, have the potential to impact on drug preparation and injection practices. Australian heroin markets have been supplied predominantly through South West and South East Asia (Gibson et al., 2005). Supply-side policies have recently changed the availability of heroin, from South East Asia to South West Asia, particularly Afghanistan. Production rates have also affected heroin supply as South East Asia's production has "decreased by 70% in the last 5 years" (Interpol, 2007) and Afghanistan's production has "increased by 59%" (Interpol, 2007).

Participants identified that the changing availability of heroin often resulted in changes in drug preparation practices with subsequent potential impact on HCV infection risk. Heroin from Afghanistan requires, among other things, heating before the heroin can be injected (Strange et al., 2001). Hence plastic spoons provided through NSPs and pharmacies may no longer be adequate. Domestic metal spoons were identified as more appropriate for use. One participant noted the impact on drug preparation practices as the result of shifts in drug availability:

> Well most of the time (you get the spoons from) a kitchen because most of the heroin that's on the streets, it's the brown, sort of brown heroin from Afghanistan. And you have to put a bit of heat with it. So you get the metal spoons from a kitchen (Luke, 33 years).

Similar to the discussion of the potential for the reuse of contaminated water above, it is possible that metal spoons are reused without decontamination in the preparation of "brown" heroin.

2.1.4.2 Drug preparation and injection practices

Difficult injections and blocked syringes

Participants identified that things could go wrong during an injecting episode that increased HCV seroconversion risk. The following example highlights the HCV risk when people "mess the shot up", which resulted in the need to put the drugs back into a spoon and be drawn up into a second syringe. This may occur, for example, when blood begins to coagulate in the syringe. When drugs are put back into a spoon, this may include blood that had been drawn into the syringe. One participant noted the risk that a blocked syringe can produce, especially if people were "out of it". She explained:

> I was having me shot. I'd messed my shot up. And put the shot back in the spoon … I hadn't cleaned the spoon properly before. Well we mixed up again in the spoon. We were really out of it, I can't remember (Jasmine, 29 years).

This example highlighted that if a person finds it difficult to inject and requires a second syringe, the drugs and possibly blood is put back into the spoon. If this spoon is reused without adequate cleaning, there is potential for HCV infection. This example has further exposure implications for injecting in public settings if there are inadequate facilities for cleaning equipment and washing hands (see Injecting in public places, page 26).

This scenario is further complicated by examining the motivations that may underlie equipment use and psychological reactions to delayed injection. Syringes may "block" and be unusable and others may understand that the use of a "blunt" needle (that is, recognising that the needle may be blunted after unsuccessful injection attempts) may compromise venous access. Further, it is important to recognise that unsuccessful attempts to inject can be frustrating and anxiety provoking, which may in turn impact on the perceived importance of HCV risk.

Another participant identified a potential HCV seroconversion risk when unable to find a vein resulting in a greater presence of blood:

> At times it, you know, the most it's taken me was like 20 minutes of injecting and re-injecting to get it in. It gets pretty horrible because, you know, multiple holes everywhere, blood's running. It's … it gets really … I don't know, ugly at times (Michael, 38 years).

This example highlighted that injection techniques are essential in minimising HCV risk exposure through the ability to minimise contact with other people's blood in a drug use setting. While there is not epidemiological evidence to support the link between difficulty injecting and HCV infection, there is some perception from participants about HCV infection risks when blood is present. When people are unable to find a vein for injecting, multiple injecting sites may be used. Where the technique is inadequate this can result in increased exposure risk from "downstream" risks relating to "unseen" blood (Davis and Rhodes, 2004).

Unable to inject oneself

When a person is unable to inject themselves, relying on others to undertake the injection could also be a seroconversion risk, especially if the person that injected others went first (Maher et al., 2006; Miller et al., 2002; Hahn et al., 2002; Patrick et al, 1997). Participants identified that the reasons for being unable to inject

themselves included not knowing how to inject and having problems finding veins. One participant explained the perceived risk of using another person to inject them:

> I think there might have been once where I got someone after they'd had a shot to actually hold my arm because I was having problems. The tourniquet was too light and I got them to loosen it once, so … Like even though it wasn't directly, you know sharing and stuff, you know, either of them could still have been a possible, possible way of transmission (Trina, 39).

This example highlighted the possible risk of HCV transmission when a person is unable to inject themselves. If the person who is injecting another has blood on them, then this blood can be transferred to the person they are injecting. To stop the transfer of blood requires adequate hand washing and hygiene that may not always take place, especially injection is occurring in public spaces (see Injecting in public spaces, page 26).

2.1.4.3 Vigilance and social settings

Some participants identified that the environment, positions of power in social networks, intimate relationships, being aware of what other social network members are doing and the size of the social network have important implications for individual vigilance and ability to exert control during injecting episodes. These examples highlighted the importance of people's social networks in supporting or rejecting values and behaviour which may minimise HCV infection risk (Amrikhanian et al., 2005; Latkin et al., 2003; Neaigus et al., 2001; Neaigus, 1998; Wizbel, 1996).

The impact of social networks on HCV risk is directly related to the level of power or dependence that individuals have with others in their social network (Katz et al., 2004; Cook and Whitmeyer, 1992). This power or dependence will ultimately determine the range of options people have to challenge behaviour they may not agree with. These options are the direct result of the relationships and positions of people in the social network related to the size, density and function of the social network (Emerson, 1972a; Emerson, 1972b) and the trust, obligation and reciprocal relationships that people have with others (Bourdieu, 1995).

Not always 'in charge' of equipment or preparation

Participants identified an association between the social context of drug use and the ability to be vigilant and diligent with respect to equipment use and cleaning. Vigilance could be decreased because people were not always in charge of equipment or preparation due to being in someone else's house or the pooling of resources to purchase drugs. For example:

> There's times when you throw in with somebody. They say, Yeah, we've got clean ones. They pull out. You're not looking because you're watching, making sure they're not trying to divvy it up. So they take some with them. Not watching what the other hand's doing; just watching what, you know … and as soon as it's mixed up (you) just stick it in and pull it up as quick as possible (Luke, 33 years).

The ability to prepare one's own drugs may reduce HCV seroconversion risk because people would then know if uncontaminated water, sterile syringes and spoons are being used. However, participants identified that they were not always in charge of the preparation process. One participant explained that "the people I do use with I tend to sort of be the one that does the, does all the sort of preparation" (Naomi, 30 years).

Power to challenge social network practice

The ability to control the drug preparation environment and equipment usage was influenced by the power to challenge unsafe practices if others were in charge of drug preparation. One participant highlighted that challenging someone to change a routine practice was not particularly easy, especially when other people were around:

> Like I said to him like, you know, 'You shouldn't be doing that'. And he goes, 'I've always done it like that'. 'You should always use a filter and everything'. And he's going, 'Yeah, but' … He goes, 'I do it that way' … And I don't think he got quite what I was trying to do. Like, you know, like I was trying to point out this chick was on the, who was waiting for hers, was on the phone. So I couldn't say too much because I wasn't sure who she was on the phone to and stuff. So I was trying to like whisper it and stuff (Trina, 39 years).

When other social network members were responsible for drug preparation, trust had to be given to that person. One participant identified how the allocation of trust can become complex when more than one person is involved in the injecting environment. In a situation where three people were injecting, he explained:

> It means you're trusting that person over there to make sure that they're actually using three clean needles and not just two clean needles and one they've used before. You're trusting that person to make a filter. Who knows? They could have bloody fingertips. You're trusting this person over here to get the water. You know, it's a really, it is a risky situation (Russell, 32 years).

In other instances, the members of the participants' injecting network indicated to participants that they did not have hepatitis C or had cleared the virus. This resulted in a perceived lack of HCV risk and decreased vigilance

when making assessments about reusing other people's equipment (see results from Part 2—HCV Testing re antibody negative tests). Two participants explained:

> I shared a needle with someone who told me they had cleared the virus. [Oh yeah] And at the time the drugs were there, the syringe was there, and he told me he was clear. I didn't give a shit and I wanted to use. One thing led to another (Karen, 34 years).

> Probably sharing a syringe with someone (my aunty) that had hep C but had cleared it. So, I thought that would be okay because they don't have the actual virus anymore—they just have the antibodies (Helen, 23 years).

Relationships and intimacy

Sexual relationships frequently incorporate a high degree of intimacy, collaboration and sharing. This is as much the case for partnerships between people who inject drugs as for other partnerships. Australian data indicates that almost 50–64% of needle reuse occurs between sexual partners (Bryant et al., 2009; NCHECR, 2007; Cao and Treloar, 2006). Beyond the sharing of needle and syringes, it is thought that a significant proportion of hepatitis C infection between sexual partners may also occur through the sharing of ancillary injecting equipment such as filters, swabs, spoons and tourniquets, but data on these practices are scarce. In Australian recent data, almost 65% of sexual partnerships where injecting occurred, ancillary equipment had been shared in the previous month (Cao and Treloar, 2006). Some studies show that the sharing of ancillary equipment is even more common among sexual partners than for other people who inject drugs (Bryant et al, 2009).

