Drawing Blood: Injecting Drug Users, Blood Borne Viruses, Testing and Vaccination

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National Drug Research Institute

Preventing harmful drug use in Australia

Curtin University of Technology, Peth, WA

January 2000

This study was funded by the Public Health Research and Development Committee of the National Health and Medical Research Council

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ISBN 1 86342 846 1

ACKNOWLEDGMENTS

This study would not have been possible without the support and assistance of a number of people. We thank our funding body and the Director of the National Centre for Research into the Prevention of Drug Abuse (now the National Drug Research Institute). Thanks are also due to the members of the Steering Committee: Dr Mike Belbin , Ms Jude Bevan, Mr Steve Blackwell, Dr Ann Cambridge, Ms Susan Carruthers, Ms Helen Fowler, Mr David Grant, Dr Tony Keller, Ms Kathryn Kerry, Dr Jan Machin and Dr David Smith. The WA Substance Users' Association, the William Street Clinic of the then WA Alcohol and Drug Authority (now Next Step) and the Sexual Health Clinic, Fremantle Hospital generously gave us space to conduct interviews and we thank them.

Finally, we thank all of those service providers and injecting drug users who gave their time and expertise to assist us in this research.

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EXECUTIVE SUMMARY

The high rate of transmission of blood borne viruses (BBVs) among injecting drug users (IDUs), and the seriousness of the resulting diseases, means that IDUs are commonly tested for BBVs, particularly if they attend drug treatment clinics. The assumption appears to be that if IDUs know their serostatus they are in a good position to protect both themselves and their communities by behaviour change and improved health care. Yet the HIV/AIDS testing literature suggests that this assumption is oversimplified, and there is little or no contemporary literature that examines the human factors involved in being tested for hepatitis C or B, or being vaccinated against hepatitis B.

The major aim of the present study was to conduct an investigation of testing IDUs for hepatitis C, hepatitis B and HIV/AIDS and vaccinating IDUs against hepatitis B, from the perspectives of both IDUs and test service providers (SPs). Perth IDUs were recruited through advertising and snowballing to take part in an anonymous and confidential semi-structured interview for which they were offered $15. SPs from every Australian jurisdiction were recruited through snowballing and networking to complete a faxed questionnaire and participate in a half hour telephone interview. The data are both quantitative and qualitative.

A total of 200 IDUs,103 men and 97 women, were interviewed. Their ages ranged from 14 to 47 years with a mean of 26.1 and a median of 24 years. The majority of respondents were not married or living with sexual partners, and nine out of ten respondents were heterosexual. Five identified themselves as of Aboriginal or Torres Strait Islander descent.

Most of the IDU respondents had used alcohol, cannabis, hallucinogens, amphetamines, heroin, ecstasy, and benzodiazepines at some time. Just under half had used methadone. Almost all of the respondents who had used heroin or amphetamines reported injecting these drugs at some time. Of the 182 respondents who had ever used heroin, 96% reported injecting within the last year and 67% within the last month. The main drug injected by over three quarters of respondents was heroin.

Around 70% of respondents had been tested for each of the three viruses an average of 7 times, and approximately 7% had received more than 10 tests within each category. Much of the testing was done in batteries of all three tests.

Almost 60% of respondents had not been vaccinated against hepatitis B, 24% had been vaccinated, 9% were hepatitis B antibody positive, and 8% did not know whether or not they had been vaccinated.

Thirty nine SPs were interviewed throughout Australia: half from rural and half from metropolitan areas. One third were recruited from each of general practices and sexual health clinics. Others worked in drug treatment centres, hospitals, and other agencies including contact tracers, prison medical services, gay and lesbian medical services, community health services and youth health services. These agencies saw an average of 706 clients per month. Service providers ordered an average of 40 hepatitis C antibody tests, 51 hepatitis B antibody tests and 52 HIV tests a month. They also carried out an average of 19 hepatitis B vaccinations a month.

Almost all IDU respondents believed that each of the BBVs was a risk for IDUs. The three major reasons for being tested were that the respondent had been exposed to risk in some way, the test was recommended or required, and/or the respondent was concerned about the possibility of passing BBVs to others. A further category, only applicable to hepatitis B testing, was that the respondent had experienced signs or symptoms of illness.

Reasons for not having never been tested included that the respondent believed that they were not at risk, they had not “got around to it” and/or they scared or nervous about test outcomes. Some respondents had never heard of a hepatitis B test.

SP informants reported that their IDU clients were offered testing if they had disclosed past or current injecting drug use during history taking, and/or if they self-referred for testing. A few said they tested IDUs routinely and some said clients were tested if there were symptoms present, an abnormal liver function test was detected, or as part of an STD screen. Over a third of SP informants said they would re-test a client every time a test was requested.

One hundred and fifty testing events were described by IDU respondents. Most of these were descriptions of batteries of all three tests and only 17% described a first test experience. Most of these testing events occurred at the individual’s request.

For many, the experience was routine. Three quarters claimed to have received no pre test counselling although some said that this was because they did not want or need it. However, some misunderstood the question “were you offered any pre-test counselling?” apparently believing that this asked whether they were referred to another person or agency for counselling prior to being tested. Whether or not respondents received pre-test counselling was related to the nature of the service provider who ordered the test. GPs and hospitals were reported as being less likely to have provided counselling than medical, sexual health and drug treatment clinics.

All SP informants said that pre- and post-test counselling was provided for a BBV test. The majority reported using pre-test counselling to assess the client’s risk, discuss transmission and prevention, give information about the viruses, tests and window periods, and establish what clients would do if they received a positive result.

IDU respondents reported that they had received their test result in a face to face interview with their test service provider on almost three quarters of occasions. However, on around one in ten occasions they had received them by telephone. Some respondents had not collected their results: most of these because they believed that they would be informed if their results were positive.

The majority of SP informants reported that they always gave BBV results face to face but a few said that they were less stringent about hepatitis C and B than HIV/AIDS results, and were prepared to give these results over the phone. SP informants’ main explanation for IDUs’ failure to collect results was that they were transient and mobile.

IDU respondents reported that no post-test counselling was given on over 80% of described test occasions. Provision of post-test counselling was related to the test result, with seropositive clients being more likely to have received counselling than those who were negative. Many of those who described post-test counselling, moreover, reported it in terms of medical advice given if they were hepatitis C positive. Only four respondents described post test counselling which was focussed on prevention. Respondents were referred to other medical or community agencies on only nine test occasions, with most of these referrals being to specialist medical services. Most said they did not know at the time about local community-based support agencies.

Almost all SP informants said they used post-test counselling to discuss prevention with clients whose results were negative. With positive results most SP informants used post-test counselling to suggest follow-up and monitoring, including further testing and referral to specialists. The majority said they also discussed transmission and prevention issues with positive clients and referred them to specialists. One in three mentioned referring to alcohol and drug services, sexual health clinics, and support services.

IDU respondents reported that on almost 40% of described test occasions they experienced anxiety which tended to be related to waiting for results. The majority of those whose results were negative said that they were pleased, relieved, or not surprised. Those who received positive test results were almost equally divided between being upset/angry/concerned, not surprised or focused on their state of illness or health.

SP informants had observed a wide range of emotional states in their BBV tested clients, but anxiety predominated. Most said they dealt with these reactions with counselling but one in three said they provided more information, and some referred these clients.

IDU respondents who had been tested at least once were asked if they had changed their behaviour in any way subsequent to their last test. The majority of respondents, regardless of the test outcome, had not changed their behaviour, with the most common reason for this that they were “already safe”.

Almost half of IDU respondents said that they knew little or nothing about hepatitis B vaccination. Many of those that had not been vaccinated had never heard of it or did not realise that such a vaccine was available and/or no-one had ever suggested they should be vaccinated or offered them the opportunity. The most common reason given for being vaccinated was that it was suggested by a doctor or clinic staff.

All SP informants believed that IDUs needed to be advised to be vaccinated and half said that vaccination came about mainly as a result of their recommendation. Some thought that vaccination needed to be pushed more.

The implications of these data are discussed in terms of the NHMRC guidelines when testing for hepatitis C. These lay out standards for pre- and post-test counselling and suggest that the outcomes of counselling should be the provision of psychosocial support, prevention of the transmission of hepatitis C and the optimisation of treatment outcomes. Our data suggest that, in the main, only the last of these outcomes was being met. Much of the counselling suggested in the guidelines was not occurring, and post-test counselling was primarily used after positive results as a medical intervention. While a range of emotional experiences related to being tested was described by IDU respondents, very few were referred to local support agencies such as the Hepatitis C Council. The testing process, as described by our IDU respondents, did not actively encourage seronegative IDUs to initiate behavioural change, nor did it encourage seropositive IDUs to regard their normal behaviour as behaviour which might transmit infection to others.

Reported low levels of vaccination are also a concern. Most of the respondents in this study had been tested because they were IDUs, but few had been vaccinated, even though many of these had received a negative hepatitis B test. It appears that opportunities for prevention of this disease had been squandered.

Testing for BBVs provides an ideal opportunity in which doctors and other service providers can help IDUs to make the behaviour changes necessary to prevent these infections, or to prevent reinfection and/or other complications associated with infection. It is also an opportunity to inform and advise IDUs about vaccination. Since so many IDUs are tested, the potential for incidence reduction and secondary prevention is enormous.

We believe that more information is needed from doctors, IDUs and other relevant parties about the limitations and difficulties with existing current pre-and post-test counselling guidelines when testing IDUs who may receive multiple tests. We have recently received funding to undertake a further in-depth examination of clinical and practical difficulties with these. The findings of the two studies should enable the development of specific recommendations on maximising the efficacy of the testing process to prevent and limit the spread of blood borne viruses among injecting drug users in Australia.

INTRODUCTION

Given the high rates of transmission of hepatitis C and hepatitis B among Australian injecting drug users (IDUs), the need to monitor HIV/AIDS in IDUs because of major epidemics in other countries, and the seriousness of the resulting diseases, it is not surprising that most Australian IDUs have been tested for hepatitis C, hepatitis B and HIV/AIDS. In the 1994 Australian Study of HIV and Injecting Drug Use (ASHIDU)[1], for example, 79% of IDU respondents had been tested for hepatitis C, 81% had been tested for hepatitis B and 91% had been tested for HIV/AIDS. These results were influenced by age and treatment status, such that older IDUs and/or those who had been in treatment were more likely to have been tested, but nevertheless, more than half of those under 24, and/or those who had never been in treatment, had been tested for all three viruses (Loxley, Carruthers & Bevan, 1995).

A considerable literature exists in relation to human factors involved in testing for HIV/AIDS, but there appears to be little or no literature related to human factors in testing for hepatitis C and hepatitis B or vaccinating against hepatitis B. In discussing testing for HIV/AIDS, Beardsell (1994) pointed out that while UK HIV/AIDS test policies appeared to be based on the assumption that there was a correlation between HIV/AIDS testing/counselling and behaviour change, that assumption was simplistic and failed to take account of the complexity of sexual and drug using behaviours, and the range of motivations for participation in testing. She cited a review of twelve studies of testing and injecting drug use which found that behaviour changes were not linked to knowledge of HIV/AIDS status. She also noted that “a negative result may lead to a false sense of security that may sustain or even increase these [risky] behaviour patterns” (p. 10).

Phillips and Coates (1995) found that social stigma and fear of discrimination, the potential for adverse consequences in social relationships if a positive HIV/AIDS result was returned, concerns about coping with test results, perceived lack of risk or need for testing and privacy concerns were all barriers to testing for HIV/AIDS. They asserted that research should investigate not only the initial decision to be tested, but also follow-

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[1] A national study of 872 IDUs recruited in four capital cities

through, and focus on elucidating factors which prevented people at risk from seeking counselling and testing. Phillips and Coates were also concerned with the role of healthcare providers in encouraging or discouraging testing, and maintained that the impact of counselling and testing on youth should be studied.

Lindan, et al (1994) investigated HIV/AIDS testing among alcoholics and drug users. They concluded that there was substantial misunderstanding or misreporting of test results, and maintained that this ..."underscores the need to improve testing and counselling procedures in this group" (p. 1155).

These reports suggest that being tested for HIV/AIDS, at least, is not necessarily a valuable or useful experience for testees. Research over some years into the relationship between injecting drug use and BBVs at this Institute has led to some similar conclusions. The thrust of our concern is that failure to take account of the complex human factors involved in testing can either deter individuals from presenting for testing, or render testing ineffectual for both the testee and her/his community. The following are some examples that have emerged from our research:

- In the Australian National AIDS and Injecting Drug Use Study (ANAIDUS), some respondents failed to understand the question: "Have you ever received a positive test result?". The most probable misinterpretation of the question was as "Have you ever been cleared of being infected with HIV/AIDS?" (Loxley, 1991).

- In a study of young IDUs, the motivation for HIV/AIDS testing was not normally that respondents believed they had put themselves at risk, but more to prove to other people that they were not infected. Testing did not usually result in behaviour change. The decision to be tested was difficult for some, and the process of testing intimidating for others, so much so that some respondents assumed their own HIV/AIDS status on the basis of others' because they were unwilling to be tested. Some respondents were unaware of services provided for testing, and others did not understand the meaning of the test results. A few respondents were unwilling to collect test results because they were afraid of the outcome (Loxley, 1998).

- In the same study, Ovenden and Loxley (1993) found that fewer than half of all respondents who had been tested for HIV/AIDS by their General Practitioner received pre- and post-test counselling which met the Australian Medical Association and Royal Australian College of General Practitioners guidelines. Some doctors had not received informed consent, and the giving out of results over the phone or by receptionists was common.

- A substantial proportion of respondents in the ASHIDU were uncertain about the meaning of a positive antibody test for hepatitis C, hepatitis B and/or HIV. Approximately 10% reported not understanding the meaning of a positive hepatitis (B or C) test, while 5% did not understand the meaning of positive HIV/AIDS test. Nearly 20% of respondents thought that a positive HIV/AIDS test indicated that the individual had AIDS. A small proportion believed that a “positive” test meant the person tested had not been exposed to the virus. Most respondents had had multiple HIV/AIDS tests with evidence in some of considerable levels of over-testing (the maximum reported number of tests was 60). Self-reported BBV serostatus and hepatitis B vaccination status were inconsistent across multiple measures, and with serology undertaken for the study (Loxley, Carruthers & Bevan, 1995).

These results suggest that there are issues relating to testing for BBV among IDUs which bear further and more specific examination. In particular, there is a need to investigate the process of testing IDUs for hepatitis C and B vaccinating them against hepatitis B, because there appears to be no contemporary research around this issue. The research reported here was funded by the Australian National Health and Medical Research Council to address these concerns.

The major aim of the study was to conduct an investigation of issues from the perspectives of both IDUs and test service providers (SPs) relating to testing IDUs for hepatitis C, hepatitis B and HIV/AIDS and vaccinating IDUs against hepatitis B. Specific objectives were:

- to develop a questionnaire to assess behavioural, cognitive and affective aspects of IDUs’ decision to be tested, the test process and test outcomes, and similar issues relating to vaccination.
- to recruit a sample of at least 200 IDUs, stratified for age and experience in drug treatment, and administer the questionnaire in individual face-to-face interviews.

- to recruit a sample of SPs from every Australian jurisdiction and interview them by telephone about their views and experiences of testing IDUs for BBVs.
- to offer each IDU respondent education and information about testing for BBVs.
- to make recommendations for future interventions and research in this field.

METHODS

OVERVIEW

Two hundred Perth IDUs were recruited through advertising and snowballing to take part in an anonymous and confidential semi-structured interview for which they were offered $15. Thirty nine SPs from every Australian jurisdiction were recruited through snowballing and networking to complete a faxed questionnaire and participate in a half hour telephone interview. Quantitative data were analysed with SPSS 6.0 (Norusis, 1993) and qualitative data with QSR NUD*IST version 4.0 (Qualitative Solutions and Research Pty. Ltd, 1997). All processes and methods were approved by the Curtin University Human Research Ethics Committee before the commencement of data collection.

INSTRUMENTS

The development of questionnaires and interview guides was informed by the literature, previous research at this Institute, and input from a Steering Group which was made up of various experts in the blood borne virus (BBV) field in Perth (see Appendix 1). The IDU questionnaire was piloted with IDUs in residential rehabilitation, and the SP questionnaire was piloted with SPs in metropolitan Perth. Copies of all questionnaires and interview guides can be seen in Appendix 2.

RECRUITMENT

Injecting drug users were recruited in Perth in three phases through advertising and snowballing. In the first phase local drug treatment agencies, sexual health clinics and needle exchanges distributed fliers advertising the study. In the second phase, fliers were distributed around university campuses, and cafes and clothing stores. In the third phase an advertisement was placed in a local free music and entertainment magazine. In each case recruitment materials stated that IDUs who had injected in the previous 12 months were sought for an anonymous and confidential 30 minute interview about their drug using experiences, for which they would be paid $15. A name and mobile phone number were given to make appointments for interview.

ASHIDU had demonstrated that younger IDUs were less likely to have been in treatment than older IDUs (Loxley, Carruthers & Bevan, 1995) and we assumed that they were therefore less likely to have been tested. We consequently deliberately over sampled IDUs under the age of 20 so that there would be adequate numbers of respondents who had never been tested. It was our intention that not more than 50% of the sample would be aged over 20 and/or not more than 50% of the sample would have been in treatment for drug-related problems.

We attempted to recruit four metropolitan and four rural test SPs in each State and Territory. Known BBV health professionals across Australia were used to assist in the recruitment of informants through snowballing and networking. Potential informants from an initial list of names were approached to see whether they conformed to the inclusion criteria of having contact with IDUs and doing BBV testing, and would be willing to participate in the study which involved completion of a faxed questionnaire and a half hour telephone interview. Those who did not fit the criteria were asked to suggest others who did. There were no refusals.

DATA COLLECTION

IDU respondents were interviewed on site at one of three agencies. Interviews were tape recorded where permission to record was obtained, and later transcribed from notes and tapes. The data were collected during the latter part of 1997 and early 1998.

A four page questionnaire containing questions about agencies, testing practices, staff training and staff knowledge of BBV was faxed to SP informants with a choice of follow up interview times. Telephone interviews took approximately 30 minutes and were transcribed from notes. The data were collected during the first half of 1997.