Sexual relationships shape the ways individuals think about, discuss and act on blood-borne virus prevention. Needle sharing between sexual partners can result in or act as a sign of emotional bonding, commitment, fidelity, mutual trust and shared intimacy (Lakon et al., 2006; Habib, 2003; McRae, 2000; Rhodes and Quirk, 1998; Davies et al., 1996). On the other hand, refusal to share can introduce the suggestion of distrust and a denial of intimacy (Unger et al., 2006; Dear, 1995; Barnard, 1993). In these ways, sexual relationships can "give rise to, and influence, risk behaviour" (Rhodes and Quirk, 1998; 158); that is, the very nature of sexual relationships—their association with ideas of commitment and intimacy—can encourage partners to share needles in order to demonstrate trust and love for each other. Where equipment sharing is "bound within notions of trust and intimacy…it is hard to define as risky behaviour" (Sheard and Thompkins, 2008; 1537).

Relationships and intimacy were cited by study participants as reasons for sharing equipment, even whilst identifying the relative ease of obtaining new equipment. Sharing in these contexts was not contained to one-off events but rather appeared to be part of the ongoing relationship:

> Oh just usually we'd only have one fit between us, so … and at first if it was a clean fit, I'd use it first. There wasn't any … because I didn't have hep C. But then it got, it became just ridiculous that we even shared the way it is today. How easy it is to get fits today, but … It was just easier (Andrew, 38 years).

Another participant identified that he only shared with his long term sexual partners "I haven't really done it (shared syringes). I've only done it with sexual partners (shared syringes). And that's long-term sexual partners, you know" (Derek, 39 years). However, this participant did not identify why he shared syringes with sexual partners.

Relationships can also increase risk if a person's partner is unaware of their injecting drug use. A structural risk can be contained in a relationship where there is no disclosure about injecting drug use or a partner is not accepting of drug use. This can result in people not wanting to keep clean equipment at home to use when needed. One participant explained that this has consequences for all injection equipment:

> With the boyfriend who doesn't use drugs. So I can't keep any clean needles at home. If I do decide I want to use, I'm in a real dilemma; where do I get everything from? I need a spoon. So I end up going to a take-away shop and buying some take-away food that includes a spoon. I might have to go to the, the chemist, if the vending machines aren't working and get a clean needle. And then, of course, there's the problem of water. And then there's a safe place to do it as well. It's, it's quite difficult because, as I say, not being able to have clean, clean needles or anything like that at home … Well I did keep them at home but he threw them all out as a sort of a statement. You know, I don't want you doing this crap! So he threw them all out, yeah (Russell, 32 years).

2.1.4.4 The influence of stigma on HCV infection risk

Numerous studies have demonstrated that hepatitis C is a highly stigmatised condition and that discrimination against people with hepatitis C is rife. The discrimination against people with hepatitis C is often motivated by stereotypical response towards people on the basis of past, current or assumed injecting drug use (Anti discrimination Board NSW, 2001). The experience or fear of discrimination can have a pervasive impact on all

aspects of living with hepatitis C, including influencing risk perception (Treloar and Rhodes, 2009).

For some participants, concern about the possible discrimination resulting from knowledge of their HCV status, meant that they did not disclose their status in injecting networks. As one participant explained:

> Like I don't want everyone to know about it. It's not that I like … yeah. Because a lot of people, like there's a stigma to it (hepatitis C) and there's just gonna, like, be people that take it the wrong way. And I don't want people to like sort of like— do you know what I mean?—have to think twice or whatever, like be cautious around me (Helen, 23 years).

At another level, there are sanctions operating regarding what is seen as a "responsible" injector (Fraser, 2004). These sanctions put much emphasis on the use of sterile injecting equipment and admitting reuse of equipment threatens the maintenance of relatively risk free and responsible injector identity (Rhodes, Davis and Judd, 2004).

Participants identified that disclosing the reuse of needles and syringes was difficult because of the stigma attached to this behaviour and the perception of them as irresponsible or careless. For example one participant highlighted that they had not disclosed sharing needles with their partner or their family:

> She doesn't know about, you know, I haven't told her that I've ever shared a needle or anything like … because now I don't, it's not something that you like to admit to you know, a lot of people. Even to mum and dad I haven't told them. They say, 'Have you ever shared?' and I say, 'No, no, never.' But I have (Luke, 33 years).

2.1.5 Why people continue to share or reuse equipment

Participants in this study were more likely to report the sharing of ancillary equipment, such as spoons and water, than they were to report needle and syringe sharing. This finding is replicated in the Australian Needle and Syringe Program Survey data (NCHECR, 2009), which found that PWID were more likely to report the reuse or sharing of "spoons (24%), water (17%), filter (12%) and tourniquets (11%)" (NCHECR, 2009; 10) than needles and syringes.

Participants provided multifaceted explanations of their decisions to continue sharing or reusing equipment. For some, decisions about practice were based on a lack of sterile equipment arising from not wanting to keep equipment at home, services not available when required, wanting to give up injecting drug use and unplanned and impromptu injecting instances. These instances created an environment where there was a lack of sterile equipment access, especially after business hours. This access was further compounded by a lack of awareness regarding risk of HCV infection from other drug preparation equipment, such as spoons and water, compared to needle and syringes (Sheard and Thompkins, 2008; Carruthers, 2003).

2.1.5.1 Awareness of risk

Participants' had different levels of awareness of risk in sharing and reusing other injection equipment, especially spoons as opposed to needles and syringes. In a number of instances participants identified that that there was awareness and norms about the reuse of needles and syringes, but this was not apparent with respect to spoons. For example one participant identified:

> Because I was thinking, 'I never shared a needle with ya'… But I didn't realise it could have been in the spoon … Because it was more, 'cause you could see the blood'. You can see the blood. You can actually see blood in a needle. You can't see blood in a spoon. You didn't know; it went down to the molecular level. You know, you sort of seem to think well look it's clean, it's plastic, you can wipe it (Caleb, 41 years).

The lack of awareness was also evident in relation to the water used during injection. Participant's identified that where ampoules of water were not available, people used cups and this could pose a threat. The participant below highlighted how water can pose a risk and the way he questioned this risk:

> Like someone gets a cup of water and they draw out of it. Its like, They're gonna draw some water, you know. You think, you know, He's dunked his thing in there. Like if I draw water, you know, can you get, you know, can you get it from there? Like I'm not sure, you know. So you think, Should I? I'll just go to the bathroom. I'll go and draw out of the tap so I don't have to stick my needle in there too, what they've dunked in, you know. So there's a lot of precarious situations (Michael, 38 years).

2.1.5.2 Unintentional reuse of equipment (strategies to identify own equipment fail)

Participants were very aware of the potential risks of sharing or reusing needles and syringes. When describing situations of reuse, participants also identified strategies they used to minimise risk. One strategy included the marking individual syringes for later use. Unfortunately the marking strategies failed when the process was rushed or people forgot who had marked or bitten the fit for later use. One participant explained:

> He'd sort of rip the packet or bite, you know. Like make a mark on the syringe so I know it's his and stuff... and you know, like you've gotta be somewhere, appointments, or just, you know, you've got, you know, a function to go to. Stuff like that. And you're running out of time. That, that's when you start panicking and kind of, you forget things. You, you think, you know, I've gotta … Whose is this? you know, like, Was it yours? I don't remember? It's the bitten one. You bit it. And it's like, No, you bit it. Your one is the bitten one. And so, crap (Michael, 38 years).

2.1.5.3 Relying on disclosure of HCV status is an inadequate strategy for the reuse and sharing of needles and syringes

Another strategy identified when reusing equipment was that the participant would ask the person that they were sharing with if they had HCV. This strategy was also seen to fail as participants identified that HCV disclosure may not always occur or that the person disclosing may be incorrectly aware of their HCV status. For example, one participant explained:

> I shared a needle with someone who told me they had cleared the virus. And at the time the drugs were there, the syringe was there, and he told me he was clear. I didn't give a shit and I wanted to use. One thing led to another (Karen, 34 years).

2.1.5.4 Bleaching is an inadequate strategy for decontaminating used needles and syringes

A recent review of the efficacy of cleaning used injection equipment in preventing HCV transmission (NCEHCR, 2008) identified that there has been no research in Australia on the efficacy of bleach on preventing HCV infection. Therefore the evidence in this area relies on international research. The review contends that bleach is the preferred chemical disinfectant for cleaning used injecting equipment to prevent HCV transmission (Tweed and Kradjen, 2004 in NCHECR, 2008). Although the use of bleach is suggested to prevent HCV transmission, there are documented disadvantages in relation to the efficacy of bleaching strategies. These include a lack of availability of bleach at the point when it is required, inadequate bleaching techniques (Shapatava et al., 2006; Tweed and Krajden, 2004; WHO, 2004; Myers et al., 2000; Siegal et al., 1994; Gleghorn et al., 1993) and compromises in bleach efficacy due to inadequate storage (Abdala et al., 2004).

Bleaching of used syringes was also identified by participants as a strategy to minimise HCV risk. The process was sometimes compromised due to inadequate knowledge of the bleaching requirements, rushing, not having the appropriate cleaning agents or where someone else was in charge of the cleaning process. One participant explained how he had time to clean the used syringe although he had used hot water during the bleaching process, whilst being aware that this process may not be effective. He explained:

> He had all just dirty ones laying around. But I had time to bleach it and think that I'm clearing it, cleaning it up. Bleaching, boiling water. Stuff like that ... But I've been told that doesn't, that's not 100 percent. You know, that's sort of not even 50 percent that it cleans it (Luke, 33 years).

Another participant identified the use of ultra violet light (via sunlight) to clean a used syringe. He explained:

> Well I was pretty careful. Like I, I don't know. Like if I couldn't get a fit I'd like go find one like where other people used. I'd find one that'd been in the sun to the point of becoming opaque. So obviously it had been exposed to UV for months and months, and months. And then I'd use that. I know it sounds dirty but fuck it worked ... I'm assuming it was the UV but, you know, obviously if it's become opaque it's been there for months. And anything viral would be dead, long dead. If not from the UV, from the time it had been there anyway (Dylan, 37 years).

Another participant identified that although he had cleaned the used equipment, he had done so without the appropriate cleaning agents and not been in charge of the cleaning process. He explained:

> It might not have been as clean as what it should have been. Because we didn't have proper bleach; we had just some sort of antibacterial wash stuff. Yeah ... we bleached it out with bleach, and washed it out three times. This time I didn't do it myself. I let the other person do it. And I don't know whether they did it properly or not (Andrew, 38 years).

There was also limited discussion related to strategies used for cleaning equipment other than needles and syringes. Like the practices around cleaning of needles and syringes, it is likely that a variety of factors mitigate against people being able to implement best practice (NCHECR, 2008; Shapatava et al., 2006; Tweed and Krajden, 2004; WHO, 2004).

2.1.6 Summary

These results highlighted that specific practices and contexts surrounding the immediate HCV transmission event were unable to be identified by most participants. Further, those participants who did identify a specific context also acknowledged a number of other HCV infection risks present around the time of HCV infection.

Participants' narratives of risk raised issues that have been previously documented in the literature (Griew et al., 2008), as well as broader notions of safety relating to the presence of blood, including swabbing and bleaching used equipment. However, there was a distinct absence of discussion of filters used in drug preparation, the reuse of which has been established as a risk factor for HCV infection (Griew et al., 2008). This demonstrates the complex interplay of health messages from different sources and the impact that provision of equipment may have on people's understandings of risk (Treloar et al., 2008).

While there is some acknowledgement in the epidemiological literature of the influence of the environment on HCV infection risk, our data show how these environments interact with the social setting and in particular, what actions are possible in such settings. Hence, these data potentially inform the conduct of surveillance and interpretation of such data and approaches to further information provision for people who inject drugs.

2.2 Hepatitis C testing

To be able to identify potential participants for this study, the eligibility criteria required participants had to have had at least one negative HCV test prior to a positive HCV test result in the two years prior to recruitment. During interviews, participants were asked about negative testing, the place and timeframe of their positive HCV test, knowledge of HCV test types and the implications of test results. Issues that were identified by participants in relation to HCV testing included confusion about positive HCV diagnosis after ongoing negative HCV test results, a lack of awareness and understanding about the tests that were undertaken and the implications of each test result and an absence of knowledge about what tests were required to provide a positive HCV diagnosis.

Analysis of interview data relating to HCV testing was done against the eight guiding principles of the National Hepatitis C Testing Policy (AGDOHA, 2007). These are;

- Confidential, voluntary testing with informed consent and pre-test and post-test discussion is fundamental to Australia's response to hepatitis C;
- Testing is of the highest possible standard;
- Testing is of benefit to the person being tested;
- Testing is accessible to all those at risk of HCV infection;
- Testing is critical to understanding the epidemiology of HCV infection in the community;
- Testing can be critical to interruption of transmission and can support harm minimisation; and
- Testing to monitor people with hepatitis C before, during and after treatment is an integral part of their care. (AGDOHA, 2007: 9)

Further, the policy is explicit on what types of tests should be performed to confirm chronic hepatitis C infection.

- Exposure to HCV is determined by testing for HCV antibodies (anti-HCV) in serum or plasma;
- Current HCV infection is usually determined by qualitative testing for HCV RNA; and
- Qualitative HCV RNA testing should be a standard component of the diagnostic work-up of all anti-HCV positive individuals. (AGDOHA, 2007: 28).

There has been little research on the diagnosing doctors' experience or needs in HCV. Although a 2006 survey of Australian general practitioners showed that two-thirds of participants felt a lot or somewhat more confident in managing people with hepatitis C than 5 years ago, substantial proportions identified ongoing training needs. Pre and post test counselling was indicated as a topic for future skills development by 32% of the sample and was the third most frequently endorsed topic (Gupta, Shah and Ward, 2006).

2.2.1 Ongoing negative hepatitis C test results

Participants reported having a number of HCV negative test results. Most participants identified that they had regularly tested negative from tests conducted at least once to twice a year. From all participant responses it was unclear as to what HCV tests were undertaken to determine the negative diagnoses. For example, when asked what the testing involved in their negative diagnosis, one participant explained that "I wouldn't have a clue. I was just told negative" (Sharon, 30 years). This lack of knowledge and understanding about testing and testing outcomes is also replicated in the findings from participant's positive result (see HCV Test Types Used for Diagnosis in this section).

> For these study participants, having had a number of negative HCV test results may have created an unrealistic sense of risk avoidance, or unrealistic optimism (Treloar and Hopwood, 2008), and therefore when the positive result was given it was met with a sense of surprise, shock and anger (19/24 participants).

The overwhelming negative response identified by participants when given a positive HCV diagnosis also highlights that these participants, hepatitis C is not normalised or accommodated in everyday life (Wozinak et al, 2007) or perceived as an eventual outcome for an injecting drug user (Davies et al., 2004). For example one participant recruited via screening for another research project, highlighted that they "had no problems doing their test, their research because I thought, yeah, I haven't got it" (Sharon, 30 years).

2.2.2 Timeframe of positive hepatitis C diagnosis

The timeframe of participant's positive HCV diagnosis occurred over a two year period. This included being diagnosed only weeks prior to the study (July 2009) as well as those who had had a received their positive diagnosis two years ago (mid-2007). The median time elapsed since positive diagnosis was 15 months. Individual participant positive HCV test timeframes are detailed in the Participant Demographics table contained in Appendix A and a summary is contained in Table 9.

Table 9: Timeframe of positive diagnosis

Timeframe	Number	% of total participants
July–December 2007	9	38
January–June 2008	6	25
July–December 2008	5	21
January–July 2009	4	16

2.2.3 Site of positive hepatitis C testing

Participants received their positive test result in rehabilitation clinics, at opiate substitution clinics (OST), in jail, from their doctor in response to the participants' requests, or as part of participation in research studies. Table 10 identifies the range of sites in which participants received their positive test and each site is discussed further in this section.

Table 10: Site of positive hepatitis C diagnosis

Site	Number	% of total participants
Clinic and health service *	10	42
Drug Rehabilitation	5	21
Hospital or GP	4	17
Research Participation	3	13
Prison	2	8

* Participants identified sexual health clinic, "clinic" and health service.

2.2.3.1 Clinic, health service, rehabilitation and custodial centre hepatitis C testing

The majority of participants (n=17) were tested at a clinic, health services, and in rehabilitation and custodial settings. A number of these participants believed that their HCV testing was due to mandatory testing policies at their clinic or whilst in residential rehabilitation or in custodial settings. Participants identified that this perceived mandatory policy required testing over a period of time, which began when they arrived at the correctional centre or rehabilitation centre or were newly registered at a clinic or use-based health service. Testing policies in these settings also resulted in HCV testing that may not have otherwise occurred. For example one participant explained:

> Because I always assumed ... it never entered my mind that I should have an HCV test ... so when my doctor said 'why don't you get done for HCV?' I said 'I don't need that' and then it wasn't until the doctor said 'do it' I said 'fuck, alright' and they did it (Dylan, 37 years).