ANALYSIS

Quantitative data for both IDUs and SPs were analysed with SPSS 6.0. Most of the analysis was descriptive, although some statistically significant bivariate data are presented. Qualitative data in the IDU study were transcribed and introduced into QSR NUD*IST 4.0 before being coded. First-level coding took place along the lines delineated by the questionnaire structure; further levels of coding explored themes emerging from the spread of responses given by respondents to these questions. These themes are presented with both typical responses and responses indicative of the range for any given line of questioning. SP data were transcribed and summary tables created for each interview questions. The presentation describes the range of responses for relevant lines of questioning.

RESULTS

Results are grouped into four broad sections: a description of each study group; events and decisions leading up to the test event (referred to as the decision to be tested); the test event itself (referred to as the test process) and the consequences of the test event. In each section, data are presented first for IDUs and then for SPs.

DESCRIPTION OF INJECTING DRUG USER RESPONDENTS

Two hundred IDUs were interviewed: 96 (48%) of these were female and 104 (52%) were male. Almost all (92%) identified as being heterosexual: there were 7 male and 12 female respondents who identified as homo- or bi-sexual. The majority (79%) of respondents were not married or living with sexual partners. The age range was 14 to 47 years, with a mean of 26.1 and a median of 24 years. The age quota was not met, with only 31% of the group being 20 years or younger.

The majority (87%) of respondents were born in Australia and five identified themselves as of Aboriginal or Torres Strait Islander descent. The second most frequent (8%) place of birth was the United Kingdom or Ireland. Most respondents (98%) reported that English was the main language spoken in the home in which they grew up.

Almost half (45%) of respondents had no education beyond Year 10. Of the remainder, 56 (28%) had completed some or all of Years 11 and 12, and 53 (27%) had completed some or all of some form of tertiary education. The majority (64%) were unemployed; 16% were in part time or casual employment and 8% were in full time work. Thirteen percent were secondary or tertiary students. The most frequent job description given by those who were employed was salesperson (30%), followed by labourer (26%) and tradesperson (15%).

The main source of income for 47% of the study group was unemployment benefits followed by other government benefits (28%). Only one in five cited employment as their primary source of income.

Fifty six percent reported having received treatment at least once for substance related disorders. Younger respondents (those 24 years of age or less) were significantly less likely than older respondents (those over 24 years)[2] to have been in treatment (35.8% vs 78.7%; $p < .001$). Forty-one percent of respondents were engaged in treatment at the time of interview, and again there was a significant age difference (18.9% of younger vs 66.0% of older, $p < .001$).

Respondents were asked which drugs they had ever used, whether they had ever injected the drugs they had used; whether they had injected that drug within the last year and whether they had injected that drug within the last month. Results are presented in Table 1 below.

Table 1: Drugs ever used, ever injected, injected in last year and injected in last month (n = 200)

	Ever Used		Ever Injected (If Ever Used)		Injected in Last Year (If Ever Used)		Injected in Last Month (If Ever Used)	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Alcohol	199	99.5	7	3.5	4	2.0	1	0.5
Cannabis	199	99.5	1	0.5	1	0.5	0	0.0
Hallucinogens	195	97.5	45	23.1	15	7.7	3	1.5
Amphetamines	193	96.5	182	94.3	137	71.0	53	27.5
Heroin	182	91.0	181	99.5	175	96.2	122	67.0
Ecstasy	159	79.5	49	30.8	15	9.4	4	2.5
Benzodiazepines	130	65.0	35	26.9	23	17.7	5	3.8
Methadone	91	45.5	30	33.0	15	16.5	7	7.7
Steroids	5	2.5	3	60.0	2	40.0	0	0.0
Other	16	8.0	2	12.5	1	6.3	1	6.3

Table 1 shows that most respondents had used alcohol, cannabis, hallucinogens, amphetamines, heroin, ecstasy, and benzodiazepines at least once. Just under half had used methadone. Steroid use was relatively uncommon.

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[2] These age groups are consistently used to characterise ‘younger’ and ‘older’ respondents._

Almost all of the respondents who had used heroin or amphetamines reported injecting these drugs at some time. Of the 182 respondents who had ever used heroin, 96% reported injecting within the last year and 67% within the last month. Seventy-one percent of respondents who had ever used amphetamines reported injecting within the last year and 28% within the last month.

Half of the respondents had last injected within the week preceding the interview while only 20% had last injected longer than 3 months prior to the interview. The main drug injected by over three quarters (78%) of respondents was heroin. The only other preferred drug nominated by more than 3% of the group was amphetamine (19%).

Twenty percent of respondents had been injecting for fewer than 2 years, one third between 2 and 5 years, 20% between 6 and 10 years, and the remaining 28% for over 10 years.

One hundred and forty two respondents (71%) had been tested at least once for at least one of the BBVs of interest to this study. The number of times respondents had been tested for each virus can be seen in Figure 1.

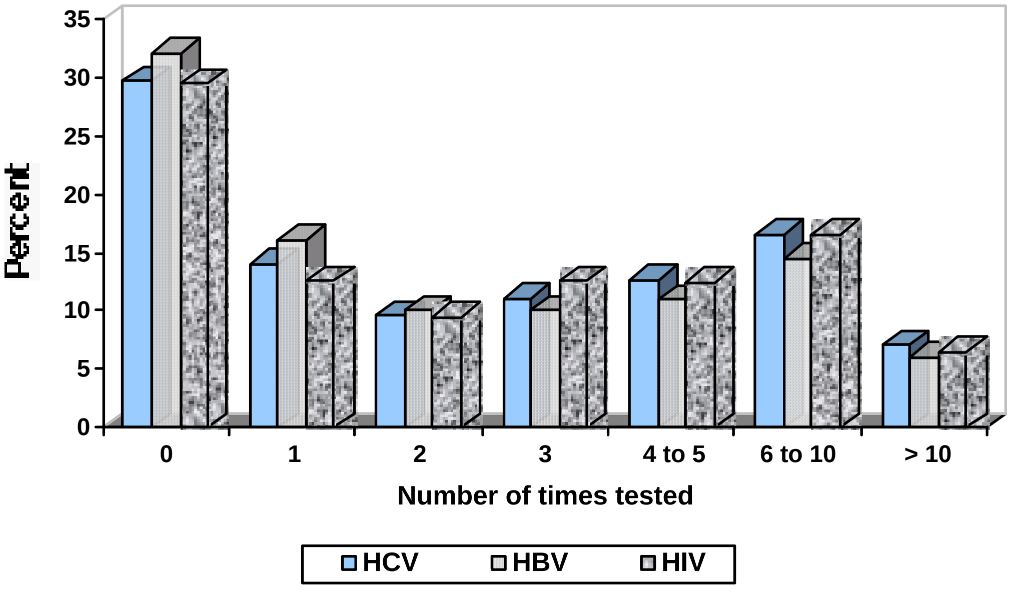

Figure 1: Number of times respondents tested by BBV (n = 142)

Seventy percent of respondents had been tested an average of 5.6 (median 4) times for hepatitis C; 68% had been tested an average of 5.8 (median 3) times for hepatitis B and 70% had been tested an average of 6.4 (median 4) times for HIV/AIDS. Between 6 and 7% of respondents had received more than 10 tests for each BBV.

Younger respondents were less likely than older respondents to have been tested for hepatitis C (49.1% vs 93.6%; p < .001), hepatitis B (50% vs 88.3%; p < .001) or HIV/AIDS (49.1% vs 94.7%, p < .001).

The mean and median times elapsing since the first and last test for each BBV is shown in Table 2.

Table 2: Months elapsed since first and last BBV test (n = 142)

	Months Elapsed Since First Test				Months Elapsed Since Last Test			
	n	Mean	Median	Range	n	Mean	Median	Range
Hepatitis C	137	47.6	46.0	1-135	139	10.7	6.5	1-75
Hepatitis B	133	63.3	58.0	1-238	135	15.3	7.0	1-142
HIV/AIDS	139	58.3	58.0	1-168	140	10.7	6.5	1-132

Two thirds of first hepatitis C tests, and 57% of first hepatitis B and HIV/AIDS tests had been had been undertaken during the previous five years. The most recent tests had been undertaken within the last three months for approximately 40% of all those tested. The frequency of testing is shown in Table 3.

Table 3: Frequency of testing

	Frequency of Testing					
	HCV (n=139)		HBV (n=131)		HIV/AIDS (n=140)	
	n	%	n	%	n	%
Once a year or less	36	25.9	32	24.4	37	26.4
At 4-6 monthly intervals	27	19.4	22	16.8	26	18.6
At 1-3 monthly intervals	16	11.5	11	8.4	15	10.7
Tested once/not tested since	25	18.0	26	19.8	25	17.9

No longer tested/bad veins	4	2.9	5	3.8	5	3.6
Irregularly/ not enough/ rarely	12	8.6	16	12.2	13	9.3
At risk/reason to get tested	7	5.0	6	4.6	8	5.7
Not specific/other	12	8.6	13	9.9	11	7.9

Table 3 shows that approximately a quarter of all respondents tested for each virus indicated they were tested annually or less frequently, while about a fifth said testing occurred every 4 to 6 months. One in ten respondents were tested at least every three months. Just under 20% reported that they had only been tested once.

Most testing had been carried out in batteries of at least two BBV tests, and a majority of respondents had never had a test for a single BBV. The most recent test experience for 85% of those who had been tested was a battery in which they were tested for all three BBVs. Of the 22 who did not receive a battery of tests on the last occasion, 15 were seropositive for at least one BBV, but many of these received that diagnosis after the last test so that seropositivity was not the reason for not undergoing a full battery. A more common reason was that the respondent had been vaccinated against hepatitis B which made the hepatitis B test irrelevant.

The types of agencies which provided the most recent tests are shown in Figure 2, in which test occasions, rather than individuals, are enumerated.

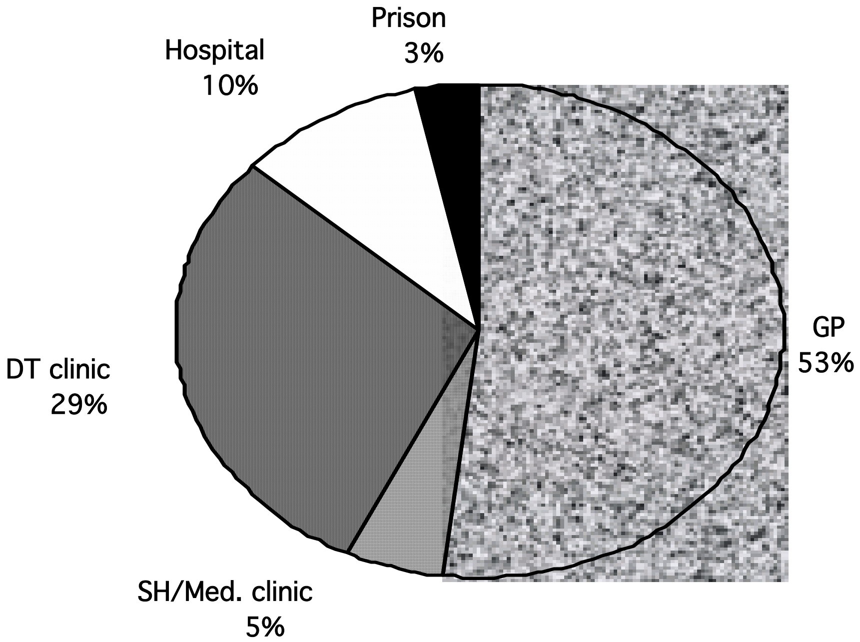

Figure 2: **Service providing most recent test(s) (n = 150) (DT = Drug treatment, SH = Sexual Health)**

Figure 2 shows that more than half of the tests were provided by GPs, with a majority of the remainder being provided in drug treatment agencies and clinics.

Fifty eight respondents (41% of those who had been tested) reported being antibody positive to one or more virus: 56 reported that they were hepatitis C positive; 12 that they were hepatitis B positive and 2 that they were HIV positive. The relationships between reported seropositivity for the different viruses are shown in Figure 3.

Figure 3: Self-reported seropositivity for hepatitis C, hepatitis B and HIV: IDU respondents (n = 58)

Figure 3 shows that a majority of those reporting hepatitis B positivity, and both of those reporting HIV positivity were also positive for hepatitis C. The majority of those reporting hepatitis C, however, were not positive for the other viruses.

DESCRIPTION OF SERVICE PROVIDER INFORMANTS

There were 39 SP informants drawn from every State and Territory. They were almost evenly divided between rural (51%) and metropolitan locations (49%) but we were not able to recruit four in each of metropolitan and regional areas in every jurisdiction as planned (Table 4). Table 5 shows the distribution of SP informants by their jurisdiction and type of agency. The majority were drawn from general practice (GP) and Sexual Health Clinics (SH). Fewer came from drug treatment centres (DT), hospitals (Hosp) and other services (contact tracer, prison medical service, gay and lesbian medical service, community health service, youth health service). There were some jurisdictional differences, with more GPs being recruited in SA and WA, and more SPs from sexual health clinics being recruited in NSW.

Table 4: Distribution of SP informants by jurisdiction and location type

State/Territory	Metro	Regional	Total
ACT	4		4

NSW	2	4	6
NT	2		2
QLD	4	3	7
SA	4	4	8
TAS	1		1
VIC	2	3	5
WA	3	3	6
Total	22	17	39

Table 5: Distribution of SP informants by agency type and jurisdiction

State/Territory	GP	SH	DT	Hosp	Other
ACT	1	2	1	0	0
NSW	2	3	1	0	0
NT	0	2	0	0	0
QLD	1	2	2	0	1
SA	4	1	1	0	2
TAS	0	1	0	0	0
VIC	2	1	0	0	2
WA	3	1	1	2	0
Total	13	13	6	2	5

The number of agency staff involved in testing for BBV ranged from 1 to 24 (mean 6.4). An average of 706 (range 3 - 4000, median 2002) clients[3] were seen by the agencies per month, with an average of 37% (median 51%) of clients disclosing that they were IDUs.

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[3] The term ‘clients’ is used consistently, although some referred to testees as ‘patients’

Most (56%) of the SPs described their client group as members of the general community, and only the drug treatment agencies and one GP described their client group as IDUs. The gender balance of clients being tested was generally relatively even.

In almost every case, IDU clients were more likely to self-refer for testing than be referred. On average, 85% of BBV clients were said to self-refer.

The number of tests ordered each month for hepatitis C (antibody), hepatitis B (surface antigen, antibody and/or core), and HIV/AIDS and/or vaccinations against hepatitis B can be seen in Table 6 which shows that there was considerable variation in the number of tests and vaccinations ordered by participating agencies or providers per month, but similar numbers of tests for HIV/AIDS and hepatitis B were ordered. Fewer hepatitis C tests were ordered overall. Most informants reported that they ordered hepatitis B surface antigen, antibody and/or core tests depending on the circumstances, although a substantial minority ordered only the first two of these.

Table 6: BBV tests and vaccinations ordered per month by SP informant agencies

	mean	**median**	**range**
Hepatitis C	40.4	175	0-350
Hepatitis B	51.3	175	0-350
HIV/AIDS	51.5	177	2-350
Vaccination	18.7	75	0-150

The relationship of the number of tests and vaccinations to agency type can be seen in Table 7.

Table 7: Mean number of BBV tests and vaccinations ordered per month by SP informant agencies, by agency type

Agency type	mean # hepatitis C tests	mean # hepatitis B tests	mean # HIV tests	mean # vaccinations
GP	11.5	10.7	13.6	6.8
Sexual Health	69.7	92.5	88.6	25.6
Drug Treatment	27.8	36.0	40.1	30.5
Hospital	106.0	103.0	103.0	1.0
Other	16.4	31.2	31.2	17.2

Table 7 shows that overall the two hospital clinics ordered the most tests while the GPs ordered the least number of tests, but that both of these agency types ordered similar numbers of tests for each virus. Other agencies ordered more HIV/AIDS and hepatitis B than hepatitis C tests: the reason for this is not clear but may relate to high rates of diagnosed hepatitis C (and hence less testing) in the target populations. The drug treatment and sexual health clinics ordered the most vaccinations.

Professional staff at the majority (86%) of the agencies received training on BBVs but fewer (59%) of the agencies offered training on IDU issues. BBV training consisted mainly of courses, seminars, workshops, conferences and journal reading. In-service training from senior staff or visiting specialists was mentioned, as were staff meetings, Continuing Medical Education (CME) activities for doctors and self directed learning. IDU training consisted of journal reading, conferences and seminars, updates from specialists, in-service, staff meetings and self directed learning. Some SP informants also said they received information from non-government organisations, clients and the community.

Almost a half of SP informants were familiar with the NH&MRC Guidelines for hepatitis C, over a third were not and a few knew of their existence but were not familiar with them. However only one in three of those that said they were familiar with the guidelines had read them. This means that approximately 15% of SP informants had actually read the guidelines.

THE DECISION TO BE TESTED

This section describes the background to the decision to be tested or not tested from the perspectives of the IDU respondents and the SP informants.

Perceptions of BBV Risk to IDUs

In order to help assess the motivations of IDU respondents for being tested and their expectations of the testing process and its consequences, they were asked whether they believed each of the three BBVs under study was a risk for IDUs. Almost all IDU respondents believed that each of the BBVs was a risk for IDUs. Reasons given for this belief were very similar for hepatitis C and HIV/AIDS with around three quarters citing the role of sharing, and one in three simply mentioning "blood" as a risk factor. Unsafe sex was mentioned as a risk for both hepatitis C and HIV by 12%. An additional risk of Hepatitis C was its prevalence, mentioned by 17%.

> [It's] *more of a risk than HIV – there's more people in the community that carry hepatitis C – you're going to come in contact with more hepatitis C carriers than HIV carriers*
> (28 year old woman)

Hepatitis B was a little different: while similar numbers thought it was risky, there was less certainty about why. Around half thought sharing was a risk, a further quarter mentioned blood, and 12% mentioned prevalence, but 20% said they did not know much about it.

Reasons for Being Tested

All IDU respondents (n = 142) who had been tested for one or more BBVs were asked "Why did you decide to get tested for [the BBV in question]". Two thirds gave just one reason for being tested.