Four participants identified that their testing for HCV was regular and had occurred for a number of years. For example, one participant explained that "being a user I made it my point to get like every six months a blood test. And that's what I've done since I was 14" (Narelle, 31 years).

2.2.3.2 Hepatitis C test undertaken by GP or in a hospital

Five participants identified that they their HCV testing through a doctor or at a hospital. Participants' motivations for requesting HCV testing were because they knew they were participating in a high risk activity, being a user, reading Users News and becoming aware, a partner or family member suggesting that it be done and for general health reasons.

2.2.3.3 Participant tested for hepatitis C as part of a research study

Three participants identified that they had received their positive diagnosis through participation in research studies. For one of these participants, their participation in the study resulted in testing that would otherwise not have occurred. She explained;

> Like now I'm glad I did the study because otherwise I never would have known, like … because it's not something you think, 'Oh yeah, I'm gonna go and get tested for hep C', Like you don't think like that. Do you know what I mean? (Jess, 38 years).

For the other participant (Helen, 23 years), HCV testing as part of the research added to her regular testing, which was done every six months because she was using with a group who she considered to be high risk.

2.2.4 Hepatitis C test types used for positive diagnosis

In total, participants identified that their health professional performed liver function and antibody tests, PCR tests and liver biopsies for their positive HCV diagnosis. The following analysis will identify the HCV test used, the result implication and participant understanding of the testing process.

2.2.4.1 Liver function and antibody tests

Participants were asked if they knew what tests had been undertaken for their HCV diagnosis. From responses provided by nine participants, the only HCV tests that had been undertaken were liver function and antibody tests. Testing for antibodies was met with some confusion by participants. For example, one participant describes that "when they did the blood test that shows, like, more in-depth blood tests, they found antibodies" (Helen, 23 years). This example highlights the perception of antibody tests as being in-depth and able to determine hepatitis C status by some participants. It also highlights that information regarding antibody tests is not being adequately discussed in pre-test discussions (see informed consent in this section).

The use of antibody and liver function tests by health professionals to provide participants with a positive test result is not best practice and does not follow the diagnostic strategies identified in the National Hepatitis C Testing Policy (2007). A positive antibody test and/or elevated liver function test alone does not in itself confirm a positive HCV diagnosis, it will only identify if a person has come into contact with the virus. Giving a person a positive HCV diagnosis based on a positive antibody test can result in an incorrect diagnosis because up to 25% of people exposed to the virus can clear the virus naturally (Cooper et al., 2007; Razali et al., 2007; Michallef et al., 2006; Gerlach et al., 2003). Applying this logic, this could have potentially resulted in two or three of the nine participants who had only been provided with an antibody test being incorrectly diagnosed with HCV.

2.2.4.2 PCR testing

A PCR test has three components, these include a qualitative PCR viral detection test that is used to determine whether a person has the presence or absence of the HCV virus in the blood and is usually undertaken to determine whether a person currently has HCV or has naturally cleared the virus. The second test is a qualitative PCR viral load that determines the level of virus in the blood. Finally, a PCR viral genotype test determines the genotype, or strain, of hepatitis C. Only two participants (Luke, 33 years; Trina, 39 years) identified that they had been given a PCR test.

Four other participants were aware of a PCR test but their responses indicated that they were aware of a PCR test rather than having undertaken it. For example, one participant explained that he thought "there are two main tests. There's one at, I think 4 months. They do a, I think it is a PCR. And if that comes back negative there is a chance of getting rid of it are 96%" (Michael, 38 years). For the other 18 participants, a PCR test was either not mentioned or completely unknown.

> Although only two participants identified that they had had a PCR test, four participants identified their genotype and had therefore had a PCR viral genotype test. The genotype strains that participants identified included genotype 1b (Jasmine, 29 years), genotype 1 (Wilson, 37 years), genotype 3 (Jess, 38 years) and genotype 2 (Steven, 42 years). One other participant identified that their doctor had told them that their genotype was the 'good one' (Dylan, 37 years).

From participant responses it appeared that a confirmatory PCR test may not have been conducted in some cases because of cost implications. For example, two participants identified that they had not had the 'more expensive' test, although in these instances the participants were not aware that the more expensive test was actually a PCR test. One participant explained:

> Unless there's a certain test that they weren't doing. I don't know. They said there's two tests. Maybe I was having one not the other … I have to get that, yeah, the more extensive test, expensive or something, yeah. I've gotta get that organised, see what the go is, yeah … Yeah, well they said because the test is very expensive so I've gotta wait to see my doctor because he'll do it for me. I can't just go to anybody. So I have to see my family doctor and he'll do it. He's on holidays. He's not coming back 'til January so I can't get the test done 'til next year (Sharon, 30 years).

These responses indicated that the service they were using for testing was unwilling or not able to provide a PCR test due to expense and some participants were told that they would have to go to another health service if they wanted this test done. For the participant above, this was an incorrect process as she was eligible for a free PCR viral detection test under the Medicare Rebate eligibility criteria.

The cost implication of a PCR test identified by participants relates to the Medicare Rebate. Within current policy, the rebate may apply to only a part of the PCR test that assesses a person's PCR viral load, which detects the presence or absence of the hepatitis C virus. The rebate inclusion criterion is contained in Box 1.

Box 1 PCR test Medicare rebate Inclusion criteria

1. "Had a positive hepatitis C antibody test combined with a normal liver function test results on two occasions six months apart, or
2. Had inconclusive hepatitis C antibody test results, or
3. Have a weakened immune systems (due to HIV/AIDS) and wish to confirm whether they are hepatitis C positive, or
4. Experienced a risk exposure (such as a needlestick injury) and wish to confirm during the 'window period' whether they have contracted the hepatitis C virus" (Hepatitis C Victoria, 2002).

> Of the nine participants who had only received an antibody test, at least three study participants were eligible for a free PCR viral detection test under the criteria listed above. These three participants could have received the test free under recent risk exposure and window period (Narelle, 31 years; Sharon, 30 years; Helen, 23 years).

It is not clear to participants why their health professional or service had not proceeded to undertake a PCR viral detection test to determine the participant's actual HCV status. This omission could be the result of a lack of knowledge about the Medicare rebate or the result of the structural and discriminatory barriers that face injecting drug users in relation to health service provision (Hopwood and Treloar, 2004; Hopwood and Treloar, 2003; Anti-Discrimination Board of NSW, 2001). The absence of PCR testing could also arise when participants were tested somewhere where they didn't have access to the Medicare rebate, those participants in jail or involved in research studies (Sharon, 30 years; Helen, 23 years), or where a Medicare card is not required for antibody testing.

2.2.4.3 Liver biopsy

Only one participant had identified that he had undergone a liver biopsy, which had occurred in February 2008. This participant was able to recall his scarring and fibrosis when prompted:

> Yes, there's a number ... And it goes 1, 2 or 3. I'm a 2 ... Yeah, I know I'm in the middle. Yeah, all I remember is I was in the middle. I'm on the verge, I'm on the verge (Wilson, 37 years).

2.2.5 Confusion about test results

In relation to the testing process, it appears that some of the study participants were given a positive HCV diagnosis from antibody and/or liver function tests, which raises questions about the general knowledge of health professionals in relation to HCV diagnostic testing and if adequate pre-test discussions occurred. These issues raise further concerns about people being provided with an incorrect HCV diagnosis and of the ability of the health professional to be able to obtain informed consent prior to testing, both of which are requirements of the Australian Government Department of Health and Ageing (AGDOHA) National Hepatitis C Testing Policy (2007).

2.2.6 Informed consent

> Participant knowledge regarding the tests being undertaken and the meaning of these results highlighted that HCV pre-test discussions were not adequate. This is either because the information is not being provided to participants at the point of testing or that the information being provided is being met with confusion and/or misunderstanding. For example, one participant highlighted the confusion that may accompany HCV testing processes. She explained that "So when they told me 'you've got antibodies' I'm like what's that? How did I get that? So yeah, I really don't know" (Sharon, 30 years).

Informed consent is a legal requirement of HCV testing as identified in The National Hepatitis C Testing Policy (2007). This policy makes it mandatory for a health professional to obtain a person's informed consent prior to HCV testing. Informed consent can only result from discussions by the health professional with the person being tested. The health professional also needs to ensure that the discussions are understood, especially with respect to the type of test and the implications of the test result.

The findings of this study indicated that there is a lack of pre-test discussions occurring about the tests themselves, the testing process and the implications of possible test results. The absence of understanding shown by participants has implications for obtaining informed consent during the testing process because informed consent can only be gained when the person is made aware and is able to understand what they are being tested for and the possible implications of the results.

2.3 Hepatitis C diagnosis

The diagnosis experience of study participant's was assessed by identifying, coding and analysing participants' experiences according to the information, counselling and referrals components of the National Hepatitis C Testing Policy (2007) for a positive hepatitis C diagnosis (see Box 2 below). The importance of these components for understanding the study participants' diagnosis experience is important because "without access to information, counselling and referral, people are disadvantaged in their attempts to cope with a newly diagnosed infection" (Hopwood and Treloar, 2004; 526).

The provision of a positive HCV test is outlined by the National Hepatitis C Testing Policy (2007). This policy identifies post-test discussions as a key principle to the policy and one which is "fundamental to Australia's response to hepatitis C" (MACASSH, 2007; 8). The policy highlights that post-test discussions "are an integral part of hepatitis C testing…and provisions of information and support is consistent with the goal of the 2nd National Hepatitis C Strategy, which includes minimising the personal and social impacts of hepatitis C infection" (AGDOHA, 2007; 24).

The policy guidelines for a positive diagnosis identify that it should be given at an appropriate time and include a post-test discussion. Post-test discussions should include "giving the test result in person and in a manner that is confidential, sensitive and appropriate to gender, cultural beliefs and practices, behaviour, ongoing risk, understanding of hepatitis C and language and literacy level; and re-assessing support mechanisms and requirements of the person and making immediate referral to a support agency to be accessed at the person's discretion" (AGDOHA, 2007; 25). The issues that should be included in a post test discussion for positive HCV diagnoses are identified in Box 2.

2.3.1 Post-test discussions that meet some components of the national hepatitis C testing policy

Participants identified instances where their positive HCV diagnosis included post-test discussions or information provision that met some of the components identified in the national testing policy such as the provision of written information, assistance with the management of emotional and psychological support needs and referrals to community based organisations. Participants' experiences related to medical referrals are discussed separately in this section.

Box 2 What should be included in post-test discussions?

- "Immediate needs and support including written referral information;
- Safer behaviours—education, information and support including needle and syringe programs if appropriate;
- Legal requirements for disclosure and how to disclose to family and friends;
- Managing or understanding strong emotions, feelings, reactions and changes;
- Options in drug treatments and medical management;
- Ongoing counselling or therapy if required;
- Complementary/alternative management options;
- Ways to deal with loss and grief, depression, anger and anxiety;
- Strategies for managing hepatitis C which are flexible and appropriate to the person's needs; and
- Legislative requirements (notification, contact tracing, storage and coding)" (AGDOHA, 2007, 25-26).

2.3.1.1 Provision of written information

At least three participants identified that they were given written information to take home after their positive HCV diagnosis. Although the National Testing Policy Guidelines identifies that written information may support the needs of people given a positive diagnosis, the effectiveness of this mode of information transfer should be assessed on an individual basis as it's adequacy for the study participants was limited. This was because people may not read the information after the appointment or it may create further structural issues by identifying a person's HCV status without their disclosure.

> For one participant, the written information provided by the health professional at the time of diagnosis may not have been read as he was unable to recall what the information contained. He explained that he was "not sure about that (the information given). Yeah, I'd have to check the paperwork I've got at home" (Matthew, 34 years).

Another instance where written information may not be appropriate involved a male participant who had not disclosed his HCV status to his girlfriend. He explained that written information would have to be hidden from his partner. In this example, the participant's concerns related to the consequences of his HCV status being uncovered even though he had chosen to not disclose this information.

2.3.1.2 Assistance with emotional and psychological needs

The following examples identify instances of assistance with emotional and psychological needs, although this assistance was not provided by diagnosing doctor. One participant identified that they were provided with ways to manage the emotional and psychological needs of a positive diagnosis as a result of being in a residential rehabilitation clinic with other people who have HCV. The participant explained that peer support from people who had been through a similar experience provided a level of emotional support that they may not have encountered had they not been in rehabilitation clinic. The participant explained;

> Being in a rehab, right, and being with other people who have got it is a lot better than finding out on your own because I could talk to other people, you know. And the staff there understood because a lot of them have it themselves, you know. And we talked about it in groups and that. And look it's not, it's not a death sentence anymore" (Caleb, 41 years).

For another participant, support with emotional needs provided after diagnosis occurred because a nurse happened to be near the participant and on seeing her distress comforted and provided emotional support and referral to a community-based. These issues helped the participant manage the strong emotions that resulted from her positive diagnosis. The participant explained:

> There was one nice nurse there. She got on the internet because there was a computer in there, and she goes,' Look' because I just started crying, you know. I was, I was just no good. And she goes, she said to me, 'It's not a death sentence, you know. It's not a death sentence. And I want you to see that, you know, you can live a healthy life with this disease, you know'. Every time she kept saying 'disease' to me I wanted to run (Narelle, 31 years).

In this example the nurse provided the participant with a link to the NSW Hep C Helpline (see peer support in this section), which the participant identified as extremely important in her ability to emotionally and psychologically deal with her positive diagnosis and future outlook.

2.3.2 Post-test discussions that did not meet components of the national hepatitis C testing policy

The majority of the study participants experienced a positive diagnosis that did not meet some, or any, of the components of the national testing policy. These experiences can be characterised by the positive test result being given at an inappropriate time, with little or not information, a lack of post-test counselling, and not addressing or being understanding of the emotional and psychological outcomes that a positive diagnosis can produce. Issues related to the legal requirements of disclosure cannot be assessed as they were not disclosed by participants during the study.

2.3.2.1 No information given at time of diagnosis

A number of participants identified that there was an inadequate level of information received at the time of diagnosis. Participants explained that at the time of their positive diagnosis they were told they had HCV but provided with little or no information about hepatitis C, safe behaviour or hepatitis C treatment and care. For example, participants highlighted that at diagnosis they received no information.

> Oh the doctor didn't say anything just that, except that I have hep C. And they didn't explain to me anything about it or anything really ... I didn't get given anything. I asked do I need to change my diet or anything and I was told, no, nothing I could do ... I don't really understand why they didn't tell me much about it because they know a lot there (Andrew, 38 years).

Another participant who had been reinfected after successful HCV treatment identified that on diagnosis of this re-infection, he did not receive any information about hepatitis C, and more specifically safe injecting practices. The participant reported that his doctor did not provide him with information because "he didn't need to did he?". That is, the doctor assumed that the participant did not require any further information. Of concern in this case is not only that the diagnosing doctor did not conduct a post-test discussion, especially related to safe practices and behaviour, but that the doctor also referred to the participant as "a bloody idiot" (Steven, 42 years) for resuming injecting and becoming re-infected.

One participant identified that post-test discussions may not have occurred at the time of his positive diagnosis because "he probably didn't seem very approachable and they didn't want to upset him". Although this example may have occurred because the health professional made a professional judgement about appropriate timing, the result was that the participant left after a positive diagnosis without any discussion or assessment of supports. He explained that there was no post-test discussion;

> Not really. He just informed me that I had it. He didn't really tell me much about it. Nothing was discussed really. Hardly anything was discussed. It was just, 'Oh yeah, it's definitely come back as hepatitis C', and that was it (Andrew, 38 years).

2.3.2.2 Inappropriate timing of diagnosis and absence of post-test discussions

Another instance of an inadequate diagnosis experience occurred when a participant was given a positive diagnosis at the end of the working day at the clinic. The example highlights that the participant was given a positive diagnosis at an inappropriate time and due to this timeframe, no post-test discussions occurred. The issue of timing was crucial in this example as it left the participant in an extremely vulnerable state that was one factor contributing to suicide attempts. In this example, the service where the participant received their positive diagnosis was also his primary source of NSP equipment and the inadequacy of the positive diagnosis resulted in the participant not returning to the service for over two years. The participant explained:

> But get this, this is the bit I still can't understand: I came in five minutes before they closed and they sat me in the room, and they said, 'Oh wow, you're positive'. And I said, 'What? For what?' They said, 'hep C'. I said, 'You've gotta be fucking joking', I was, actually was devastated you know. The fact that I had a blood-borne, communicable disease … and they're like, 'But we can't give you any counselling at the moment, we've got, because we're about to close. 'And I'm like, 'Why the fuck did you tell me now when you could have told me when I came in the next time', which was only two days ago—two days after that—when I had an appointment... And I was actually really devastated. I was left to leave with this information, go back to work (to undertake sex work), up the wall, thinking, 'Fuck, am I gonna infect people (when I have sex with them)? What am I … I didn't know. I didn't know transmission ways. I didn't know if it was like blood-borne, semen-borne. Is it in my hair? Is it in my saliva? I didn't know. And here they are just letting me just walk out the door ... I tried to kill myself a couple of times ... It's a mixture of stuff but the hep C kind of topped it off (Wilson, 37 years).