As discussed above, the majority of respondents who had been tested for BBVs had received a battery of all three tests at one time, and gave responses which indicated that they thought of the battery as being one test. Even when the tests had been conducted individually their reasons for being tested were similar for all three tests, except in the case of hepatitis B testing, where an additional reason to be tested, discussed below, was mentioned. Therefore, except where indicated, the following description of responses to questions about reasons for being tested have not been separated according to virus.

There were three major categories of reasons for being tested:

- the respondent had been exposed to risk in some way;
- it was recommended or required; and/or
- the respondent was concerned about the possibility of passing on BBVs to others

A further category, only applicable to hepatitis B testing, was that the respondent had experienced signs or symptoms of illness.

Seventy two respondents (51% of those tested) stated that at least one of their reasons for being tested was that they had been exposed to BBV transmission risks. The three sources of risk mentioned were unsafe injecting practices, unsafe sex and associating with others who were seropositive or engaged in high risk behaviours. Half of these responses related to their own unsafe injecting practices. Some of these appeared to be occasional or one-off exposures to risk:

> *A stuff up - basically I had my own needle - my two friends were sharing one that they were going to clean, but my friend gave me one she'd used, so we all ended up sharing, so I decided to get tested*
> (23 year old woman)

Others described behaviour which was now, by inference, behind them:

> *I'd been using a syringe in jail that everyone had been using and it was put to me when I first came on methadone that I should be tested and I did*
> (36 year old man)

Some appeared to be describing more regular practices:

> *Because I had hepatitis B and I've been sharing - just to check it out*
> *(28 year old man)*

Almost a quarter of respondents who had been tested mentioned that having had unsafe sex or requiring an examination for sexually transmissible diseases had contributed to their decision to be tested.

> *I was 18, young and had unprotected sex, and it (HIV) was a really big thing, everyone was really paranoid about it. Newspapers make you really scared*
> (26 year old man)

Again, some respondents discussed sexual behaviour in terms of one-off events or behaviour from the past. Finally, one in three of those who had been tested mentioned being "generally at risk" or (more rarely) being close to others the respondent identified as being at risk:

> *Because when I found out that my boyfriend was a dealer and a full on user and had been in jail for 3 years and been using, I thought "Whoa, shit" because there's big shortage of syringes in jail and thought I'd better get a test done*
> (27 year old woman)

Older respondents were twice as likely as younger (32% vs 15%) to list unsafe injecting as a reason for being tested but the reverse was true for sexual risk: younger respondents were more than twice as likely to list sexual risk as a factor than older (40% vs 16%).

Thirty three respondents (23% of those tested) stated that at least one of their reasons for being tested was a recommendation or requirement from a doctor, treatment agency or prison. Six of the seven respondents who referred to being tested in prison explicitly stated that testing was compulsory. For other respondents the degree of coercion involved was often less clear. In some instances there was clearly a high degree of coercion involved, as when respondents were told that testing was necessary before a treatment or procedure would be carried out:

> *It was a requirement - a gastro specified that I do that before an examination, because I disclosed I'd injected once "I won't touch you unless you've had a test". Wasn't my decision, just included in pathology package*
> (27 year old man)

In other cases the test appeared to be simply the result of a healthcare professional encouraging the respondent to be tested:

> *Because I went to [local drug treatment agency] and they said that I should get tested and I thought I was pregnant and the doctor convinced me to have all these other tests too*
> (17 year old woman)

Even where some degree of coercion seemed to be involved, respondents often indicated that they thought it was a good idea:

> *It was a policy at the rehab and I thought it was a good idea to get everything checked out*
> (37 year old woman)

Older respondents and those who had been in drug treatment were more likely to indicate that testing had been required or recommended than younger respondents and those who had never been in treatment. Those who were seropositive for at least one BBV were twice as likely to mention a recommendation or requirement as a causative factor in being tested as those who were not known to be seropositive. In some of these cases, however, serostatus did not influence the recommendation as it was established at the test in question. Almost 20% of respondents who had been tested suggested that it was the possibility of infecting another person that prompted a test. Slightly more than half of these mentioned this concern in connection with a relationship and/or with an intention to have children in the future:

> *I'd been injecting a little while and had just started a new relationship. We thought it was a good idea to be tested before we had sex without condoms*
> (20 year old man)

As noted above, 66% of those tested gave only one reason for being tested, while the remaining 34% gave more than one reason. The following diagram shows where overlaps occurred.

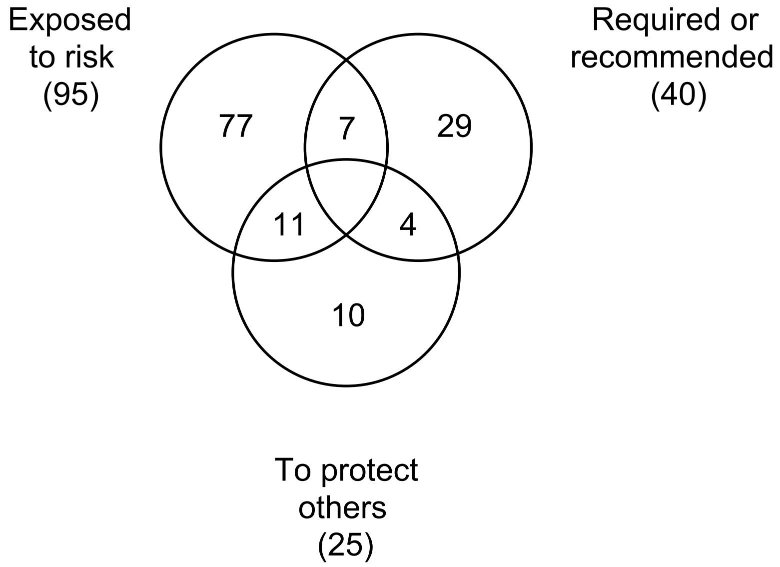

Figure 4: **Relationships between reasons for being tested: IDU respondents (n = 138)**

Figure 4 shows that the overwhelming reason for being tested was that the respondent believed that s/he had been exposed to risk, but that other reasons were important too.

The same themes as those identified as reasons for being tested for hepatitis C and HIV/AIDS were also identified as reasons for being tested for hepatitis B. However, an additional theme was also noted. Six percent of those who had been tested for hepatitis B indicated that the reason for their test was that they had symptoms of the virus:

> *Because I was yellow and not feeling too good, and mates had it, so I got checked*
> (28 year old man)
>
> *Bad pain in my stomach, couldn't hardly walk, was sleeping a lot, skin was yellow (thought I had a good suntan) and eyes were yellow. My boyfriend and I used to share needles - he was a carrier*
> (37 year old woman)

Reasons for Not Being Tested

Fifty eight respondents (20%) had never been tested for any of the BBVs under study and eight had been tested for fewer than all three (Figure 5).

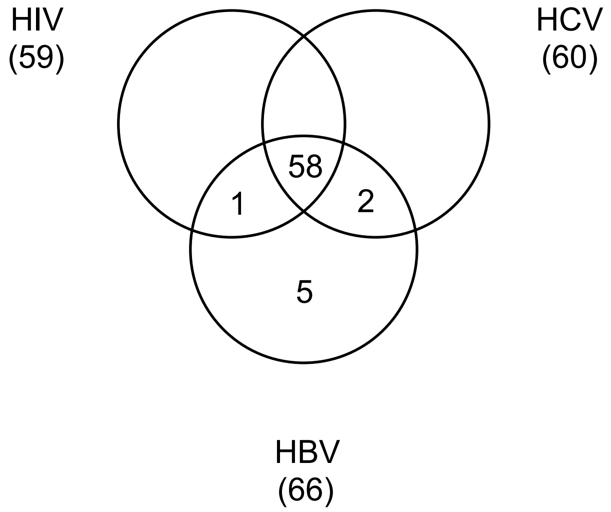

Figure 5: Interactions between non-testing for BBVs

Figure 5 shows that most non-testing related to all three viruses. It should be noted however, that some respondents who had been tested in batteries were not certain about all the tests that might have been undertaken.

Those who reported that they had never been tested for one or more of the BBVs under study were asked why not. Answers given to these questions did not appear to be differentiated across BBVs, except in the case of hepatitis B where there was a specific additional reason which is described below.

Almost half of those who said they had not been tested for a given BBV gave multiple reasons for not having done so. These answers fell into four broad categories:

- Respondents believed that they were not at risk
- Respondents had not “got around to it”
- Respondents were scared or nervous about test outcomes
- (For hepatitis B only) respondents had not heard of the test

Forty three respondents (72% of those who had not been tested) indicated that they did not feel a test was necessary or that they did not consider themselves at risk of contracting the virus in question. The three reasons people gave for this belief were that they practiced safe injecting, that they practiced safe sex and/or that they were simply “not at risk”.

> *I've thought about it, but never gotten around to it. I really don't think I'd have anything like HIV or the heps because I'm so careful about injecting - I use a new fit every time and clean equipment. It's unnecessary to share anything when you can get stuff so easily from the* [needle exchange] *van and chemists and* [local fixed site needle exchange] *etc.*
> (18 year old woman)

Forty respondents (67%) indicated that they had not got around to it or were "just lazy".

> *Bit lazy. I go into doctors to get them and they give me referrals to … and I never get around to going and doing them.*
> (21 year old man)

These 40 respondents included individuals who made comments to the effect that they had "considered being tested" but who gave no further reason for not being tested, and also includes two individuals who said they were not sure why they hadn't been tested.

Eight respondents (13%) indicated that they had not been tested because they reluctant or scared to know their serostatus:

> *I knew you'd ask me that, God, well to be honest, I've been a bit frightened, you see, I stopped using all drugs over 10 months ago, like at the beginning of last year, and when I was using I was pretty careful usually, you know, "new fit every hit", and all the rest, but I did have a few slips over the years so I really should be tested*
> (20 year old man)

None of these 8 respondents gave "being scared" as a sole reason for not being tested. All, like the respondent above, gave more than one reason.

Figure 6 shows the relationships between different categories of reason given for not being tested for any or all of the three BBVs.

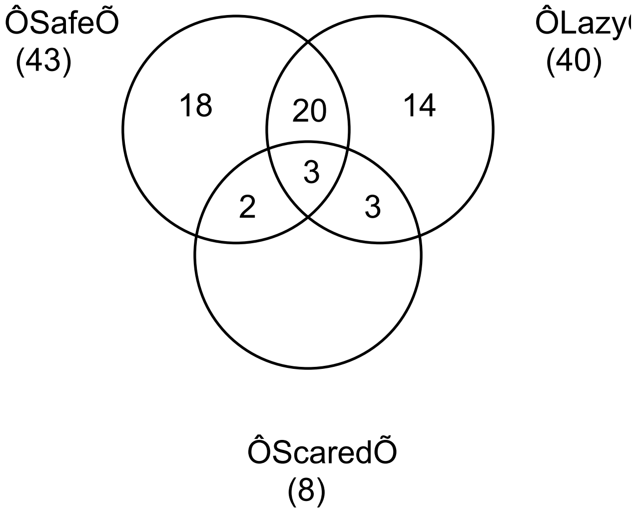

Figure 6: **Relationships between reasons for not being tested: IDU respondents (n = 60)**

Figure 6 shows, again, the importance of multiple reasons and particularly, the overlap for considering oneself “safe” but also “lazy”.

The reasons for not being tested for hepatitis B were similar to those described for hepatitis C and HIV/AIDS but an additional theme, ignorance of the virus and/or the test for the virus, was also identified. Six respondents either did not know what the hepatitis B virus was or did not know that a test for it was available:

> *I wouldn’t have thought about it apart from in any relation to a general illness. I haven’t been tested for measles either, like that sort of thing. I don’t really know much about it*
> (21 year old woman)

All respondents, regardless of whether they had ever been tested for a given BBV, were asked “Have you ever refused to be tested for [the BBV in question] when it has been recommended?”. Only 4 respondents reported that they had at some point refused a test and they each gave different reasons for refusing:

> *Yes, here* [drug treatment agency] *they used to throw them on you "no methadone" etc., I said no because I didn't have the time.*
> (47 year old man)

> *I refused a test here* [drug treatment agency]*, wasn't ready for it, I'd been using with junkies over from Sydney, everyone rooting each other and shooting up, bad situation, felt strongly I was at risk and didn't want to have it. Did go later though.*
> (26 year old man)

> *Yes, in a job situation - my boss said I'd have to have monthly blood tests to see if I was using drugs - by a private doctor – at* [a private massage parlour]
> (19 year old woman)

> *Yes, only once and that was 26 years ago. I was in jail in Adelaide (medieval days)* [they] *offered prisoners pack of cigarettes if submitted to blood test for STDs and on principle alone I refused it.*
> (46 year old man)

All of these individuals also stated that they had at some point been tested for the BBV in question, either prior to and/or since the time they refused testing.

Only 4 respondents reported that they had even been refused a test, and there were only two descriptions of this:

> *Yes, it was an older doctor in the suburbs and I basically got the "filthy junkie trash" attitude "you'll have to go off and pay for them yourself at the pathology centre".*
> (23 year old woman)

> *Yes, that was the very first time I went for testing and the doctor laughed at me.*
> (38 year old man)

The Decision to Test – SP Informants

SP informants were asked about the circumstances in which BBV testing was or was not ordered. For the most part, their IDU clients were offered testing if they had disclosed past or current injecting drug use during history taking, and/or if they self-referred for testing. Less frequent circumstances were client disclosures of sharing injecting equipment or unsafe sex, and referrals from other agencies. A few SP informants (particularly those who worked in methadone clinics), said they tested IDUs routinely and some said clients were tested if there were symptoms present, an abnormal liver function test (LFT) was detected, or as part of an STD screen.

The majority of SP informants believed that IDUs requested testing because they knew someone who was, or had recently been diagnosed, positive. One in three stated that IDUs were well educated and aware of the risks, and a similar number believed that IDUs requested testing after some media publicity or health education about BBVs. Other perceived reasons for requesting testing included IDUs’ concern about symptoms, a desire to give up drug use, and/or make lifestyle changes and concerns about transmission of BBVs to significant others.

Over a third of SP informants said they would re-test a client every time a test was requested: this often related to the perception that risk behaviour was continuing as in the following:

> *Some people come every three to six months and hide the fact that they're continuing to use unsafe practises.*

The majority of SP informants, however, said they questioned why re-testing was being requested; whether any further risky behaviour had occurred; and/or whether client had doubts about previous results or were obsessional. Most said they would re-test if there was a valid reason. In fact, a majority said they had never refused to give a BBV test when it was requested by them. As one put it:

> *If they ask for it there is some worrying reason. I allay their worry and guilt and get it done, then use the results as a counselling point.*

Another said, *"sometimes it's a waste of time, but we never refuse"*. Those that had refused testing had usually done so because of a perceived inability of the client to give informed consent, whether from intoxication or mental instability, at that time. Some said they refused to test if they were concerned about client self-harm, for example in response to statements like *"I'll throw myself off a building if I'm positive."* Some said they refused because the client had been recently tested and was still in the window period, or were what they termed "chronic" or "obsessive" testers. One said they regularly pointed out to clients that *"testing does not offer protection"*.

There was a wide variation in the range of responses to the question about when to re-test, but most SP informants said that it depended on the risk behaviour of the client. The most prevalent re-test frequency was every 3-6 months, but some reported preferring to test once a year.

Some SP informants said that they accepted that:

> *"Some people's sole safe practise consists of getting re-tested every three months"*

Almost two thirds of SP informants said they had had clients refuse a BBV test after being advised to have one. Some said that when clients refused a test they would explain the importance of knowing their BBV status in terms of prevention and management. As one remarked, *"the devil you know is the devil you can deal with"*. Some said they provided refusers with information on risks and harm minimisation. A few said they invited refusers back later, or brought it up from time to time as part of ongoing clinical management. Most said it was the client's decision. The reasons clients gave for refusing testing were that they didn't feel ready to know their status, or didn't want to find out at all. A few SP informants said clients wanted to think about it, or go to their own GP (if at an agency) for testing. Some said clients did not think they were at risk, were scared of the blood test itself or had been tested previously.

THE TEST PROCESS

IDU respondents were asked to given details of the most recent occasion on which they had been tested for each virus. These descriptions are outlined in this section, with each major theme followed, where available, by relevant comments from SP informants.

One hundred and fifty testing events were described by IDU respondents . Of these, 119 (79%) were descriptions of batteries of all three tests. The remainder were 31 descriptions by 22 respondents of one or two tests conducted on a single occasion. In describing these events, only 17% of respondents was describing to a first test experience. For many, the experience was routine. Comments along these lines included:

> *I just had to have a blood test, I didn't even get the results, they're just in my file, if I had anything they'd tell me*
> (31 year old woman)

> *Very routine, went in, took blood, got results, no surprises*
> (35 year old man)

> *I'd given up using … because of that I suppose, just standard - get checked for everything - had quite a few done*
> (38 year old woman)

> *Went in, did a test and that was it, never thought much of it*
> (27 year old man)

Even for those having a first test the experience could be uneventful:

> *I just had blood tests that took a long time, it was fine*
> (22 year old woman)

Sixty three percent of these testing events occurred at the individual's request: a further 14% were recommended by their service provider, and 7% occurred as a requirement before entering treatment. A small group of respondents reported that their most recent tests were compulsory for other reasons: in hospitals, detention centres, because the respondent was a sex worker or as part of a pregnancy check.