2.3.2.3 Test result confusion and lack of emotional sensitivity

For another participant, the inadequacy of their diagnosis experience resulted from the possibility that they may have been incorrectly diagnosed with HCV and that there was a lack of information and post-test counselling received by the participant. The instance was further compounded by an inappropriate response by the health professional that occurred when the participant was given their diagnosis. She explained:

> 'I have never tested positive for hep C' and the health professional responded by saying 'Oh that's a dreadful thing. It's a dreadful thing to have happened' (Naomi, 30 years).

2.3.3 Implications of not meeting people's emotional and psychological needs

Nineteen participants identified that a positive HCV diagnosis produced emotional and psychological distress including instances of depression, anger, shock, denial and disappointment. The importance of this aspect in post-test counselling is not only highlighted in the significant number of participants who identified the negative psychological and emotional effects of a positive diagnosis but also in their subsequent reductions of safe injecting and health seeking behaviour after a positive HCV diagnosis.

2.3.3.1 Diagnosis lowers concern about safe injecting and other behaviour

Although a positive HCV diagnosis can result in increased vigilance around safe injection behaviour, it can also result in reduced vigilance and behaviour that increased risk. For one participant, the positive diagnosis had a significant psychological impact that resulted in this participant becoming less vigilant with injecting practices. The participant explained:

> Since I've got the hep C I've probably cared less about injecting practices ... Prior to getting hep C I probably never share a tourniquet or anything like that. But now I'm more likely to share ... I guess it had like a big sort of psychological impact (Naomi, 30 years).

> The psychological impact of a positive diagnosis and lack of information, for another participant resulted in the participant resuming heavy drinking. He explained that "I think because I thought, 'Oh fuck I'm gonna die', so I started drinking again" (Dylan, 37 years).

These examples highlight that a positive diagnosis can negatively shape outlook for the future and result in unsafe and riskier injection behaviours if the diagnosis does not include post-test discussions that assist people in living with hepatitis C.

2.3.3.2 Reduced health seeking behaviour

The effect of a positive diagnosis can also result in people not returning to the doctor. Two participants identified this as an effect of their positive diagnosis. One participant explained:

> I haven't even gone to get another blood test since then. It's like I don't want to. I don't, I don't know, ever since I heard that I just … I don't know. I was always checking up and now that I've got it I just don't want to know (Trina, 39 years).

The other participant did not return to the clinic due to the inadequate treatment he received at diagnosis (see example in Inappropriate Timing of Diagnosis and Complete Absence of Post-test Discussions).

2.3.4 Peer and community-based organisational support

For five participants, the lack of information and emotional and psychological support provided by their health professional had been somewhat alleviated by support from their peers and community-based organisations. These responses highlight the importance of understanding, empathy and support from peers, which was perceived as more appropriate from people and organisations that "understood" their circumstances and one that could be provided at anytime of the day or night.

> I mean, I cry sometimes and sometimes I get angry with myself, and … that's when these guys and the Hep C Council, and Lifeline—they're all like really good, you know. I've used all the services: phoning, like … Because I mean I can't pinpoint when I'm gonna get depressed. And just say it is one o'clock in the morning and I can't get back to sleep because it's on my mind, I can ring these guys, you know. And they've just been great, you know. Like all these services that are available; I'm not alone... I've been told a thousand times 'you're not alone.' But that particular phone call is what made me really, truly believe it, that I am not alone ... Because I mean I get depressed sometimes about it, you know. Because I feel sometimes that, you know, I'm this diseased person and like I just feel different now (Narelle, 31 years).

> I have support. I have friends and people who have hep C, and I can talk to them and people who are in rehab were really supportive. So I found that it helped, actually. Because a lot of the girls had been through similar situations. So I always had someone to talk to, which took me a while because I'm pretty insular. It took me a long time to open up and talk to people about what was going on. But yeah, I eventually got there and it was to my benefit to talk to people (Karen, 34 years).

> You know, because you're in a room with people who understand you. You don't have to explain yourself, you know. I could go out and talk about my drug use to normal or let's say straight people. They'd say, 'You're crazy!' Being in a room of addicts—You know? And … it doesn't matter—the stories can be different but the similarities are all the same. You know? (Caleb, 41 years).

The use of informal social network or organisational peer support is supported by the National Hepatitis C Testing Policy (AGDOHA, 2007) and in the literature (Aitken et al., 2002; Hopwood and Treloar, 2003) because it is provides a level of support that may not be able to be provided in general health services. This is because it is provided by peers who share similar situations, is seen to be less judgemental and can occur at the time when it is required.

2.3.5 Post-test discussion referrals

2.3.5.1 Referrals made at time of diagnosis

The National Hepatitis C Testing Policy (2007) identifies that people receiving a positive diagnosis should be provided to referrals to appropriate services. Seven participants identified that they had not been referred to anyone at the time of their positive diagnosis. Combined with the lack of information and counselling provided to some participants at the time of diagnosis, the message that this sent was that HCV is not serious. One participant explained:

> They didn't really give me any information. All they showed me was my blood tests. And I said to her, I said, 'It's positive isn't it?' She said, 'Yeah. You've got hep C'. And I said, 'Yeah, I thought so' ... She (the health professional) never said anything to me. That's, I think that's another reason why I didn't think seriously, because if the doctors aren't telling me to do anything … obviously it's not that serious (Cathy, 21 years).

2.3.5.2 Referrals to hepatitis C treatment

> Seven participants identified that they had been, or thought they had been, referred to a doctor or liver specialist, although it appears that these referrals may not have been take up either because they said they 'honestly couldn't remember" where the referral was made to (Jasmine, 29 years) or because the referral were made for a time in future (that is, after the research interview) (Dylan, 37 years; George, 42 years).

Two participants explained that they were referred, or told that they could speak to, a hepatitis C nurse at OST clinics. Although neither of these participants had utilised this referral. One participant said that they had not yet used the referral because they "hate the [OST] clinic. Hate everything about the clinic" (Naomi, 30 years). Although the national policy identifies that referrals should be taken up by the participant at their own discretion, these examples highlight that when referrals are made to services that are perceived as inappropriate, these referrals will not be utilised.

> Participants identified that they were being referred to HCV treatment services although the actual uptake of these referrals was somewhat limited. One participant identified that because he had genotype 3 he was interested in treatment "because the chances of getting rid of it were a lot greater" (Derek, 39 years).

Another participant who had been referred to HCV treatment explained that a professional, who he thought was a trainee doctor, "was pushing the treatment and that I had a problem with him doing that" (Matthew, 34 years). The participant saw this trainee doctor whilst

at an appointment for another health condition. The recommendation was made for treatment about 6 months prior to the interview and the participant had not followed up on this.

For others, although treatment referrals may have been made the negative stories they hear from their peers about side effects reduced interest in HCV treatment. For example one participant explained;

> I was supposed to see that guy, Dr D. But I haven't seen him yet … Because I've heard so many bad things about the treatment … I'll wait 'til something different comes out (Jess, 38 years).

For one participant, a referral had been made to hepatitis C treatment, although she had decided to delay the start of treatment due to her job and because she was scared. The participant explained:

> I think I'll wait for a little while till I feel ready, because I don't really want to get on it and mess up. You know, so … And now my job has become really stable and I've got now my part-time, full-time position, so yeah, so now … in probably the next like period of time I will actually commit to going on that. But I'm a bit scared at the moment (Jasmine, 29 years).

There were also two participants who had asked their health professional about the possibility of HCV treatment but were refused access to treatment. For one participant this was because he was still injecting drugs. Although this used to be an exclusion criterion for HCV treatment, current injecting drug use is no longer an exclusion criterion. The participant explained:

> Because I talked to him about Interferon and he said I'd prefer if you waited a bit ... He won't let me on the treatment now. He goes, you've gotta be at least a year clean … (Caleb, 41 years).

The second participant was told that she needed to have hepatitis C for one year prior to undertaking treatment.

> So, I'm not allowed to go onto the treatment at least until I've had the disease for at least a year … So next July we're gonna keep, every six months we gonna do liver function tests I think they're called (Narelle, 31 years).

One participant identified that he was surprised that any health professional had not made him aware of HCV treatment or referred to HCV treatment. This may seem especially confusing to the participant as he also identified that he had been told he had the "good genotype". The participant explained:

> No options for treatment were given to me or anything like that, which I thought was a bit strange. No-one's really offered me options for treatment. Even the (rehabilitation) clinic are very, not even talking to me about options of treatment I've been seeing lots of different people. But … there's, none of them have really pointed me in the direction of the person to speak to about treatment … but I'm going to ask my doctor the next time I see him so I can get in done in a, like, private doctor—not the clinic doctor (Andrew, 38 years).

2.3.5.3 Problems with accessing treatment referral services

Participants identified that when they were referred to other health services, there were problems with contact and follow-up requiring participants to chase health professionals over a period of time to set up appointments. This resulted in participants "giving up" as other life issues took priority. For example one participant who had since started HCV treatment explained the problems in trying to contact specific people and services for appointments:

> I looked into getting on Interferon, yeah. But the lady never got back to me. I chased her up for a few months but she never got back to me … it got to the point where I rocked in there a few times and even saw the lady on the desk, and said, Listen, you know, this girl asked me to ring her and I've been ringing her (for a couple of months). Now I'm in here' … so … (the participant was not able to recontact the health professional) and so I've sort of lost track with that. You know what I mean? So … like it is on the cards but (Derek, 39 years).

Another participant explains that the timing of a referral, especially around Christmas breaks, can also result in having to chase the professional with little or no response. In this instance the participant went to the service and was greeted by the receptionist who basically told them not to worry about their hepatitis C.

> Then we booked in to see the lady at (a major Sydney hospital), yeah. And then because it was Christmas, the lady was going away and she was due back on a certain date. And sure enough, I was chasing her up, chasing her up, chasing her up … nothing, nothing, nothing. And then the receptionist lady turned around and said, she goes, she goes, 'Yeah, I've got hep C'. She goes, 'The thing is that you'll be', she goes, 'You'll be …' she just said, 'How old are you?' And I said, 'Nearly 40'. She said, 'You'll be dead before it even takes any effect on you, you know. Before you suffer any effects from it, you know, the chances of you being dead before it actually takes a hold on you'" (Derek, 39 years).

2.3.6 Summary

Participants' narratives of HCV testing were characterised by confusion. This was because of a lack of awareness and understanding about the HCV tests that were undertaken, the implications of test results and an absence of knowledge about what tests were required to provide a positive HCV diagnosis. Confusion in participant narratives surrounding testing has important implications for pre-test discussions and informed consent, which are components of the National Hepatitis C Testing Policy.

Overall, HCV diagnosis experience of participants was poor. As described by participants, post-test discussions were inadequate particularly because of the lack of information provided to participants. Other diagnoses were received at an inappropriate time, evidence of the use of inappropriate tests and a lack of emotional sensitivity of the health professional when giving the positive diagnosis.

Participants' narratives of diagnosis could not be differentiated according to the site in which testing occurred. This is concerning as settings such as prison, rehabilitation and clinics and health services targeting PWID may be conducting HCV tests on large numbers of their clients. Support for diagnosing doctors and their patients in these settings are also indicated by these results. GPs may be involved in the diagnosis of a small number of infections in their careers. Support for this group to provide diagnoses at the standard of the National testing policy is also suggested by these data.

The study acknowledges a self-selected and small sample. However, these results reflect and extend findings of previous larger scale study of diagnosis experience of people living with hepatitis C in NSW (Hopwood and Treloar, 2004).

2.4 Phase Two recommendations

Access to adequate volumes and type of injecting equipment

These findings highlight the need for increased access to both greater volume and specific types of sterile injecting equipment. We recommend that NSW Health:

- continue to enhance distribution of greater volumes of injecting equipment via NSP and pharmacy services
- continue to explore ways to support peer distribution of injecting equipment
- develop, in partnership with NUAA, education messages to inform clients that restrictions on amounts of equipment have been removed
- consider providing sterile water in a range of volumes to facilitate client choice and safer practice (i.e. both 1ml and 5ml ampoules to avoid re-use/sharing of 5ml ampoules)
- consider provision of winged infusion sets through NSPs

Adequate provision of pharmacotherapy in custodial settings

Our results highlight the vulnerability to infection produced by states of opiate withdrawal, including forced withdrawal from pharmacotherapy treatment as a result of detention in settings where continued access to prescribed pharmacotherapy is not provided.

We recommend that NSW Health, via MACH, instigate high level discussions with the Department of Corrective Services and the NSW Police Force regarding the right to access to pharmacotherapy as an essential medication for people in custodial settings.

Access of people in custodial settings to prevention programs of a standard equivalent to that available in the community

These findings highlight the seroconversion risk of injecting in prison. The C-Change report of the Anti-Discrimination Board enquiry into hepatitis C related discrimination noted that pressing concerns for people in prison was access to health care, health promotion and prevention programs at a standard equivalent to community programs.

We recommend that NSW Health consider means to support access to sterile injecting equipment for people in prison.

Messages and strategies to address transmission risk between couples who inject

These findings highlight that decisions of sexual partners to share injecting equipment may have lead to hepatitis C seroconversion. However, the evidence-base for health promotion for injecting couples is limited.

We recommend that NSW Health promote research and consultation on this topic to inform health promotion messages and strategies specifically targeted to men and women.

Development of guidelines for people who inject regarding appropriate testing frequency

The findings highlight that participants had difficulty identifying particular events which could have resulted in exposure and possible seroconversion. Rather, participants

acknowledged a range of potential risk practices for hepatitis C infection.

We recommend that NSW Health, in partnership with NUAA, develop guidelines for seeking hepatitis C testing such as a self-assessment tool based on a range of risk practices.

Increasing awareness of national Hepatitis C Testing Strategy key principles to improve diagnosis quality

This study demonstrated that few diagnosis experiences were adequate according to the principles of the National Hepatitis C Testing Strategy particularly with regard to the confidential and voluntary nature of testing with informed consent and pre- and post-test discussion.

We recommend that NSW Health issue new policy directives to emphasise the testing policy recommendations including information about the Medicare rebate eligibility for hepatitis C RNA testing, and that this directive be circulated to all Area Health Services, including Justice Health.

Support for general practitioners providing hepatitis C diagnoses

It is acknowledged that only a small proportion of general practitioners will develop specialist skills in hepatitis C and most general practitioners will only deliver a small number of hepatitis C diagnoses in their careers.

We recommend that NSW Health consider opportunities to extend the ASHM mentoring program for GPs who have not previously given a HIV diagnosis, to support appropriate hepatitis C diagnosis experiences.

Further, we recommend that NSW Health consider liaison with diagnostic laboratory services to provide diagnosing doctors with a resource sheet delivered with pathology reports (via fax or electronically) which includes key information to be provided to the patient, including referral to community-based organisations.

Areas for future research

Findings from this qualitative data characterise the HCV diagnosis experience as sub-optimal. These findings support and extend earlier quantitative and qualitative research from NSW which established low levels of information provision and referral provided at diagnosis (and lower for people who inject drugs) (Hopwood et al., 2004). The impact of diagnosis experience on future care and treatment is unknown.

We recommend further research in this area to explore the impact of diagnosis experience on future engagement with treatment and care and other hepatitis C-related health outcomes.

Further, there is an emerging body of work examining the influence of social networks on injecting practice. Our findings extend this work to suggest ways in which people who inject are constrained in their decisions about and ability to use sterile injecting equipment. We recommend further research in this area to extend understandings of practice and explore implications for the measurement of injecting risk.

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Appendix A
Laboratory test results: definitions

Table 11: Public laboratory HCV antibody test codes

Hep C (1) antibody	Hep C (2) antibody	Interpretation
NEG	<blank>/ NEG	HCV antibody negative
NEG	POS	Indeterminate
<blank>/POS	POS	HCV antibody positive
POS	NEG/ EQU/INS/INSP	Indeterminate
INS/INSP	POS	HCV antibody positive
INS/INSP	NEG	HCV antibody negative
INS/INSP	<blank>/INS/INSP	Insufficient sample for testing
EQU	NEG	HCV antibody negative
SC	<blank>	See comment
NOSP	<blank>	No specimen received

Table 12: Public laboratory HCV PCR test codes

Test set	Result	Interpretation
V755	Detected	HCV RNA positive
V761B	<615 IU/mL	Below detection limit, cannot assume HCV RNA negative
	615-7692310	HCV RNA positive
V330R	Not detected	HCV RNA negative
	Detected	HCV RNA positive
V330L	Not detected	HCV RNA negative
	Detected, <15IU/mL	HCV RNA positive
	Detected, <43 IU/mL	HCV RNA positive
	43-69000000	HCV RNA positive
	Detected, >69000000	HCV RNA positive

Table 13: Private laboratory HCV antibody test codes

HCV antibody	Interpretation
P	HCV antibody positive
N	HCV antibody negative
RR	HCV antibody positive
RRC	HCV antibody positive
E	Indeterminate
L	Low - indeterminate
IN	Insufficient sample for testing

Appendix B
Interview schedule

Seroconversion/transmission event/s

Ask participant to describe in their own words how they believe they became HCV infected.

- Explore the following once they have given an initial response
- Describe what happened. Was this episode a typical or usual scenario, or if different, how?
- Or if a specific incident isn't known:
- Can you identify any instances or time periods of risky behaviour in the last 1–2 years where you think you might have got the virus? Can you tell me what happened that time? (probes: who, where, context etc).