Preparation for Testing

Three quarters of IDU respondents claimed to have received no pre test counselling although some said that this was because they did not want or need it:

> *No, not really - had enough knowledge myself - knew it's a killer and that's all I have to know to want to find out if I've got it or not*
> (19 year old man)

> *No because I said don't worry about it. Don't think I really need it - I've had it before*
> (31 year old woman)

> *No, don't need it. Have been through all that before*
> (35 year old man)

However, it is clear that some respondents misunderstood the question "were you offered any pre-test counselling?" apparently believing that this asked whether they were referred to another person or agency for counselling prior to being tested:

> *No, if I'd asked they probably could have arranged something*
> (27 year old man)

> *Pretty sure they asked me questions about my knowledge and gave me the option of having counselling*
> (28 year old woman)

> *Offered. I said no it's better to find out first and then get counselling*
> (32 year old woman)

Of those who underwent pre-test counselling, a few described it in very positive terms:

> *Yes - all the info and emotional support, possible outcomes of the test. All round it was a good experience really very positive. Resulted in me feeling that even if I was positive it wasn't a disaster or the end of the world. He told me - don't take too many tablets, don't drink much, you've got to be careful. He's a good doctor*
> (27 year old woman)

But for some, even though the counselling was thorough, the experience might have been a waste of time:

> *Yes, 20 minutes - I think just explaining what it was and how transmitted. I think they said some positive things like if you are positive can live OK and survive quite positively. But I was sure I was OK so didn't pay much attention*
> (28 year old man)

And for others the experience was far from positive:

> *Just told me all about hep B and C and stuff, he didn't say what to expect if they came up positive. I wouldn't know what to do - probably kill myself*
> (17 year old woman)

Pre-test counselling seemed to have been generally focussed on all three viruses and tests, which was presumably because most testing was in batteries:

> *Yes, what tests were, what HIV, Hep B and C were, how transmitted and meaning of a positive result, what I'd do if I was positive etc*
> (28 year old man)

Whether or not respondents received pre-test counselling was related to the nature of the service provider who ordered the test. There was a significant difference ($p < .005$) in the provision of pre-test counselling, with GPs and hospitals being reported as less likely to have provided counselling than medical, sexual health and drug treatment clinics. All SP informants said that pre- and post-test counselling was provided for a BBV test. This was usually carried out by doctors, nurses, counsellors or social workers. In most cases, the person who took the blood did the counselling, although a few agencies sent their clients to pathology laboratories for phlebotomy. About half of the SP informants said the time spent on counselling varied enormously and depended on factors such as the level of knowledge of the client, whether they had or had not been tested before, their background and circumstances, risk factors, their needs at the time, and the test outcome. This variety is illustrated by the following comments from SP informants who were asked how long they spent on test counselling:

> *Depends, rarely less then half an hour, can be up to three or four hours. About half an hour for pre- and if HIV positive, will spend about 20 minutes on post. It's an opportunistic environment, if they engage well we'll make the most of it. Not as much time as we should.*

The majority of SP informants reported using pre-test counselling to assess the client's risk, discuss transmission and prevention, give information about the viruses, tests and window period, and establish what clients would do if they received a positive result. About a third discussed follow-up testing, treatment and the social impact of results. Twelve (31%) informants specifically mentioned that they informed clients about the notifiability of results, confidentiality, referral and/or that results could only be given in person. The level of client's understanding was also ascertained by some. Disease progression, emotional impact and support networks, sexual and drug use histories, effect on lifestyle, and issues of disclosure, insurance, employment and legal obligations were also mentioned. A few said they encouraged clients to ask questions, provided them with written information and discussed false positives and negatives, coding of pathology forms, re-testing and/or whether the client knew of anyone with these viruses. Very few said they mentioned hepatitis B vaccination at that time.

The pre-test counselling practice of one SP informant, however, had changed with experience:

> *I used to spend hours discussing every little thing* [but] *there's a limit to which they can assimilate information; the more you give them, there is a rapid and exponential drop off in the value of information …*

Less than one in three of IDU respondents could recall that they had both confidentiality provisions and the notifiability of positive results explained to them, but even fewer were definite that neither had been explained. In many cases they could not remember. Some, however, were sceptical about confidentiality:

> *If I was HIV positive would the doctor have to tell anyone? Is it just a statistic or my name? So they'd know who I was ... they already know far too much ...*
> (33 year old woman)

> *Don't know how far confidentiality would stretch*
> (28 year old woman)

IDU respondents said they had given informed consent for the test on almost 80% of occasions, although it is not clear in every case what this involved. A minority said they had signed a consent form. The remainder could not recall or apparently did not consent, as in the case of the following respondent who was tested in hospital:

> *They just said they were going to blood test you for everything and that's it, for the safety of the other patients too*
> (18 year old woman)

SP informants were asked how they ensured that clients gave informed consent for BBV testing. A majority said they explained the significance and meaning of tests verbally, often as part of pre-test counselling, and obtained verbal consent, and a few also used a formal checklist which was signed by clients. A few gave their clients literature on testing to aid informed consent.

Follow-up to Testing

IDU respondents reported that they had received their test result in a face to face interview with their test service provider on almost three quarters of occasions. However, on around one in ten occasions they had received them by telephone, although in one case a distinction was made according to test:

> *I got phoned for all of them except HIV - had to go into doctor*
> (17 year old woman)

A few also received their results in some other way, such as the following:

> *The receptionist opened the file on the table in doctor's office and HIV positive was highlighted*
> (30 year old woman)

> *My mum called the doctor because she's friends with him and he told her*
> (22 year old woman)

> *Went into practice, secretary looked through files and handed me a form, [I]walked out the door, opened it and it said negative*
> (27 year old man)

Some respondents had not collected their results. A few of these were waiting for results from very recent tests, and most of the remainder believed that they would be informed if their results were positive:

> *Just didn't bother, if you've got it they'll tell you*
> (38 year old woman tested at drug treatment clinic)
>
> *They didn't give me the results, they didn't come in and tell me I had something* [so I] *assume I don't*
> (18 year old woman, tested in hospital)
>
> *You don't get results unless you've got something - they told me that when I asked for results. If I had something they would have segregated you straight away. That's how you know - they segregate everyone HIV and Hep into infirmary block*
> (22 year old man tested in prison)
>
> *Forgetting or not being bothered to collect results as in the following was rare: I haven't, I've been meaning to go in there the next couple of days, but I'm quite confident*
> (21 year old man).

The majority (82%) of SP informants reported that they always gave BBV results face to face during a follow-up appointment, but a few reported that they were less stringent about hepatitis C and B results than with HIV/AIDS results, and were prepared to give these over the phone. One reported giving hepatitis B and C negative – but not positive – results over the phone. They estimated that an average of 91% of their clients collected their test results. Approximately half said they would write to or telephone clients with positive results who did not return, but would do nothing about uncollected negative results. One in three attempted to contact clients who did not return, whatever the result. A number commented that it was often difficult to contact some clients, especially travellers or transients.

SP informants' main explanation for IDUs' failure to collect results was that they were transient and mobile; one in three said that IDUs did not want to know, were fearful of results or simply forgot to collect results; some thought that test results were not a priority for some IDUs or that they did not care; and others said that IDUs assumed that SPs would call if there was something wrong, even when the contrary was explicitly explained. Some believed that failure to collect results was due to disorganised chaotic lives, although others explicitly disagreed with this view. Other perceived influences on non-collection of results were poor rapport with the testing doctor, life circumstances such as going to prison, being intoxicated at the time of testing, or having compulsory tests.

IDU respondents reported that no post-test counselling was given on 81% of described test occasions. There were no SP differences in this, but whether or not post-test counselling was received was related to the test result. Specifically, clients who received post-test counselling were more likely to be seropositive for at least one test than clients who were not counselled. (Figure 7).

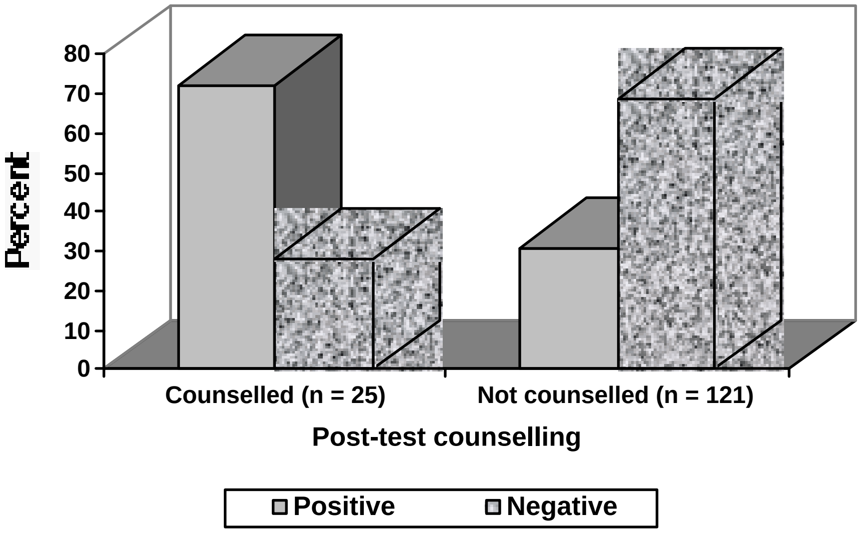

Figure 7: Post test counselling by test outcome: most recent testing occasions (n = 146)

It should, however, be noted that post-test counselling was said to have been received on only 30% of test events resulting in at least one positive result, as shown in Figure 8:

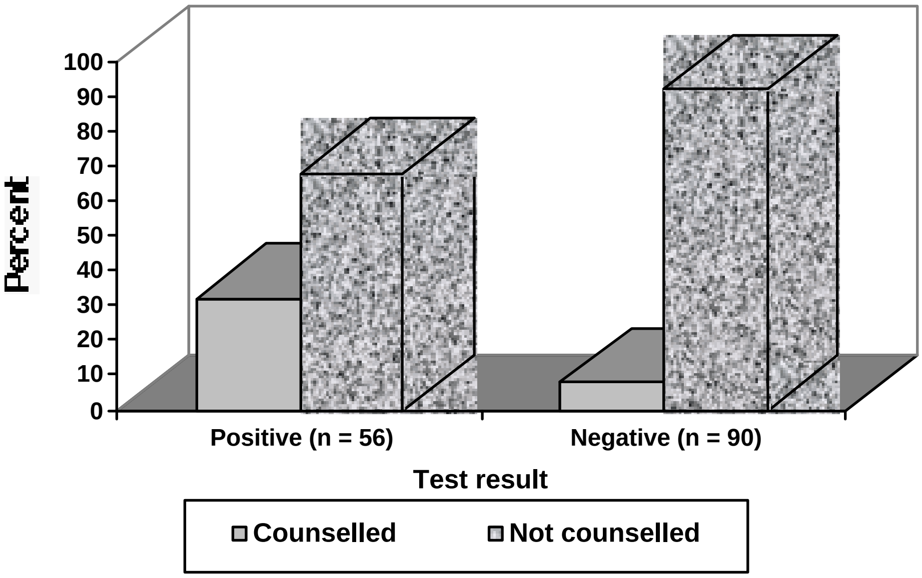

Figure 8: **Test outcome by post-test counselling: most recent testing occasions (n = 146)**

IDU respondents tended to be supportive of the view that the major role of post-test counselling was to follow up positive results. When they were asked whether they had been offered received post-test counselling, they made comments such as the following:

> *Not really because it was negative. If it was positive I would've definitely*
> (33 year old man)

> *Because it came back negative I didn't need any. They did say that it was available*
> (34 year old man)

> *No but if you had it I think she* [the doctor] *would've*
> (37 year old woman)

Many of those who described post-test counselling, moreover, reported it in terms of medical advice given if they were hepatitis C positive:

> *I suppose I was given some counselling by the doctor who knew about my situation, more along the lines of advice on how to contain and preserve my liver - stop drinking, things I already knew about*
> (27 year old man)

> *Not for HIV, but for hep C. I came up positive which was a bit of a shock. Talked about what it meant, what it would do, lifestyle and treatment and stuff*
> (31 year old man)

Only four respondents described post test counselling which was focussed on prevention:

> *She just explained the results and suggested I use condoms and keep injecting safely*
> (19 year old woman)

> *Gave a lecture about using safely - but there should be more information on when and where you can get needles - in all areas and at all times of night …*
> (19 year old woman)

Most IDU respondents (71% of occasions) did not take written information away with them from the test. In most cases it was not offered or available, but some felt the information was superfluous or unnecessary:

> *Had pamphlets there, but didn't take any, have pretty good knowledge*
> (26 year old woman)

> *Yes - pamphlets - can't remember. Threw them away, didn't really read them. If I want to find something out I just ask somebody*
> (17 year old man)

> *She offered me some pamphlets to read, but I didn't think I needed them after she explained everything so well*
> (19 year old woman)

On some occasions, however, written material was very much appreciated:

> *Yes - with pre-test - HIV, all heps, and I think things to do with legal rights and confidentiality issues. Everything was covered, he was such a fantastic doctor*
> (27 year old woman)

IDU respondents reported that they were referred to other medical or community agencies on only nine test occasions: of these, seven were occasions where at least one result was positive (six hepatitis C, one HIV/AIDS, one hepatitis C and HIV/AIDS). Most of these positive clients were referred to specialist medical services, although two were referred to the Hepatitis C Council of WA. Two respondents who were negative were referred: one to a youth health clinic and one to a clinic for hepatitis B vaccination. Perhaps because of this low rate of referral, most IDU respondents said they did not know at the time about local community-based support agencies such as the Hepatitis C Council or the WA AIDS Council.

Almost all (90%) SP informants said they used post-test counselling to discuss prevention with clients whose results were negative. About two thirds talked to clients about the window period and the possibility of a need for re-testing. Some discussed what a negative result meant. Around 20% told clients how lucky they were considering their risk behaviours, congratulated them on being negative and encouraged them to continue to stay so. One said clients were told that it was not appropriate to continue being tested if they continued with risk behaviours. A few offered hepatitis B vaccination to negative clients at that time. A few offered virtually no post-test counselling after a negative result.

With positive results (predominantly hepatitis C) most SP informants used post-test counselling to suggest follow-up and monitoring, including further testing (liver function test, PCR testing, liver biopsy) and referral to specialists. The majority also discussed transmission and prevention issues, including not sharing injecting equipment, razors or toothbrushes, and cleaning up blood spills. About half said that in the first session after a positive diagnosis they dealt with the client’s shock and other emotional reactions, allowed time for them to digest information and made sure that clients understood the implications of a positive result. Treatment options as well as possible sources of support were also discussed. Other topics mentioned were lifestyle issues such alcohol and drug use, diet, exercise and learning to live with the virus, and disclosure issues about the infection. A few SPs reported encouraging clients to ask questions, some gave written information and a few said they tried to focus on the positive aspects of the result. Combinations of these themes demonstrated that there was considerable variety in post-test counselling with positive clients.

Almost all SP informants said they made written information and resources available to clients who wanted them. These ranged from government publications, information from Hepatitis C Councils, pamphlets from the Gastroenterological Institute, other pamphlets and handouts and referral information. Some said they had a wide range of information on all BBVs available in their waiting rooms but not specifically handed to clients. A few said they had up to date information on HIV/AIDS and hepatitis C, but their hepatitis B information was outdated. A number said they were more likely to give written information if the client tested positive. There were some negative views about the provision of written information, however, including the concern that clients would be overloaded, as in the following comment:

> *I don't routinely give out literature, people don't want to walk out with a bundle of stuff*

Other concerns were that literature should not replace discussion:

> *.. people don't read pamphlets. I like to encourage them to talk about any issues. People have specific needs and it's more important to talk to them about everything.*

Several SP informants said whether they gave out written material or not was dependent on the client's needs as well as their literacy, knowledge, capacity to cope and curiosity.

The majority of SP informants said that they referred their BBV positive clients to specialists (consultants, physicians, gastroenterologists), with approximately half saying they referred to hospitals. Referral was generally for medical reasons related to hepatitis C. About a third mentioned referring to alcohol and drug services and sexual health clinics, and a similar number said they referred clients to support services, with counselling and Hepatitis C Councils receiving the most mentions. A few said they referred clients whenever they felt they could not meet their needs or requests.

IDU respondents were asked about their cognitions and emotions about the test process. They reported that on just over half of the described test occasions they were not bothered, worried or anxious. In some cases this was because of a perception that they had not practiced unsafe behaviour, and so had nothing to worry about:

> *Wasn't worried, didn't really know what was going on, but I knew I didn't have any of those diseases*
> (19 yr old man)

For some the test process was routine, but one felt that because he was powerless there was no point in worrying:

> *Nothing - I'm just used to it now. I've done a few years jail, home detention, work release, all these different things so I'm used to being shunted around and shown nothing. I just let it go, if you let it get to you you'll end up a screaming mess*
> (42 year old man)

Other themes included fatalism: when asked what he was thinking or feeling about being tested, this man said:

> *That it's a pain in the butt, mainly, just it's a waste of time. You're gonna die sooner or later, that's why people do drugs, depends if you want to burn out or fade away...*
> (26 year old man)

Some just hoped that they would be alright:

> *Just that I hope it comes back negative, wasn't really worried, better to be safe than sorry*
> (38 year old woman)

On almost 40% of occasions, however, respondents experienced some anxiety. This tended to be related to waiting for results:

> *Waiting for the results I was scared just in case anything did come up - devastate family and girlfriend. Worried for myself and all the people that are close to me*
> (19 year old man)

Others were concerned because they knew that they had practised unsafe behaviour:

> *Had a slight reservation that either of us could have HIV or hepatitis C (not hepatitis B) – partner's history of bizarre and casual sex encounters, possible for HIV. Was quite scared actually, even though there was no evidence that we had anything. So easy to catch, everyone can get it*
> (26 year old man)

And one found the process intimidating:

> *I was pretty nervous actually. I was scared about asking for the test I thought she'd* [the doctor] *think I was a slut and a junkie, but she was so nice and understanding. That calmed me down, but it was nerve wracking waiting so long for the results*
> (19 year old woman – first test)

Some respondents were very anxious indeed:

> *When I found out this person I had shared with had hep C I started to really worry. It was scary waiting for the results - I was pretty anxious. I knew I didn't have to worry about HIV, but thought for sure I'd have hep C. I'd heard how contagious it was. I was right.*
> (34 year old man)

> *I was pretty worried actually - I've done some stupid things in the past like sharing when I'm desperate and that and unsafe sex, so I was really rapt when the results came back all negative! I thought I might at least have hep C, but I got away with nothing. I was surprised and pleased*
>
> (28 year old man)

IDU respondents complained about the treatment they had received in relation to only 8% of testing occasions. Most of these complaints were about the perceived attitudes of SPs towards drug users:

> *The doctor was pretty good but the fact that he knew I was a heroin user - was pretty firm and rude the first time*
>
> (19 year old man)

On the other hand, a few respondents thought they were treated really well:

> *I was given opportunity, support and everything else*
>
> (29 year old woman)

Finally, respondents were asked to describe any other memorable test incidents. There were 32 such descriptions. For the most part the descriptions were negative, and many related to the respondent's perception that they were not given adequate information. For example:

> *No pre-test/post-test counselling. Wait - even if you've heard it again and again, should mention risks and what to avoid to not get viruses and also how regularly to be tested and places to go if you think you've been in contact with viruses to get tested again*
>
> (23 year old woman)

Others felt they had received inadequate support:

> *If I was negative for everything I would expect him to recommend more testing in three months. If I was positive I would expect a referral to the Hepatitis C Council and ways of dealing with it, referring me to people who can help me mentally and physically*
>
> (19 year old woman)

> *I think it's really vitally important for a doctor to determine exactly what the clients' past is. Just because I say I've had tests before doesn't mean I'm gonna handle it alright and I just dunno I think it's very important, I think that post counselling as well is really important, even if you're negative, I remember being asked what I'd do if I were positive and that made me stop and think, made it more real, sent me away with a much more profound attitude*
> (27 year old woman)

But some had experienced shifts in professionals' attitudes over time:

> *I find doctors more understanding these days than what they were 15 years ago - more seem to know more and are a lot more friendly*
> (33 year old man)

Respondents were asked "Tell me how you felt when you found out your last test result?" The majority of those whose results were negative said that they were pleased, relieved, or not surprised. For example:

> *I don't know how to describe it, I guess I did one of those Toyota commercials - jumped up in the air "Yay!", rapt*
> (27 year old man)

> *Very very relieved because I was worried to death*
> (36 year old man)

Those who received positive test results (almost entirely hepatitis C) were almost equally divided between a range of responses: being upset/angry/concerned; not surprised; focusing on their state of illness or health; feeling positive about their diagnosis or describing being upset at first, but coming to terms with the diagnosis over time.