If method/time of acquisition unknown and/or non-IDU:

- Have you had any body art done in the last 1–2 years? (tattooing, piercing (temporary or permanent), cutting, scarification, professional or at home/friend/jail) Was there anything about the process that seemed risky for passing on hepatitis C (i.e. a chance for someone else's blood to enter your bloodstream).
- Can you think of any times in the last 1–2 years where you might have had contact with someone else's blood other than through sharing fits or injecting equipment? (probes: fights/accidents/injuries/cleaning/injecting others)
- What about exposure at home? (probes: razors/toothbrushes etc)

Testing history

- What was your reason for being tested for the hepatitis C virus? (explore who initiated the test)
- Can you tell me the approximate dates of your last two negative hepatitis C tests? (if appropriate)
- When did they receive the positive test result?

Diagnosis experience

- Who told them they had hepatitis?
- What were the circumstances? (explore where it took place and who was present)
- What information were they given at the time of diagnosis?
- Were they offered referrals to other services, treatment options?
- How did they react to the diagnosis?
- What did they think at this stage it would mean in their life?

Knowledge

- What did you know about hepatitis C prior to diagnosis?
- Explore knowledge pre/post diagnosis about injecting safety, hep C, hep C treatment, misinformation.
- Explore sources of knowledge—where they get information from about Hepatitis C, safe injecting and drug use
- Explore links to acquisition
- How common do you think hepatitis C is among people who inject drugs [if relevant]?
- How many people do you know have hepatitis C?
- Before you were diagnosed, what did you think about your chances of getting hepatitis C?
- Can you tell me what you know of available treatments for hepatitis C? (identify what they knew pre- and post- diagnosis

- What do you think of these treatments? Would you consider them for yourself? (perceived effectiveness/side effects)

Contexts/networks

- In this section explore the context/circumstances leading up to HCV infection. Their biography of this period, i.e. what was happening in their life that might have influenced their risk for hepatitis C.
- Ask about their social life, changes, stability.
- Ask about social networks, family, friends and relationships
- Let's start with your friends. Who do you mostly hang around? (probes: any changes around time of HCV acquisition/how/gender/age/ethnicity/ proportion IDU)
- How about your relationships with your family or partner? (probes: any changes around time of HCV acquisition /failed relationships/break-ups etc/nature and type of contact with family/partner/children)
- What about your living arrangements? Any changes around time of HCV acquisition? (probes: how/homelessness?)
- Has your financial situation changed? (probes: changes in government benefits/patterns of income generation/crime/sex work/support habit by ?)
- How about your drug use? Did it change at all around time of HCV acquisition? (probes: using more or less/drug type [cocaine/ice]/frequency of injection/increased tolerance/use after a period of abstinence or MMT/usually or often hanging out when using)
- What about your sex life? Any changes? What has been happening in the last 2 years/ compare around time of HCV acquisition? \
- Probes: new partners/paid sex/sex for drugs, Safer sex (condoms/dams)—consistent use?
- Who with: regular partners / casual?
- Blood during sex: menstruation, rough sex
- Changes in practices around time of HCV acquisition?
- Higher risk practices: group sex, anal sex, fisting (vaginal or anal), BDSM with body fluid/blood present or possibly present (cutting, piercing, whipping)

Drug Use

- Explore the type of drugs used, how they were used, frequency, who they use with.
- Where they use
- Get them to describe in detail a typical injecting event
- Get them to describe in detail an injecting event that they regard as atypical
- Explore what they consider to be safe injecting practices? Probe safety in relation to self and others
- Ask about sharing of equipment, injecting others and coming into contact with blood
- Ask about drug treatment

Equipment

- Explore where they get equipment, type of equipment they typically access, explore coverage/quantity/access

Post diagnosis experience

- Explore treatment—hep C and drugs, injecting, relationships, health, wellbeing, Sense of future

- Do you / have you told anyone else about your diagnosis (disclosed positive status)? If told, who do you choose to tell? Why / why not? What words do you use?
- Have you ever been accidentally pricked/jabbed with someone else's used needle and syringe or other sharps? Why/when did this happen? Describe the situation. Around time of HCV acquisition?
- What did you do in your injecting [or sexual / other if relevant] practice that was influenced by your awareness of hepatitis C?

Is it important to you to work out how you got the virus or who you got it from?

- Probes: why/why not?

Would you like to find out more about your hepatitis C?

- If yes, make referral

Appendix C

HCV seroconversion project: participant demographics (*n*=24)

Case	Pseudo	Age	Gender	ATSI	COB	Cultural background	Language	AHS location	Type of Residence	Main drug injected	Income	Prison	Recent Prison <2 yrs	Positive HCV diagnosis	Place of positive HCV diagnosis
1	Andrew	38	Male	Yes	Australia	Aboriginal-Australian	English	NCAHS	Public rental	Heroin	Pension	Yes	Yes	May 2008	Rehab
2	Anthony	44	Male	No	UK	Anglo-Australian	English	SESIASH	Emergency	Heroin	Wage	Yes	No	End 2007	Clinic
3	Caleb	41	Male	No	Greece	Greek-Australian	English	SESIASH	Private rental	Heroin	Unemployment benefit	No	No	July 2008	Rehab
4	Cathy	21	Female	No	Australia	Aboriginal-Australian	English	SESIASH	Public rental	Meth	Unemployment Benefit	No	No	Early 2009	Research
5	Derek	39	Male	No	UK	Anglo-Australian	English	SESIASH	Public rental	Heroin	Pension	No	No	Nov 2008	Clinic
6	Dylan	37	Male	No	Australia	Anglo-Australian	English	SESIASH	Rehab	Heroin	Unemployment benefit	No	No	Dec 2008	Rehab
7	George	42	Male	No	Australia	Anglo-Australian	English	SESIASH	Public rental	Meth	Pension	Yes	No	Mar 2008	GP
8	Helen	23	Female	Yes	Australia	Aboriginal-Australian	English	SWSAHS	Private rental	Meth	Unemployment benefit	No	No	Mar 2009	Research
9	Jasmine	29	Female	No	Australia	Anglo-Australian	English	SESIASH	Unassigned	Heroin	Wage	Yes	No	Nov 2007	GP
10	Jess	38	Transgender (MTF)	Yes	Australia	Anglo-Australian	English	SESIASH	Public rental	Cocaine	Pension	Yes	Yes	Dec 2007	Clinic
11	John	30	Male	Yes	Australia	Aboriginal-Australian	English	SWSAHS	Public rental	Heroin	Unemployment benefit	Yes	Yes	Late 2008	Research
12	Karen	34	Female	No	Australia	Anglo-Australian	English	SESIASH	Emergency	Heroin	Unemployment benefit	Yes	No	Dec 2007	Hospital
13	Luke	33	Male	No	Australia	Anglo-Australian	English	SESIAHS	Private rental	Heroin	Wage	No	No	Mid 2007	Rehab
14	Matthew	34	Male	No	UK	Anglo-Australian	English	SESIASH	Public rental	Meth	Unemployment benefit	No	No	Early 2008	Rehab
15	Michael	38	Male	No	Australia	Anglo-Australian	English	SESIASH	Own Home	Heroin	Unemployment benefit	No	No	2007	Clinic
16	Naomi	30	Female	No	Australia	Anglo-Australian	English	SWSAHS	Private rental	Heroin	Wage	No	No	Feb 2009	Clinic
17	Narelle	31	Female	Yes	Australia	Aboriginal-Australian	English	SWAHS	Public rental	Heroin	Unemployment benefit	Yes	Yes	Jul 2009	Prison
18	Peter	49	Male	No	Australia	Anglo-Australian	English	SESIASH	Private rental	Meth	Unemployment benefit	No	No	Nov 2007	Clinic
19	Russell	32	Male	Yes	Australia	Anglo-Australian	English	SESIASH	Private rental	Heroin	Unemployment benefit	Yes	Yes	Feb 2008	Clinic
20	Sharon	30	Female	Yes	Australia	Aboriginal-Australian	English	SWSAHS	Jail	Heroin	Pension	Yes	Yes	Nov 2008	Prison
21	Steven	42	Male	No	Australia	Anglo-Australian	English	SESIASH	Unassigned	Heroin	Unassigned	Yes	Yes	Mar 2008	Clinic
22	Teagan	29	Female	No	Australia	Anglo-Australian	English	SESIASH	Private rental	Heroin	Wage	Yes	No	Early 2008	Clinic
23	Trina	39	Female	No	Australia	Anglo-Australian	English	HNEAHS	Own Home	Heroin	Pension	No	No	July 2007	GP
24	Wilson	37	Male	No	Australia	Anglo-Australian	English	SESIASH	Public rental	Heroin	Pension	Yes	No	Dec 2007	Clinic

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