For example:

> *When I first found out I was positive I was horrified, couldn't believe it, broke down, didn't think that I'd have it. I hadn't been using around that time, I'd just had a baby and was breast feeding. It was devastating. I felt like I was used as a guinea pig*
> (31 year old woman)

> *The first time I was told I was positive I was not really surprised because of the situation - I had put myself in a situation where other people were positive, so I wasn't really surprised, but kind of a bit anxious*
> (25 year old woman)

> *It hadn't got any worse - liver count was up but probably due to drinking than to hepatitis C. When I found out I was positive it was a big shock, because I'm omnipotent, I don't get sick, or old …*
> (33 year old woman)

> *Positive - I suppose I was still a bit nervous but I felt it was all quite manageable with the counselling that was offered with it. A very thorough doctor*
> (27 year old woman)

> *I felt you know "death sentence" almost like I had AIDS really, because there's no cure for it. But the doctor did say that some people, their bodies do get rid of it and look after it, at first it was dismal, but when doctor explained that I'm not a chronic carrier, OK*
> (32 year old man)

SP informants were asked what range of emotions they saw in relation to BBV testing and how they dealt with these. They described a wide range of emotions, but anxiety received the most mentions, followed by acceptance, resignation, anger and fear. Relief over a negative result was also common, as was concern for others (partners, children), surprise, and grief. Other groups of related emotions included disbelief, shock, panic, hysteria and obsessing; apprehension, stress, frustration and angst; distress, despair, dismay, devastation and blame; disgust, dirtiness, regret, remorse, guilt, disappointment, sadness and denial. There were also reports of some clients being blasé, nonchalant, calm, indifferent, apathetic or complacent, while others reacted with bravado, curiosity or interest. A few said clients asked "why me?" or said "I deserve it". Some SPs said the strongest reactions they got were from people who had not injected for years and returned positive results.

Most dealt with these reactions with counselling. A third said they provided more information and some said they referred clients on. Some said they offered support and spoke of the importance of active listening and allowing plenty of time for the client to come to terms with the result. Some tried to normalise the situation by letting clients know their reactions weren't unusual. A few said they tried to give patients hope with facts about the viruses. One GP admitted to not dealing with these issues very well:

> *I deal with them probably pretty badly. I don't think I deal well with IDUs, I think I deal with them mechanistically and can tend to be a bit guarded.*

One service provider said:

> *Sometimes I'm as relieved, surprised and anxious as they are*

THE CONSEQUENCES OF TESTING

Many of the reasons given by IDUs for being tested were consistent with the types of response test-seeking respondents would have given to a doctor or clinician to explain their desire to be tested. Such responses, while of value in their own right, offer limited insight into the relationship between the testing process and the respondent's behaviour. With the possible exception of those who stated they sought testing in connection with a relationship, the reasons given for seeking testing did not indicate how respondents used the information gained through the testing process.

A series of questions sought to explore this relationship between test results and the subsequent behaviour of respondents. These questions addressed the respondent's reaction to the test results, the impact of the respondent's positive or negative serostatus on their life, and changes to behaviour following the test.

This section is divided into three parts. The first section discusses the impact of negative results, the second section discusses the impact of positive results and the third section discusses changes to behaviour following testing, regardless of the results.

Negative Results

Every respondent who had received a negative test result was asked: "Tell me how you felt when you found out your last [BBV in question] test result" and "What effect does your negative serostatus have on your life?" In most cases the responses to these questions were not differentiated by the virus concerned. Responses to the two questions about reaction to negative test results have therefore been grouped except where indicated.

One hundred and thirty nine respondents described how they felt about being negative for one or more BBVs, with many giving more than one response.

The majority indicated that they were relieved about the result, even if they had been expecting it:

> *Relieved in a way even though I was sure I was clean*
> (18 year old woman)

This relief was sometimes expressed in a quite judgemental manner:

> *Just relived, very relieved. Gave me a feeling, a sense of cleanliness. Felt clean, not like "junkie scum" You see some people around with no respect for themselves*
> (19 year old man)

A small number added that as well as being relieved, they believed that their negative result was also a matter of luck and a couple added that as well as being relieved, their negative result was an inspiration to be more careful:

> *I was really rapt - and very surprised. I'd been too nervous to get tested before, but I was glad I had to start the* [methadone] *program. I really couldn't believe I was all clear considering a few occasions of pretty dodgy behaviour in my past! It's really motivated me to be super careful from now on.*
> (28 year old man)

A few respondents said that as well as being relieved, they believed their negative result vindicated their behaviour:

> *Relieved and sort of glad with myself as well, knowing I've been careful when using, knowing I did the right thing, haven't shared*
> (23 year old man)

Respondents were asked what effect their negative status had on their life, and gave multiple responses, again not differentiated by BBVs. Nearly a quarter said discovering they were negative had no impact on their lives, and made no further comment.

Almost half of those who discussed the effect of their negative serostatus took this question as a point at which to say how happy they were that they were negative. Some said that it was good they were negative and then discussed how they would feel or what it would mean if they had been positive:

> *Like I said, a lot, as if I was positive I think it would be totally different - I don't think I'd be into drugs, and that's most of my social life right now*
> (22 year old man)

A few discussed their negative status in terms of what it meant they could do, namely have unprotected sex:

> *It's nice to be able to have sex with my partner without having to panic about the safe sex thing all the time*
> (23 year old woman)

> *None, just means can have sex without condoms*
> (20 year old man)

and two people explicitly stated that knowing they were negative made them behave less safely:

> *Good effect - I wish I was a lot smarter than I am - wish I didn't share - I'm glad and proud and relieved that I don't have any of these things as positive - don't you think it's pathetic that I'm one of these people that am happy that I'm negative, but then goes out and shares again? I feel so stupid - that's the reason I get tested, then I'm relieved, but then go out and share again. It's so wrong and I did it. I think my boyfriend would as well, even though we made an oath not to.*
> (21 year old woman)

> *It makes me be less cautious when it comes to matters of transmittable diseases. Reckless. It's the opposite to self-preservation I s'pose. My body's OK and I can still go out and stuff it up anyway - until it's stuffed up I won't look after it*
> (23 year old man)

A number of people, on the other hand, felt that their result influenced behaviour in a positive manner:

> *Because I'm negative I certainly go out of my way to not put myself in a position where I could become positive; I don't share needles with anyone except partner and I don't use a needle that I'm not sure of its history.*
> (44 year old man)

Positive Results

Every respondent who had received a positive test result was asked "Tell me how you felt when you found out your last [BBV in question] test result" and "What effect does your positive serostatus have on your life?" Most responses related to hepatitis C with fewer discussing hepatitis B, and only 2 discussing HIV.

Fifty nine respondents described their initial response to finding they were hepatitis C positive. Just over 40% said they were not surprised, but in many of these cases the testing event being discussed was a follow-up to an earlier positive screening test result, so their lack of surprise was at the confirmation, and in some cases the test event they were describing turned out to be a liver function test or similar post-test evaluation.

A small number said they were unsurprised because their past behaviour was such that they expected to be positive:

> *I was relieved I didn't have HIV - I knew I probably didn't, but you never know, I did some pretty wacky stuff in the past. I was really expecting to have hep C, so that was no surprise but not very nice nonetheless.*
> (36 year old man)

One in three said they were surprised, upset or angry to find that they were hepatitis C positive:

> *Fairly devastated really - almost more so than HIV - double whammy*
> (36 year old woman)

> *Really annoyed, as said before, at the person and at myself for being so stupid and careless*
> (37 year old man)

On at least one occasion the respondent indicated that part of their anger was in connection with the way the testing process had been handled:

> *I felt angry because it meant that I was probably hepatitis C positive at my second test and I wasn't contacted*
> (44 year old man)

A few respondents indicated they were indifferent to finding they were hepatitis C positive, but in at least one case, this appeared to be due to lack of knowledge about hepatitis C:

> *Didn't sort of care because I didn't have HIV - didn't know much about hepatitis C*
> (31 year old woman)

In terms of the impact of their positive status on their lives, only a small minority had found that being hepatitis C positive had had no effect. Most described the effects in terms of other people and/or their own physical and emotional health.

For some the major impact of their serostatus was the effect of negative or ignorant community attitudes towards people with hepatitis C:

> *I .. was babysitting a little girl – she asked for my drink and I said no. Her mum asked why, and I told her I had hepatitis C, and she never employed me again. That upset me*
> (31 year old woman)

Many of these respondents discussed the impacts of such attitudes on their relationships:

> [It] *was quite a shock to me and contributed to break up of my marriage. Wife didn't want me in the house when I was hepatitis C positive. Didn't want to have sex any more or touching the cutlery.*
> (42 year old man)

Thirty six respondents discussed the direct effects of their serostatus: emotional impacts, physical symptoms, the need to alter their diet and drug use, and generally the need to look after their health more closely:

> *It just makes me feel tired in the afternoons and I have a hard time getting up in the mornings*
> (33 year old man)

> *I'm very tired a lot and I suffer depression, have to always be on antidepressants.*
> (32 year old woman)

> *I curb it pretty well with diet and I'm taking antioxidants and vitamin E*
> (42 year old man)

> [I have to]*watch alcohol and paracetamol consumption*
> (30 year old man)

> *Gotta stop drinking* - *Friday night asked to a birthday party with a keg so I didn't go, so it's affected me socially.*
> (19 year old woman)

Three of these respondents, however, explicitly stated that they did not do the things they had been told they should:

> *Well I'm conscious of it and conscious of liver damage but I don't do the recommended things like not drink.*
> (44 year old man)

Almost half discussed the impact of their serostatus on their need to consider others, for example in relation to transmission issues or on being around (or having) children:

> *I would never lend anyone a syringe of mine or use anyone else's syringe apart from my sex partner, and not if I had one of my own*
> (33 year old woman)

> *I haven't been in a relationship for a long time; gotta be really careful especially when I've got my period and especially with the kids. I'm forever telling them not to touch needles or other people bleeding to prevent transmission*
> (31 year old woman)

Ten of the 12 people who indicated they were hepatitis B positive described the effect of this on their lives. The majority described themselves as long-term carriers (usually with no physical symptoms) who felt "*fine*" or "*nothing*" with respect to their most recent test.

Only two people indicated that their last test had been the one at which they had discovered their serostatus. One of these people expressed surprise; the other resignation:

> *Surprised really because I've never felt sick*
> (37 year old man)

> *Other IDUs were coming down with hepatitis B at the time so it wasn't really a shock, it was just one of those things you got*
> (31 year old woman)

In response to the question about the impact of their hepatitis B status on their life, most who had been carriers for some time said their status had little effect on their life, and the remainder expressed some concern:

> *I've gotta be more careful, gotta tell people*
> (37 year old man)

> *None really, I've been carrying it that long - if I got in a relationship be morally bound to tell them. Been carrying it for over 10 years, been offered to go on interferon treatment, haven't done it yet. Rarely think about it - realise I've gotta look after my liver. Having it for so long concerns me - liver not functioning properly*
> (42 year old man)

There were only two HIV positive people in the group: both women. One had received her result with acceptance, while the other did not state how the test result had affected her. Both HIV positive respondents made some comment about the effect on their lives.

> *It's been very roller-coaster ride - good/bad days. Can't forget but react in different ways.*
> *A lot has changed in 10 years - but a lot hasn't*
> (36 year old woman)

> *Being celibate, and just making sure that picks and spoons were clean and all that*
> (39 year old woman)

Changes to Behaviour Following Testing

Respondents who had been tested at least once were asked if they had changed their behaviour in any way subsequent to their last test. Those who answered "yes" were then asked what these changes were and if they had changed their behaviour back. Those who answered "no" were asked why not.

Figure 9 shows behaviour change by test outcome: that is, whether the respondent was found to be positive for one or more viruses.

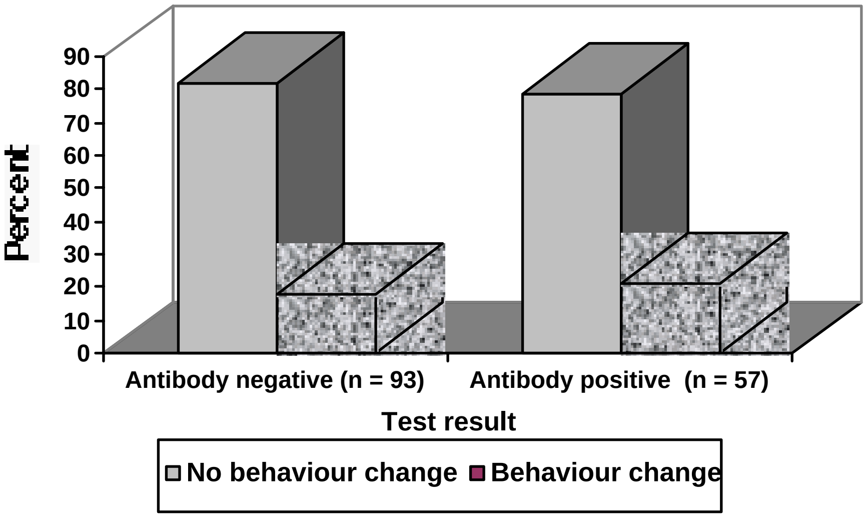

Figure 9: **Behaviour change after most recent testing occasion testing, by test(s) outcome (n = 150)**

Figure 9 shows that the majority of respondents, regardless of the test outcome, did not change their behaviour after the test.

In their descriptions of the 150 most recent test events, respondents reported behaviour change following just 19% of these events. Almost all described these changes. These descriptions have been related to the outcome of the test.

Respondents from 57 most recent test occasions had at least one positive result. Twelve (21%) of these said they had made some behaviour changes subsequent to the test: five towards reducing or stopping drug use; five towards reducing injecting or sexual risk and two used more drugs or started to inject. Thus 10 had moved towards safer, and two towards less safe behaviour. Some examples of these follow:

> *Yes, Don't drink, eat healthily, I'll probably still use heroin and be incredibly careful about it. Now that I can't drink, I'm thinking it's the one thing I can do. Only other drug I take is Ecstasy.*
> (19 year old woman)

> *Yes, I didn't put myself at risk - made sure I didn't share spoons, needles, filters, water. I didn't know you can catch it from spoons*
> (32 year old woman)

> *Yes, might have used a bit more 'cos everything* [liver function]*was getting better*
> (30 year old man)

Following the 93 test occasions which resulted in only negative results, there were 17 (18%) behaviour changes: 10 towards less risk, four towards more risk and three towards reduced stress or feelings of happiness.

> *Yes, just a bit more at ease, a bit more happier probably,*
> (42 year old man)

Of those who reported more risk, two said they were more inclined to have unprotected sex:

> *Yes, more relaxed, - knowing that I was all clear. Had unprotected sex with partner*
> (23 year old woman)

> *Yes, started having sex with my girlfriend without condoms.*
> (20 year old man)

One person described changes with mixed or unclear implications for safer use:

> *Yes, maybe to check the spoon and cotton were clean - was aware but didn't make a big deal about it. On the other hand for a while the idea that I already had hepatitis C made me feel less anxious about using someone else with hepatitis C's syringe. I know you can cross-infect, but.. ?*
> (27 year old man)

Only one person said she had made some behaviour changes then changed back to prior behaviour patterns:

> *Probably only lasted about a month because I stopped [sex] work and settled back into my long term relationship - haven't had to put them to the test*
> (28 year old woman)

As shown in Figure 9, the majority of tested respondents indicated that they had made no changes to their behaviour following their last test. The most common reason given by respondents for not changing behaviour was that they were "already safe":

> *No, because obviously the things that I'm doing are pretty safe - just keep using frangers* [condoms] *and make sure I don't share needles*
> (18 year old woman)

> *No, because obviously I was maintaining safe practices therefore I shouldn't try and change/lower them in any way*
> (23 year old man)

Eight hepatitis C positive people said they had made no change because they were already positive. For half of these the lack of change since the last test was because they had discovered their serostatus prior to the last test and had changed their behaviour at this point:

> *Because I think I got hep C in about the first year of using and in the last 8 I haven't caught anything - I've been a hell of a lot more careful*
> (31 year old woman)

whereas others seemed to think of their positive serostatus as meaning they no longer had anything to avoid:

> *No, because the way I was living my life, I continued to live my life in that way - basically knew it would come back positive*
> (38 year old woman)

Some people said they had not changed their behaviour because their result was negative:

> *No, not really no - I was pretty sure I didn't have it to start with and they said I definitely didn't have - just continued on with same behaviours*
> (33 year old man)

Whereas others said they had made no changes because they no longer used drugs:

No, had stopped using anyway
(29 year old woman)

A few respondents indicated that they had only been tested because of what they felt to be one-off or rare aberrations in a context of otherwise safe use:

Just got test done to make sure because sometimes when you're out of it things get mixed up
(33 year old man)

I wasn't getting tested because I'd been unclean or irresponsible - my partner had
(22 year old woman)

Three people indicated that they had not changed their behaviours despite their understanding that their behaviours were high risk and they were currently seronegative:

I'm pretty much doing the same things that will cause me to get into trouble - sharing etc.
(21 year old woman)

HEPATITIS B VACCINATION

IDU respondents were asked "What do you understand about hepatitis B vaccination?" There were a variety of answers. Almost half of the group said that they knew little or about it:

Not much, would I have had it when I was a baby?
(21 year old male)

One in four respondents demonstrated some understanding that hepatitis B vaccination helps prevent hepatitis B. This understanding was expressed in a variety of ways:

Given a very small sample of hepatitis B in order that immune system responds by creating hepatitis B antibodies, immunising you to future exposure to hepatitis B viral particles
(27 year old male)

Just stops you from getting it, doesn't it?
(19 year old female)

Fifteen percent of respondents provided a response indicating both that they understood the concept of immunity/vaccination and that they realised hepatitis B vaccination involved a series of injections over time:

> *I've been vaccinated. Don't know anything really. I've had my two shots (3 mths and 6 mths), presume I'm immune to it. Leave it to the medical profession for the rest of it*
> (40 year old female)

Some respondents knew that hepatitis B vaccination involved a series of shots over time but did not mention anything about immunity:

> *You have 3 shots over a period of so many months and don't have to go back for another for 5 years or something*
> (18 year old male)

Respondents were asked if they had ever been vaccinated against hepatitis B. Almost 60% reported that they had not; 24% said that they had; 9% were hepatitis B positive (immune); and 8% were unsure. Two thirds of those who had been tested for hepatitis B had not been vaccinated despite the fact that so few were immune.

Not Being Vaccinated

There were 119 people who had not been vaccinated against hepatitis B, and one whose course was incomplete. All were asked “Why haven't you been vaccinated against hepatitis B?” The most common response, given by almost half of this group, was that had never heard of vaccination against hepatitis B or did not realise that such a vaccine was available:

> *Never been offered, never knew it was available until yesterday*
> (23 year old woman)

> *Not to my knowledge - I wasn’t aware what the actual virus is, so didn’t realise there’s a vaccination*
> (21 year old man)

> *Didn’t know there was a vaccination or that hep B had anything to do with injecting drugs*
> (23 year old woman)

Another frequently occurring theme, related to the above, was that no-one had ever suggested they should be vaccinated or offered them the opportunity:

> *I've never asked for one, or been offered one. I suppose I don't think I'd need one*
> (28 year old man)

Some respondents suggested that their reason for not being vaccinated was that they were at a low risk of hepatitis B infection and that vaccination was therefore unnecessary:

> *I didn't know you could - suppose I did know but never considered myself at risk, but I have a very small understanding of how you contract hepatitis B, gather it's through blood*
> (19 year old man)

> *Just never got around to it, didn't think I was in a high risk category*
> (29 year old woman)

A number of respondents said they had not got around to being vaccinated although they knew it was available:

> *Never really been interested, or thought about it that much. I've never been in a place long enough to do it. It takes a month doesn't it?*
> (25 year old man)

> *I don't know - I've been told to by friends "You should get one because you never know" but I never got around to it*
> (21 year old woman)

And only a few indicated that they were considering it:

> *As I said I've only just found out about it. I'd like to find out more about it and if I think it's appropriate then I shall do so*
> (31 year old woman)

A few respondents expressed reluctance to be vaccinated on the grounds that they were opposed to immunisation, disliked intra-muscular shots or were reluctant to visit a doctor:

> *Don't like needles! Mainlining's just a little prick, but into the muscle hurts*
> (32 year old man)

> *I don't know, - I've done some naturopathy and don't believe in immunisation*
> (19 year old woman)

Five respondents mentioned cost as a contributing factor to the decision not to be vaccinated:

> *Started to be* [vaccinated] *but they didn't tell me that it cost, so they charged me $70 for the first shot and test. Couldn't afford it*
> (19 year old woman)

Those who had not been vaccinated were asked how they felt about that. The most common response, by more than half, was that they were unperturbed:

> *Not really that bothered, I didn't really feel at risk for it, so it's not something that really keeps me awake at night*
> (19 year old man)

> *Fine I guess - most people on the streets aren't vaccinated*
> (17 year old woman)

To some, this was related to a belief that they were not at risk of contracting hepatitis B:

> *Not too bad 'cause I don't think I'm a high risk 'cause I don't use that often and if I do I don't always use needles and when I do use needles they're always clean and I'm not living with anyone that's got hep C or anything at the moment*
> (22 year old woman)

Nearly a third, however, said that they would be interested in being vaccinated:

> *Maybe I should get one now I know there is one, as I use needles*
> (23 year old man)

Six respondents expressed their disappointment that they had never been informed that such a vaccination was available:

> *I'm a bit pissed off actually that I've never heard of it. I would have had it* [vaccination]*before now*
> (18 year old woman)

A few respondents were worried because they had not been vaccinated, and two felt that vaccination should be readily available and affordable:

> *I think it's a shame that the government won't put it on Medicare because it's something that's affecting a lot of people and they should do something about it - I don't think it's right that people can't be protected against a disease like that just because they can't afford it*
> (16 year old woman)

Those who had not been vaccinated were asked whether they were more careful because of this. The majority said they were not, and almost all of those who said they were said they employed safe injecting or sexual practices.

Sixteen respondents were unable to say whether or not they had been vaccinated and were asked why they did not know. There were only two themes in the responses to this question: no memory of being vaccinated and/or believing that vaccination may have taken place during childhood.

> *I don't think so - I don't know much about it. I don't think I have - is it one of those things you get at school?*
> (21 year old woman)

> *I don't know - I might have been at school or when I was a baby? No one's ever directly mentioned it to me*
> (17 year old man)

> *I may have been but I don't know - haven't had vaccination for anything, last I can remember is tetanus - don't go to doctors much*
> (37 year old man)

Being Vaccinated

The 48 vaccinated respondents had been vaccinated between 0 and 190 (median 32) months previously. A quarter had been vaccinated within the previous year and almost half within the previous two years. One in five had been vaccinated more than five years previously. Two thirds had received three injections; 14% had received two injections and 5 said they had received a booster shot some time after the course of vaccination. Twenty percent said they had been tested after the course of vaccination to check the level of immunity. Sixteen percent said they had been tested before commencing vaccination. Three people said they had not had any blood tests and one person could not remember whether they had been tested. The median length of time for the entire course was 5 – 6 months. Most respondents (86%) did not have to pay for their vaccination; the reported cost from those who did pay varied between $40 and $70 for a full vaccination, or between $12 and $25 per injection.

The most common reason for being vaccinated, mentioned by 45%, was that vaccination was suggested by a doctor or clinic staff:

> *At my doctor's recommendation - basically through my drug use. There was a lot about hepatitis B that I didn't know and discovered I'd been in a lot of risk situations*
> (23 year old woman)

> *When I got my test results back the doctor suggested I have hep B vaccination, I thought it was a good idea - better safe than sorry. I've just had my last shot about a month ago*
> (28 year old man)

The second most frequently mentioned reason for being vaccinated was to guard against hepatitis B:

> *Just started. hepatitis B can be more dangerous than hepatitis C in acute phase and makes you more sick and when you're a drug user - can't be too careful, got to take all the precautions you can. It's readily available at the clinic and* [they] *encourage you*
> (28 year old woman)

Around 20% indicated that their decision to be vaccinated was job related:

> *Was a policy going through a company I was working for in Qld - part of health and safety*
> (33 year old man)

> *Because I was a volunteer at a needle exchange - all volunteers have opportunity to be vaccinated - might as well get it for free while I can*
> (21 year old woman)

While for others, overseas travel plans contributed to the decision to be vaccinated:

> *Because it was a service that was offered that didn't cost anything and I was going to travel - walking around with bare feet in not so clean countries*
> (23 year old man)

Vaccinated respondents were asked how they felt about being vaccinated; three quarters of those said they felt happy about it, and more than a third suggested that they felt safe from contracting hepatitis B:

> *Good, at least I know I'm not gonna catch that*
> (38 year old man)

A few respondents indicated that vaccination was not a bad thing but were not enthusiastic about it either:

> *I'm pretty indifferent … , it's handy but I'm not terribly thrilled or upset about it*
> (26 year old woman)

When asked what difference being vaccinated made to their lives, most said it made little or no difference, but one in five said they felt relieved about being vaccinated or that it gave them peace of mind:

> *It doesn't make any difference except I know peace of mind in my head that it's been done, that base has been covered, but whether I'd been vaccinated or not I doubt I would have changed any aspect of my lifestyle*
> (27 year old man)

Almost all (81%) of the vaccinated respondents indicated that they had completed the course. The remainder, except for one who was unsure, had not completed. A few said that reminders by their doctor facilitated the completion of the course. One person finished the course because he was in prison, while another had his vaccination arranged by his employer.

Half of those who had not finished their course said that they had either forgotten to complete it or had not followed it up:

> *No, started two times the series but never followed up, so had two needles in two years. But have decided never to be exposed to hepatitis B, use safely*
> (31 year old woman)

The interviewer conducted a short education session on hepatitis B vaccination with each respondent at this stage of the interview. Respondents were then asked “Now that you know a bit more about vaccination, would you consider being vaccinated?” Most of those that had not been vaccinated were open to the idea: they cited protection against catching hepatitis B; having an intention to be vaccinated and “seeming like a good idea” as reasons. A number of respondents indicated they would consider being vaccinated although they did not regard themselves as being at particular risk.

The education session included the information that IDUs could be vaccinated free of charge. This point was raised by 10% of respondents who said they would consider being vaccinated:

> *Yes, if it's for free I might as well get it done. I thought it cost $50 or something - I'm not gonna spent $50 on that when I can go and have a hit*
> (21 year old man)

Having now received information about vaccination was mentioned by some respondents who indicated they would consider it: :

> *Yes, definitely - I can't believe I haven't heard of it until now. Anything to stop from getting these, you know hep B, HIV and hep C. I wish there was a vaccination for all of them*
> (18 year old woman)

A number of respondents said they would consider vaccination because they believed themselves to be at risk of infection, either through their own activities or those of a close other and a few said they would also like to speak to their doctor about vaccination. Three respondents mentioned that they had hepatitis C and that vaccination against hepatitis B could help prevent them from becoming even more sick.

The twenty-three respondents who said they would not consider vaccination included 15 who said they were immune, four who said they were not at risk of contracting hepatitis B, two people who were opposed to immunisation in general and one who said the needles used for vaccination were "too big".

SP Informants' Views on Hepatitis B Vaccination

SP informants were asked a range of specific questions about vaccination and their vaccinated clients. Almost half said that their vaccinated clients were predominantly IDUs, a third said they were indigenous Australians and a third that they were occupationally related (eg. own staff, health professionals, emergency workers such as police, fire brigade, aged carers). Some said anyone who was hepatitis B negative was offered vaccination as well as anyone who requested the vaccination, or as one said *"anyone I can talk into it"*. Other groups mentioned were gay men, sex workers, sexually active youth, Asians, non-English speaking ethnic minorities, the families of those who were hepatitis B positive, players of contact sports and travellers.

All SP informants believed that IDUs needed to be advised to be vaccinated. Half said that vaccination came about mainly as a result of their recommendation; almost a third that clients requested it, and some that it was a bit of both (request and recommendation). Some thought that hepatitis B vaccination needed to be pushed more:

> *I don't think the message about hepatitis B vaccination has got through as much as it might to IDUs*

and at least one admitted

> *I think it's a good idea, I haven't been doing vaccinations for hepatitis B*

When asked how they ensured that clients gave informed consent for a vaccination, almost three quarters of the SPs said they explained what vaccination was, why it was important, the benefits and what was involved as well as side effects. A few gave written information, and fewer said they had clients sign a consent form. A few commented that it was simply a part of pre- and post-test counselling.

SP informants were asked how well clients complied with the vaccination regimen. Almost half said they experienced close to 100% compliance, while a few suggested that clients with an occupational motive for vaccination were more compliant than others. Some said clients dropped out after the first or second shot, while a few said they improved compliance with an accelerated regime (second injection one week after the first, and the third a month later with a booster if required). Almost half used a reminder system where clients were sent letters reminding them to come in for subsequent shots. Almost half of the SPs had experienced no differences in compliance between IDU clients and others.

Almost half (48%) of SP informants did not charge for hepatitis B vaccination, and another quarter did not charge those at high risk. Among those that charged, prices ranged from $7.00 to $30.00 per injection with a mean of $16.00. Almost a third thought this cost was difficult for clients, but others commented that the cost was reasonable spaced over the six month period. A few believed that hepatitis B vaccination should be universal.

DISCUSSION

This discussion provides a brief commentary on the data using the same headings as were used in the data presentation.

DESCRIPTION OF RESPONDENTS

The IDUs respondents were similar in many ways to other groups of IDUs that we have recruited in Perth, although they were, on average, younger by some 3-4 years than the stereotypical IDU found in Australian research. That occurred because of the deliberate over-sampling of younger respondents which, although the age quota was not met, affected the overall age distribution. The age distribution is also reflected in rates of treatment experience, in that only 50% of the group had ever participated in a methadone program. The proportion who had injected heroin, compared to the proportion who had injected amphetamines in the month prior to interview (67% of heroin users compared to 28% of amphetamine users) is an indicator of the popularity of heroin compared to amphetamines in Perth at that time.

Seventy percent of the IDU respondents generally, and almost all of those over the age of 24, had been tested for all three viruses. This compares well to the ASHIDU data in which between 79 and 91% of IDU respondents had been tested for the three BBVs. It also demonstrates the ubiquity of testing in this population.

While it is clear that the SPs were not representative of their population, they were drawn from a wide range of services, and from each Australian jurisdiction. They conducted, on average 40-50 tests for each virus per month, so were well experienced in testing for BBV. It could, therefore, be argued that the method of recruitment maximised the possibility that those that were most interested in, and educated about, BBV in IDU would be recruited.

THE DECISION TO BE TESTED

The reasons given by SPs and IDUs for suggesting or requesting testing were remarkably similar. The SPs referred to at-risk behaviour, requests for testing, routine testing (eg when IDUs entered treatment); symptoms of infection and BBV testing as part of STD screening. Most, moreover, said they would not refuse to test when this was requested. The IDUs’ reasons for testing were that they had engaged in risky behaviour, that they were undergoing screening for STDs, that their medical practitioner had suggested it, or that they were required to by their medical practitioner, drug treatment agency or detention facility. Importantly, there was a considerable flavour in the IDUs' responses that the real function of testing was to "prove" themselves "clean": this is attested to by the frequency of testing with approximately a quarter of the group being tested between 2 and 4 times a year and a quarter being tested annually. The data suggest that IDUs requested testing so that they could reassure themselves that they were not a risk to themselves or others, but that recognition that their behaviour put them at risk resulted in frequent testing for reassurance. In this they were supported by the SPs who were, on the whole, prepared to test whenever they were asked. Accounts of the emotional responses to negative test results, ranging from relief to exhilaration, bear out these contentions.

Both data sets suggest that testees and testers acted from an implicit quarantine model. Testees wanted to know their status in the assumption that if they found they were positive they could self-quarantine: if not the status quo could be maintained. Testers acted within a quarantine model by assuming that regular testing was valuable to detect the infected as early as possible before they could unknowingly infect others, and that the knowledge they were positive would allow the testee to self-quarantine. Whether or not those assumptions appear justified in the light of the data about the consequences of testing will be discussed at a later point.

THE TEST PROCESS

Guidelines for service providers when testing for hepatitis C have been prepared by the National Health and Medical Research Council (NHMRC, 1997).[4] These, *inter alia*, lay out standards for pre and post test counselling, suggesting that the outcomes of counselling should be the provision of psychosocial support, prevention of the transmission of hepatitis C and the optimisation of treatment outcomes. Our data suggest that, in the main, only the last of these outcomes is being met.

According to the guidelines, pre-test counselling should:

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[4] Later guidelines – eg RACGP, 1998 - were not available at the time of data collection.

- assess risk
- provide clinical information
- enable the patient to decide whether they should be tested
- provide information about the test and the possible consequences of testing, including confidentiality and notifiability
- provide information on testing benefits
- establish the ability to give informed consent
- identify support available to the patient.

As we have seen, the majority of our tested respondents reported that they received no pre-test counselling although it is not always clear what they believed was meant by the term. Many of them, moreover, said they neither wanted or needed counselling, and this was often accompanied by remarks about the routine nature of the test for them, and the fact that they had been tested before and did not need all the information again. The notion that pre-test counselling should contribute to the decision to be tested was inapplicable in many cases when the IDU was requesting the test.

IDUs' recollection of whether the confidentiality and notifiability provisions were clearly explained was somewhat hazy, suggesting that this was not a high priority for them, and only one in three of our SPs mentioned that they explained confidentiality and notifiability although whether this related to actual practice or failure to mention it is unclear. Nevertheless, neither group appeared to put much weight on this part of the procedure. Informed consent, on the other hand, assumed a greater significance: 80% of the IDUs said they had given it, and the majority of SPs explained how they obtained it.

According to the guidelines, the results of a hepatitis test should always be given face to face, whatever the reason for testing or the test outcome. This appeared to be generally understood by the SP informants although a few still gave hepatitis results over the phone and HIV/AIDS results in person. Most IDU respondents received their results in person, although one in ten were telephoned and there were a few horrific stories of other approaches. The chronology of these stories, however, has not been assessed, and they may have occurred in earlier years before guidelines were developed.

In terms of post-test counselling, the guidelines state that the aims are to ensure that the patient understands the meaning and implications of the test result, and that appropriate referrals and psychosocial interventions occur if required. If the patient is negative, counselling should provide information to prevent exposure to the virus, and the individual should be assisted to adopt relevant skills to remain infection free. The positive patient should be provided with immediate counselling or support and information to prevent transmission to others, and the extent of personal support should be assessed. Referral to external sources of support such as longer-term counselling or a local Hepatitis C Council is recommended.

The IDUs reported what appeared to be inadequate or non-existent post-test counselling in many cases. Post-test counselling was said to have been provided on fewer than 20% of most recent test occasions, and where it was provided it was almost always in the context of positive results. Even allowing for misunderstandings of the term “post-test counselling”, these are disturbing findings.

Our data suggest that much of the counselling suggested in the guidelines was not occurring, and that post-test counselling was primarily used after positive results as a medical intervention. Very few IDUs reported counselling following negative results, or referral to support agencies. Moreover, as with pre-test counselling, they clearly had little tolerance for a lot of discussion once they had a negative result: they felt that they understood how to prevent transmission and they wanted to take their results and go.

Written information was similarly not highly regarded. Some did not collect test results, apparently believing that they would be told if anything was wrong. Although this may have been an unconscious cover for some underlying anxiety about the result, in some cases it was clearly related to the respondent being in (drug) treatment and believing that results would be conveyed by the case manager if there was any need.

SP informants, who, it should be emphasised, were not the same testers as those referred to by the IDU respondents, seemed more inclined than testers reported by IDUs, to offer post-test counselling after negative results, and their descriptions of post-test counselling were comprehensive, although not all of them offered all the topics. Their assumptions about why IDUs did not collect test results were somewhat different from those given by the IDU respondents, and they may have failed to appreciate the extent to which information given to clients should emphasise that blood borne viruses are not like other infections, and test results will only be conveyed in person.

IDU respondents described a range of emotional experiences related to being tested. They reported being anxious on almost half of described testing occasions, mainly while waiting for results and in some cases because they knew they had engaged in unsafe behaviour. Responses to negative test results were, as noted above, often described as relief or delight. Those who received positive test results experienced a range of responses, including very strong anxiety. It is not clear how their testers responded to their emotional reactions, except, of course, that most IDUs said they received no post-test counselling and it may have been that their tester did not know how they were feeling. What is clear is that very few were referred to local support agencies such as the Hepatitis C Council who would have been in a good position to assist them to come to terms with positive diagnoses.

SP informants had generally observed the same emotions in their clients that IDU respondents described. Most said they dealt with these reactions with counselling, information provision and referral. The SP informant who said s/he did not deal with her/his client's emotional responses well was being very honest, and it is to be hoped that s/he had developed some alternatives mechanisms for supporting positive clients.

THE CONSEQUENCES OF TESTING

In the section on reasons for being tested, it was noted that many of the reasons given by IDUs for seeking testing were derived from rationales that would have been given to the doctor or clinic when requesting the test. Little information was obtained about the relationship of the testing process to the needs of the respondent (with the possible exception of those who stated they sought testing in connection with a relationship).

More information about IDUs' relationship to the testing process was obtained through questions about their response to their test results. Respondent's comments about their feelings about negative results often indicated a sense of validation, which suggests that the testing process may have served to reinforce current behaviour patterns as being behaviours which were "safe". Respondents who tested positive, on the other hand, often seem resigned or unsurprised: they had expected to be positive and the test confirmed it.

Further comments made by both positive and negative respondents about their behaviour since last tested demonstrated that there had been no real behaviour change. In some instances, where behaviour change had occurred, this was, if anything, in the direction of more risk. Those who reported positive behaviour changes were often referring to health related change, such as reduced use of drugs or improved diet, which were designed to promote the health of the individual rather than reduce transmission of the virus.

These comments suggest that the IDU respondents had a dichotomous understanding of risk: that is, they conceived of any given behaviour as being either safe or risky. Many testees described their normal injecting behaviour as safe, particularly when explaining why they had not changed their behaviour following testing. While many also admitted they had on occasion behaved in ways which they understood to be risky, this was not often seen as being part of their current, normal behaviour, although these occasional aberrations were high on the list of motivations to seek testing.

As suggested earlier, both testees and testers also appeared to be acting from an implicit quarantine model, in which testing would allow an individual to self-quarantine following a positive result. The frequency with which IDU respondents sought testing, the commonality of risk-exposure as a motivation to seek testing, and the willingness of testers to provide testing to those at risk all support this suggestion.

Those who tested negative were confirmed in their belief that their normal behaviour was safe, as proven by their negative result. They may have explained their negative test result following exposure to risk in a number of ways, from luck through to the view that perhaps the risk behaviour was not that risky after all. From a quarantine perspective, they may have had no motivation to make any behaviour change, because they believed their negative status did not put others at risk.

Those who tested positive may have interpreted this as confirming their suspicions that a given event or series of events were the point at which they contracted the BBV in question. Normal or current behaviour was not necessarily implicated, which might help to explain why the majority of seropositive respondents stated that they had not changed their behaviour since their last test, even though a significant number *also* expressed concern about passing the BBV on to others.

As has been demonstrated, the efficacy of testing IDUs for BBVs, as it is often currently practiced, appears to be hardly related to the test situation being a vehicle for counselling and the promotion of behaviour change. The testing process as described by our IDU respondents did not actively encourage seronegative IDUs to initiate behavioural change, nor did it encourage seropositive IDUs to regard their normal behaviour as behaviour which might transmit infection to others.

HEPATITIS B VACCINATION

Only 24% of the sample had been vaccinated against hepatitis B. Many of the non-vaccinated had been tested for hepatitis B and found to be seronegative. Many of those who had not been vaccinated, moreover, reported that had never heard of it or been offered it. Some did not understand why IDUs were at risk of hepatitis B, or why they should be vaccinated. Some were concerned about cost when the experience of those who had been vaccinated demonstrated that free vaccination was available. Most of the minority who had been vaccinated had completed the course and were pleased that they had done so, although it is interesting that some of their reasons for being vaccinated had little to do with injecting as a risky lifestyle. Information provision prompted a number of the non-vaccinated to profess interest in seeking it out.

As with the reports about test counselling, these results are too strong to be explained away as the poor memory of a few IDUs, and are disturbing. It is now 15 years since the NHMRC called for all IDUs to be vaccinated because of their high risk status (Gust, 1992) and it seems extraordinary that when so many of the respondents in this study had been tested because they were IDUs, so few had been vaccinated, particularly when many of these had received a negative hepatitis B test. Clearly, opportunities for prevention of this disease had been squandered.

CONCLUSION AND RECOMMENDATIONS

The cost of a BBVI screen (all three tests) is in the order of $25 – 30. We have seen that the SPs ordered many tests each month, and that the tested IDUs had typically had more than one test. The majority of IDU respondents had not been vaccinated against hepatitis B, despite having been tested and being seronegative. Many claimed they had never been told about vaccination.

This study has shown that the process of testing, as reported by the IDUs, was, in many cases, far from satisfactory. Clients were motivated to avoid behaviour change; test service providers were willing to test whenever requested to do so and some testees were apparently using testing to prove themselves uninfected: all these findings suggest that much testing may not have been serving any purpose other than to diagnose infection and implement appropriate medical interventions. While not decrying this as a motivation, it is clear that testing for BBVs also provides an ideal opportunity in which doctors and other service providers can help IDUs to make the behaviour changes necessary to prevent these infections, or to prevent reinfection and/or other complications associated with hepatitis C infection. It is also an ideal opportunity in which to encourage IDUs to be vaccinated against hepatitis B. Since so many IDUs are tested, the potential for incidence reduction and secondary prevention is enormous.

These comments raise a number of questions, which we believe test service providers should be considering when an IDU requests a BBV screen – particularly if the client is regularly tested in this way.

- What is the understanding of the test service provider? That a test event is not only a medical, but also a psycho-social intervention to prevent risk behaviour through good pre- and post test counselling, follow-up and referral? Or that the test event is primarily a medical intervention which is designed to diagnose infection so that it can be treated?

- What are the expectations of IDU clients? That a test event is an opportunity for them to discuss why they believe they could be infected and how they can avoid further risk, and establish whether they are infected and if so how they can minimise risk to others and maximise their health? Or that a test is a way of establishing whether or not they are infected, so that if they can continue with their current practices until or unless they become infected?

- How well do the expectations of the test service provider and the client match? If they do not, how can they be brought closer together?

The resolution of these questions may involve more research. We believe that more information is needed from doctors, IDUs and other interested parties about the limitations and difficulties with the existing testing guidelines. We have recently received funding to undertake research to develop more detailed recommendations about the testing process, and particularly pre- and post-test counselling. Some of the questions to be examined include:

- How appropriate are the current guidelines for either hepatitis C or HIV/AIDS testing, when most IDUs undertake these tests in batteries?
- How relevant are the guidelines to IDUs who are regularly tested?
- Under what circumstances should the guidelines be followed closely?
- Under what circumstances are the guidelines not appropriate?
- What should the role of testing be in promoting change towards safer behaviour? How can that best be facilitated?
- How practical is it to expect GPs, particularly, to implement the guidelines given the cost recovery structures of most practices?
- What are the barriers to the vaccination of IDUs against hepatitis B? How can these best be overcome?
- Are service providers unwilling to suggest vaccination if they believe that clients well be put off by the cost?

The findings of the two studies should enable the development of specific recommendations on maximising the efficacy of the testing process to prevent and limit the spread of blood borne viruses in injecting drug users in Australia.

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APPENDIX 1

STEERING GROUP MEMBERSHIP

Dr Mike Belbin

General Practitioner

Ms Jude Bevan

Communicable Disease Control Unit, Health Dept of WA

Dr Steve Blackwell

Community Methadone Program, WA Alcohol and Drug Authority

Dr Ann Cambridge

Medical Officer, WA AIDS Council

Ms Susan Carruthers

Hepatitis C Council

Ms Helen Fowler

Clinical Psychologist, Royal Perth Hospital

Mr David Grant

WA Substance Users Association

Ms Kathryn Kerry

Communicable Disease Control Unit, Health Dept of WA

Dr Tony Keller

Director, Blood Transfusion Service

Dr Jan Machin

Director, Fremantle Hospital Sexual Health Clinic

Dr David Smith

Acting Clinical Director, PATHCENTRE

APPENDIX 2

QUESTIONNAIRES AND INTERVIEW GUIDES

TESTING FOR BLOOD BORNE VIRUSES IN INJECTING DRUG USERS QUESTIONNAIRE

Questionnaire Number ☐☐☐ 1-3

Date ☐☐☐☐ 4-7

Recruited from:_______________☐☐ 8-9

SECTION A : DEMOGRAPHICS

A1. Are you:

Male	1
Female	2
Transgender	3

☐ 10

A2. How old are you? ....

☐☐ 11-12

A3. What is your current residential postcode? ....

☐☐☐☐ 13-16

A4. Are you currently:

Single/separated/divorced	1
Married/living with sexual partner	2

☐ 17

A5. How would you describe your sexual preference?

Gay/Lesbian	1
Straight/Heterosexual	2
Bisexual	3
Other (specify)	4........................

☐ 18

A6. What is the highest level of education completed?

Primary school	1
Junior high (Yr 10)	2
Senior high (Yr 12)	3

TAFE/Trade/Tech	4
University/College	5
Other (specify)	6.................................

☐ 19

A7. How are you employed at the moment?

Student - secondary	1 (☞ Q.A9)
Student - tertiary	2 (☞ Q.A9)
Full time	3
Part time/Casual	4
Home Duties	5 (☞ Q.A9)
Unemployed	6 (☞ Q.A9)
Other (specify)	7 ....

☐ 20

A8. What is your current job? ....

☐ 21

A9. What is your MAIN source of income?

Unemployment benefits	1
Sickness benefits	2
Pension	3
Drug dealing	4
Job	5
Other illegal activities	6
None	7
Other (specify)	8.............................

☐ 22

A10. What country were you born in?

Australia	1
Other (specify)	2...

☐ 23

A11. Are you of Aboriginal or Torres Strait Islander descent?

Yes	1
No	2

☐ 24

A12. What language was the main one spoken at the home you grew up in?

English	1
Other (specify)	2..

☐ 25

Warning: New Record

SECTION B: DRUG USE BEHAVIOUR

New Record

B1. Have you:

DRUG TYPE	EVER USED	EVER INJECTED	INJECTED IN LAST YEAR	INJECTED IN LAST MTH	NUMBER OF TREATMENT EVER (8 = lots)	CURRENT TREATMENT TYPE *
01 **Alcohol**						
02 **Benzodiazepines**						
03 **Cannabis**						
04 **Hallucinogens**						
05 **Heroin**						
06 **Methadone**						
07 **Amphetamines**						
08 **Ecstasy**						
09 **Steroids**						
10 **Other**						

1-10 11-20 21-30 31-40 41-49 50-58

Other=____(other opiates = 11)

* detox = 1 RR/TC = 2 meth = 3 GP = 4 couns = 5 NA = 6 hosp = 7 other = 8

B2. At what age did you first inject? __________

☐☐ 59-60

B3. When did you last inject? ___________

☐☐☐ 61-63

B4. What is the main drug that you inject?_________________________

☐☐ 64-65

B5. What drug did you last inject?_______________________________

☐☐ 66-67

B6. How frequently do you inject (in a typical week in the last month)/before you were in treatment?

More than 2-3 times a day	1
Once a day	2
Every second day	3
Twice a week	4
Once a week	5
Less frequently	6
Not at all	7

☐ 68

Wanring: New Record
New Record

SECTION C: RISK TAKING BEHAVIOUR

C1. How often have you injected a drug in the past month?

Haven't had a hit	1 (☞ Q.C7)
Less than once a week	2
Once a week	3
More than weekly, not daily	4
Once a day	5
2-3 times a day	6
More than 3 times a day	7

☐ 1

C2. How many times in the past month have you used a needle after someone else (including your lover) has already used it?

Never	1
Once	2
Two times	3
3-5 times	4
6-10 times	5
More than 10 times	6

☐ 2

C3. What is the total number of people (including your lover) who have used a needle before you in the past month?

None	1
One	2

Two	3
3-5	4
6-10	5
More than 10	6

☐ 3

C4. How many times in the past month has someone else (including your lover) used a needle after you have used it?

Never	1
Once	2
Two times	3
3-5 times	4
6-10 times	5
More than 10 times	6

☐ 4

C5. In the past month which of the following people have you shared a needle with?

Regular sex partner	1	☐	5
Close friend	2	☐	6
Casual sex partner	3	☐	7
Someone I don't know very well	4	☐	8
No-one	5	☐	9
Other (specify)................................	6	☐	10

C6. How many times in the past month have you shared other injecting equipment (eg spoons, filters, water, tourniquet) with someone else (including your lover)?

Never	1
Once	2
Two times	3
3-5 times	4
6-10 times	5
More than 10 times	6

☐ 11

C7. How many people have you had vaginal/anal intercourse with in the past month?

None	1 (☞ Q.D1)
One	2
Two	3
3-5	4
6-10	5
More than 10	6

☐ 12

C8. If you had intercourse in the past month how often did you or the person you had sex with use condoms?

Never	1
Rarely	2
Sometimes	3
Often	4
Every time	5
No intercourse	6

☐ 13

C9. In the past month which of the following people have you had intercourse with?

Regular sex partner	1	☐	14
Close friend	2	☐	15
Casual sex partner	3	☐	16
Someone I don't know very well	4	☐	17

No-one	5	☐	18
Other (specify)..................................6	☐	19	

SECTION D - KNOWLEDGE

D1. Do you think that HIV/AIDS is a risk for IDUs?

Yes	1
No	2

☐ 20

If yes, why?____

D2. Do you think that HCV is a risk for IDUs?

Yes	1
No	2

☐ 21

If yes, why?____

D3. Do you think that HBV is a risk for IDUs?

Yes	1
No	2

☐ 22

If yes, why?____

____

D4. What do you understand about HBV vaccination? (about immunity)

____

____

____

____

SECTION E: HIV

E1. Have you ever had a HIV/AIDS test?

Yes 1 (☞ Q.E3)
No 2 (☞ Q E2)

☐ 23

E2. Why haven't you been tested for HIV/AIDS?

____

____

____

____

(☞ Q.E10)

E3. How many HIV/AIDS tests have you had? ______________________ ☐☐ 24-25

E4. How many times have you had a HIV/AIDS test on it's own?__________ ☐☐ 26-27
(if always in a battery, rest of the questions apply to all tests - HBV, HCV, HIV)

E5. When was your first HIV/AIDS test?_____/_____/_____ mths ☐☐☐ 28-30

E6. When was your last HIV/AIDS test? _____/_____/_____ mths ☐☐☐ 31-33

E7. Where was your last test? ____

E8. How often do you get tested? (At what intervals) ____________________

E9. What was the result of your last HIV/AIDS test?

Antibody positive	1 (☞ Q E13)
Antibody negative	2 (☞ Q E11)
Unclear/Indeterminate	3 (☞ Q E11)
Don't know - didn't pick up	4 (☞ Q E10)
Refusal	5
Other (specify)	6..............................

☐ 34

E10. Why didn't you pick up your HIV/AIDS test results?

____

____

____

____

E11. Do you think you are now antibody positive for HIV/AIDS?

Yes	1
No	2

☐ 35

Why/Why not?____

____

____

____

____

E12. What effect does this belief have on your life?

____

____

(if not tested☞ Q.E24)

E13. Why did you decide to get tested for HIV/AIDS? (1st time; other times)
(doctor's s/friends suggestion/media etc; what risk factors did the Dr mention/did you identify?)

E14. Tell me about your experience when you were last tested for HIV/AIDS: (prompts)

PROMPTS :

(a) How did the test come about (your request/recommended)?

(b) Were you offered pre test counselling? What did this consist of? How long?

(c) Confidentiality? Was this explained? HDWA notification process explained?
Contact tracing?

(d) Did you give informed consent?(was it explained? did you sign anything?)

(e) Were you offered post test counselling? What did this consist of? How long?

(f) How did you get the results? (face to face? Who from? Did you understand them?)

(g) Were you provided with written information? What?

(h) Were you referred anywhere else? Where? What about follow-up?

(i) Ask about awareness of available agencies (eg HCC, WAAC)

What were you thinking?

What were you feeling?

How were you treated? (by who?)

WHAT ABOUT FOR OTHER TEST INCIDENTS? - anything else you want to tell me about tests you've had?

E15. Have you ever had a bad experience when being tested for HIV /AIDS?
(not just the result)

Yes	1
No	2 (☞ Q E16)

☐ 36

Describe:(when did this happen?)

E16. Tell me how you felt when you found out your last HIV/AIDS test result:

If HIV+ ☞ Q E17; if HIV- ☞ Q E18

E17. What effect does your positive HIV/AIDS serostatus have on your life?
(lifestyle, relationships, behaviours):

(☞ Q E19)

E18. What effect does your negative HIV/AIDS serostatus have on your life?
(lifestyle, relationships, behaviours):

E19. Was there any change in your behaviours after you received your last result?
(treatment, lifestyle)

Yes 1 (☞ Q.E20)
No 2 (☞ Q.E23)

☐ 37

E20. What were these changes? (prompts - injecting, sexual, household etc)

____

____

____

____

E21. How long did these changes last?______________________________

____

____

____

(if forever ☞ Q.E24)

E22. Why did you change your behaviour back?

____

____

____

____

(☞ Q.E24)

E23. Why didn't you change your behaviour? ________________________

____

____

____

____

E24. Have you ever refused to be tested for HIV/AIDS when it has been recommended?

Yes 1
No 2 (☞ Q.E25)

☐ 38

What happened?____

____

____

____

E25. Have you ever been refused HIV/AIDS testing when you have requested it?

Yes 1
No 2 (☞ Q.F1)

☐ 39

What happened?____

____

____

____

Warning: New Record

New Record

SECTION F: HCV

F1. Have you ever had a hepatitis C test?

Yes 1 (☞ Q.F3)
No 2 (☞ Q.F2)

☐ 1

F2. Why haven't you been tested for HCV?

____

____

____

____

(☞ Q.F10)

F3. How many hepatitis C tests have you had? ______________________ ☐☐ 2-3

F4. How many times have you had a HCV test on it's own? ___________ ☐☐ 4-5

F5. When was your first hepatitis C test? _____/_____/_____ mths ☐☐☐ 6-8

F6. When was your last hepatitis C test? _____/_____/_____ mths ☐☐☐ 9-11

F7. Where was your last test?______________________________________

F8. How often do you get tested? (At what intervals) ____________________

F9. What was the result of your last HCV test?

Antibody positive	1 (☞ Q F13)
Antibody negative	2 (☞ Q F11)
Unclear/Indeterminate	3 (☞ Q F11)
Don't know - didn't pick up	4 (☞ Q F10)
Refusal	5
Other (specify)	6.............................

☐ 12

F10. Why didn't you pick up your HCV test results?

____

____

____

____

F11. Do you think you are now antibody positive for hepatitis C?

Yes	1
No	2

☐ 13

Why/Why not?____

____

____

____

F12. What effect does this belief have on your life?

____

____

____

____

(if not tested ☞ Q F24)

F13. Why did you decide to get tested for hepatitis C? (1st time; other times)
(doctor's/friend's suggestion/media; risk factors mentioned by Dr/you identified risk factors)

____

____

____

____

F14. Tell me about your experience when you were last tested for HCV: (prompts)

____

____

____

____

PROMPTS :

(a) How did the test come about (your request/recommended)?

(b) Were you offered pre test counselling? What did this consist of? How long?

(c) Confidentiality? Was this explained? HDWA notification process explained?
Contact tracing?

(d) Did you give informed consent?(was it explained? did you sign anything?)

(e) Were you offered post test counselling? What did this consist of? How long?

(f) How did you get the results? (face to face? Who from? Did you understand them?)

(g) Were you provided with written information? What?

(h) Were you referred anywhere else? Where? What about follow-up?

(i) Ask about awareness of available agencies (eg HCC, WAAC)

What were you thinking?

What were you feeling?

How were you treated? (by who?)

WHAT ABOUT FOR OTHER TEST INCIDENTS? - anything else you want to tell me about tests you've had?

F15. Have you ever had a bad experience when being tested for HCV?
(not just the result)

Yes	1
No	2 (☞ Q F16)

☐ 14

Describe:(when did this happen?)______________________________________

____

____

____

____

F16. Tell me how you felt when you found out your last HCV test result:

____

____

____

____

If HCV+ ☞ Q F17; if HCV- ☞ Q F18

F17. What effect does your positive HCV serostatus have on your life?

(lifestyle, relationships, behaviours):

____

____

____

____

(☞ Q F19)

F18. What effect does your negative HCV serostatus have on your life?

____

____

____

____

F19. Was there any change in your behaviours after you received your result?
(treatment, lifestyle)

Yes 1 (☞ Q.F20)
No 2 (☞ Q.F23)

☐ 15

F20. What were these changes? (prompts - injecting, sexual, household etc)

____

____

____

____

F21. How long did these changes last?______________________________________

____

____

____

(if forever ☞ Q F24)

F22. Why did you change your behaviour? (back) ______________________________

____

____

____

____

(☞ Q F24)

F23. Why didn't you change your behaviour? _________________________________

____

____

____

F24. Have you ever refused to be tested for HCV when it has been recommended?

Yes 1
No 2 (☞ Q F25)

☐ 16

What happened?______________________________

F26. Have you ever been refused HCV testing when you have requested it?

Yes 1
No 2 (☞ Q G1)

☐ 17

What happened?______________________________

SECTION G: HBV

G1. Have you ever had a hepatitis B test?

Yes	1 (☞ Q.G3)
No	2 (☞ Q.G2)

☐ 18

G2. Why haven't you been tested for HBV?

____

____

____

____

(☞ Q.G10)

G3. How many hepatitis B tests have you had? ____________________ ☐☐ 19-20

G4. How many times have you had a HBV test on it's own? ___________ ☐☐ 21-22

G5. When was your first hepatitis B test? _____/_____/_____ mths ☐☐☐ 23-25

G6. When was your last hepatitis B test? _____/_____/_____ mths ☐☐☐ 26-28

G7. Where was your last test?____

G8. How often do you get tested? (At what intervals) ____________________

G9. What was the result of your last HBV test?

Antibody positive	1 (☞ Q G13)
Antibody negative	2 (☞ Q G11)
Unclear/Indeterminate	3 (☞ Q G11)
Don't know - didn't pick up	4 (☞ Q G10)
Refusal	5

Other (specify) 6.............................

☐ 29

G10. Why didn't you pick up your HBV test results?

____

____

____

____

G11. Do you think you are antibody positive for hepatitis B?

Yes	1
No	2

☐ 30

Why/Why not?____

____

____

____

____

G12. What effect does this belief have on your life?

____

____

____

____

(if not tested ☞ Q G24)

G13. Why did you decide to get tested for hepatitis B? (1st time; other times)
(doctor's/friend's suggestion/media etc; Dr mentioned risk fators/you identified risk factors)

____

____

G14. Tell me about your experience when you were last tested for HBV:(prompts)

PROMPTS :

(a) How did the test come about (your request/recommended)?

(b) Were you offered pre test counselling? What did this consist of? How long?

(c) Confidentiality? Was this explained? HDWA notification process explained?
Contact tracing?

(d) Did you give informed consent?(was it explained? did you sign anything?)

(e) Were you offered post test counselling? What did this consist of? How long?

(f) How did you get the results? (face to face? Who from? Did you understand them?)

(g) Were you provided with written information? What?

(h) Were you referred anywhere else? Where? What about follow-up?

(i) Ask about awareness of available agencies (eg HCC, WAAC)

What were you thinking?

What were you feeling?

How were you treated? (by who?)

WHAT ABOUT FOR OTHER TEST INCIDENTS? - anything else you want to tell me about tests you've had?

G15. Have you ever had a bad experience when being tested for HBV?
(not just the result)

Yes	1
No	2 (☞ Q G16)

☐ 31

Describe: (when did this happen?)____

____

____

____

____

G16. Tell me how you felt when you found out your last HBV test result:

If HBV+ ☞ Q G17; if HIV- ☞ Q G18

G17. What effect does your positive HBV serostatus have on your life?
(lifestyle, relationships, behaviours):

(☞ Q G19)

G18. What effect does your negative HBV serostatus have on your life?

G19. Was there any change in your behaviours after you received your result?
(treatment, lifestyle)

Yes 1 (☞ Q.G20)
No 2 (☞ Q.G23)

☐ 32

G20. What were these changes? (prompts - injecting, sexual, household etc)

____

____

____

____

G21. How long did these changes last?______________________________

____

____

____

(if forever ☞ Q.G24)

G22. Why did you change your behaviour? (back) ______________________________

____

____

____

____

(☞ Q.G24)

G23. Why didn't you change your behaviour? ______________________________

____

____

____

____

G24. Have you ever refused to be tested for HBV when it has been recommended?

Yes	1
No	2 (☞ Q.G25)

☐ 33

What happened?____

____

____

____

G23. Have you ever been refused HBV testing when you have requested it?

Yes	1
No	2 (☞ Q.H1)

☐ 34

What happened?____

____

____

____

Warning: New Record

New Record

SECTION H: HBV VACCINATION

H1. Have you been vaccinated against hepatitis B?

Yes	1 (☞ Q.H6)
No	2 (☞ Q.H2)
Don't know	3 (☞ Q.H5)
Never heard of vax	4 (☞ Q.H14)
HBV +ve: immune	5 (☞ Section I)

☐ 1

H2. Why haven't you been vaccinated against HBV?

____

____

____

H3. How do you feel about not being vaccinated?

____

____

____

____

H4. Are you more careful because you haven't been vaccinated?

Yes 1

No 2 (☞ Q.H14)

☐ 2

If yes, how? (prompt - behaviour changes)

____

____

____

(☞ Q.H14)

H5. Why don't you know if you've been vaccinated? (☞ Q.H14)

____

____

____

____

H6. Why did you get vaccinated for hepatitis B?

____

____

____

____

H7. How long ago were you vaccinated? ____________________ mths ☐☐☐ 3-5

H8. Tell me about the number of needles you had for the vaccination:(boosters & tests)

____

____

____

____

H9. Did you finish the whole course?

Yes	1
No	2
Don't know	3

☐ 6

Why/why not? ____

____

____

____

H10. Over what period did the course take place? ______________________

H11. Did you have to pay?

Yes	1	How much? $__________/shot
No	2	

☐ 7

H12. How do you feel about being vaccinated?

____

____

____

____

H13. What difference does it make to your life if you've been vaccinated?
(prompt - behaviour changes)

____

____

____

EDUCATION SESSION ON HBV VACCINATION

H14. Now that you know a bit more about HBV vaccination, would you consider being vaccinated?

Yes	1
No	2
Don't know	3
Been vaccinated	4

☐ 8

Why/why not?

(where, when??)

SECTION I: HEALTH PROMOTION. HARM REDUCTION MESSAGE

Give referral sheet.

Plus info on: blood awareness; safer injecting and sex; basic transmission info

Do you have any questions?

INTERVIEWER ASSESSMENT

Record observations about the interview.

How co-operative did you find the interviewee?

0 25 50 75 100 ☐☐☐ 9-11

How truthful did you think the interviewee was?

0 25 50 75 100 ☐☐☐ 12-14

End Record

OTHER COMMENTS:

NATIONAL CENTRE FOR RESEARCH INTO THE PREVENTION OF DRUG ABUSE
GPO BOX U1987, PERTH WA 6001
TELEPHONE: 09 368 2055 FAX: 09 367 8141

curtin
University of Technology
Perth Western Australia

TESTING FOR BLOOD BORNE VIRAL INFECTIONS IN INJECTING DRUG USERS

Project Director: Dr Wendy Loxley **Project Officer: Paige Sullivan**

TO:	FROM: Paige Sullivan
NUMBER:	DATE:
TOTAL PAGES SENT: 4	

I am writing in regard to our recent telephone conversation in which I informed you of the above study and you agreed to be one of the key service providers to be interviewed. Could you please fill in the following questions within one week from today (by by Monday 26 May), **and fax it back with your answers. Could you please fax back this coverpage ASAP so I can schedule your interview**. Please keep a copy of this questionnaire for further discussion during the interview. I will then inform you of the time of your half hour telephone interview by phone, and look forward to speaking to you again at this time. Thank you in advance for your involvement in the study.

Sincerely,

Paige Sullivan, Project Officer

Please circle the times most suitable for you to undertake a thirty minute follow up phone interview. I will work out the interstate time differences accordingly (please circle more than one).

Tuesday 3 June 10am 11am 1pm 2pm 3pm

Wednesday 4 June 10am 11am 1pm 2pm 3pm

Thursday 5 June 10am * 1pm 2pm 3pm

Friday 6 June 10am 11am 1pm 2pm 3pm

Monday 9 June * 11am 1pm 2pm 3pm

Tuesday 10 June 10am 11am 1pm 2pm 3pm

Wednesday 11 June 10am 11am 1pm 2pm 3pm

Thursday 12 June 10am * 1pm 2pm 3pm

Friday 13 June 10am 11am 1pm 2pm 3pm

Monday 16 June * 11am 1pm 2pm 3pm

Tuesday 17 June 10am 11am 1pm 2pm 3pm

Wednesday 18 June 10am 11am 1pm 2pm 3pm

*** I am unavailable.**

Agency/Practice Name:

Address:

Agency/Practice Type and Role:

Your Name, Title and Role:

Funding Source (if applicable):

SECTION A: DEMOGRAPHICS AND STATISTICS - ID Number ☐☐

A1. How many staff members at your agency/practice are involved in testing injecting drug users (IDU) for blood borne viruses (BBV)? (ie - taking blood & counselling)

A2. Who makes up your client group? (eg general community, IDUs, gay men, youth etc)

A3. On average, how many individual clients does your agency/practice see per month? (please include first contacts and repeats if possible)

A4. Approximately how many of those clients self disclose that they are current or past injecting drug users?

A5. What is the approximate range in ages for clients having blood borne virus tests at your agency/practice?

A6. What is the approximate gender breakdown for clients having blood borne virus tests at your agency/practice?

A7. On average, how many Hepatitis B tests are done in your agency/practice per month?

What proportion of these are current/past IDUs?

How many of these tests are done post-vaccination?

Which HBV tests do you request?

Test	**Please tick**	**Circumstances**
Surface Antigen		
Antibody		
Core		
All three		

A8. On average, how many Hepatitis C antibody tests are done in your agency/practice per month? How many PCR tests?

What proportion of these are current/past IDUs?

A9. On average, how many HIV antibody tests are done in your agency/practice per month?

What proportion of these are current/past IDUs?

A10. On average, how many Hepatitis B vaccinations are given in your agency/practice per month?

What proportion of these are current/past IDUs?

A11. Approximately what percentage of your BBV tested IDU clients are:

Referred by GPs and other agencies? __________%

Self-referred/Off the street? __________%

Referral source unknown? __________%

SECTION B: TRAINING AND KNOWLEDGE

B1. Do professional staff receive training on blood borne viruses? (please circle) Yes No

If yes, who from and what does it entail (briefly)?

B2. Do professional staff receive training on IDUs? (please circle) Yes No

If yes, who from and what does it entail (briefly)?

B3. How do staff keep up to date and informed in the BBV/IDU area?

B4. Which other agencies and services are available to you for referral of BBV clients?

B5. In what circumstances does referral to other agencies or services take place?

Please fax back the cover sheet with your interview time preferences ASAP. Please fax the completed questions by Monday 26 May 1997 on (08) 9367 8141. Thank you for your time.

Date __________ Time: start__________finish_________ ID Number: ☐☐

BBV AND TESTING STUDY: SERVICE PROVIDER INTERVIEW SCHEDULE

B6. Are you familiar with the NH&MRC draft guidelines for hepatitis C? Yes No

SECTION C: PROTOCOLS/POLICIES/GUIDELINES

C1. What stages of the testing process are done in the agency?

pre-test counselling ☐
taking blood ☐
post-test counselling ☐
referral ☐
follow-up ☐

C2. In what circumstances are current and past IDUs tested for BBVs
(HBV,HCV,HIV, battery) PROMPT - assessment for risk behaviours for BBVs

C3. Do clients ever refuse to have a BBV test after being advised to? Yes No

If so, what do you do?

C4. Do you ever refuse to test a client? Yes No

Under what circumstances?

C5. How do you ensure the client's informed consent for a BBV test?

(prompt - HD notification?)

C6. Is pre- and post-test counselling provided for a BBV test?

C7. Who provides this counselling?

C8. How much time is spent on pre- and post-test counselling for BBV tests?

C9. What is covered in pre- and post-test counselling for BBVs?

Pre -

Post +ve -

Post -ve - (prompt - harm reduction strategies discussed?)

C10. Are written info/resources are provided to the client? Yes No

C11. How are the results usually given for BBV test? (face to face, phone, written)

C12. On average, what percentage of clients pick up their results?

C13. What happens if clients don't pick up their results?

C14. What happens after a positive test result has been given?
(follow up? referral - who? treatment?)

C15. What happens when a clients requests re-testing? (How much is asked about previous tests; client motivation for re-testing)

C16. Do you ever refuse to re-test a client? Yes No

If yes, under what circumstances?

C17. At what intervals do you suggest clients be re-tested?

C18. What practices are undertaken to ensure the client's confidentiality? (What are clients told about confidentiality?)

C19. Do you have a policy for control of intoxicated or difficult clients? Yes No

If yes, what does it state?

If not, what do you do?

SECTION D: HEPATITIS B VACCINATIONS

D1. What is the nature of clients that get vaccinated?
(IDU? Gay men? Sex workers? Youth? Other?)

D2. How does a hep B vaccination usually come about?
(Client request/ Recommended)

D3. How do you ensure the client's informed consent for a hep B vaccination?

D4. On average, how well do clients comply with the full hep B vaccination regime?

How do IDUs compare to others?

If not, what is done? (follow-up?)

D5. Is there a cost to the client for hep B vaccination ? Yes No

If so, how much is charged? $________________

Do you think the cost of hep B vaccine is diffcult for clients? Yes No

SECTION E: IDUS

E1. Why do you think IDUs self-refer to your agency/practice? (concerned abouthealth)

E2. For those who self-refer for testing, what are the range of things that you believe cause IDUs to want to be tested?

E3. Do you believe some IDUs need to be advised to be tested/vaccinated?   Yes   No
If yes, under what circumstances? If no, why not?

E4. In your experience, why do you believe that some IDUs fail to collect test results?

E5. In your experiences, what is the range of emotional responses by IDU clients to the test process?

How do you deal with these?