

**TALKING ABOUT TESTING: OPPORTUNITIES FOR  
PREVENTION IN BLOOD BORNE VIRUS TESTING AND  
VACCINATION WITH INJECTORS**

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Preventing harmful drug use in Australia

**Curtin University of Technology**

October 2001

**This study was funded by the National Health and Medical Research  
Council (Program of Social and Behavioural Research into Hepatitis C)  
and the Division of Health Sciences, Curtin University**



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**ISBN: 1 74067 110 4**



## **ACKNOWLEDGMENTS**

This study would not have been possible without the support of a number of organisations and individuals. We would like to thank our funders: the National Health and Medical Research Council through the Program of Social and Behavioural Research into Hepatitis C, and the Division of Health Sciences, Curtin University.

We would also like to thank the consultants and other researchers who made a valuable contribution to the study:

- Dr. Moira Sim (Next Step Specialist Drug and Alcohol Services)
- Mr. Justin Woodruff, Mr. Rosco Woods and Ms. Janet Bradbury (WA Substance Users' Association)
- Ms. Judith Pugh and Ms. Judyth Watson (Hepatitis C Council of WA)
- Dr. Lewis Marshall (public health physician)

We would like to thank Trinity Youth Options, the Perth Inner City Youth Service, the Hills Youth Centre, the Hepatitis C Council of WA and the WA Substance Users Association who promoted interviews and focus groups to their members. The Perth Inner City Youth Service, the Hills Youth Centre, the Good Read Café and the Moon Café generously gave us space to conduct interviews.

Finally, we would like to thank the 40 injectors and health professionals who shared their experiences and opinions with us.



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## EXECUTIVE SUMMARY

Australian injecting drug users are commonly tested for hepatitis C, hepatitis B and HIV/AIDS, but while a considerable literature exists in relation to human factors involved in testing for HIV/AIDS, there appears to be little or no literature related to human factors in testing for hepatitis C and B, or vaccinating against hepatitis B. Some studies suggest that being tested is not necessarily a valuable or useful experience for individuals and/or 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 those tested and her/his community.

In 1997 the NHMRC funded the National Drug Research Institute (NDRI) to conduct an investigation of some of the human issues involved in testing injectors for blood borne viruses (BBVs) and vaccinating them against hepatitis B. Two hundred injectors and 39 test service providers participated in the research. The study showed that the process of testing was, in many cases, far from satisfactory and that the only purpose served by much of the testing appeared to be the diagnosis of infection and the implementation of appropriate medical interventions. This falls well short of the intention of NHMRC Guidelines for Pre- and Post-test Counselling for Hepatitis C which suggest that the outcomes should be the provision of psychosocial support, prevention of the transmission of hepatitis C and the optimisation of treatment outcomes. The data suggested that, in the main, only the last of these outcomes was being met. Reported low levels of hepatitis B vaccination were also a concern.

The present study is an examination of clinical and practical difficulties with the NHMRC Guidelines. This project aimed to deepen knowledge about the process of testing injectors for hepatitis C and other blood borne viral infections and to develop concrete recommendations for changes to the Guidelines for pre- and post-test counselling. The project was informed at every stage by consultants drawn from a range of relevant organisations. The data collection methodology was primarily qualitative, using a number of different techniques (interviews, focus groups and consultations) to develop a total data set upon which conclusions and recommendations were based.

There were two phases in the study. In Phase 1, 19 tested injectors and 21 health professionals (test service providers and key informants) were interviewed about the Guidelines. As part of the interviews, test service providers were presented with two scenarios relating to hypothetical requests for BBV tests and asked what they would do in each situation. The data from Phase I were discussed by the consultants and investigators and led to the development of proposed modifications to the Guidelines.

In Phase Two, the draft modified guidelines were presented to two focus groups for their comments, and their comments were further discussed by the consultants.

Our final proposals for modifications to the existing NHMRC Guidelines for hepatitis C testing have taken as many as possible of these disparate points of view into consideration. We also suggest that the modified guidelines should be generalised to all BBV testing with injectors, since most tests occur in batteries rather than singly. Our proposed guidelines, therefore, relate to BBV testing with injectors. The proposed guidelines are attached at the end of this summary.

There are a number of other issues which have emerged as concerns and need to be addressed:

- The specific resource needs of rural/regional test service providers (TSPs) in relation to BBV testing

- The importance of effective relationships between TSPs and injectors

- The appropriateness of the language used in the guidelines

- The use of the terms “pre- and post-test discussion” rather than “pre- and post-test counselling” to reduce confusion, more accurately reflect the focus of these sessions, and defuse any concern or anxiety as to what might be expected from “counselling”

- If new guidelines are suggested, TSPs will need to be made aware of them and receive some support in their implementation. A further strategy would be to inform injectors about what they could expect when they request BBV testing.

In conclusion, we believe that a test event is not only a medical but also a psychosocial intervention to prevent risk behaviour. Both injectors and TSPs need to have the expectation that a test event is an opportunity for them to discuss why the

injector could be infected and how further risk to the individual and the community could be avoided.



## PROPOSED GUIDELINES FOR BBV TESTING WITH INJECTORS

**Pre-test discussion** should always be in person no matter what the reason for the test. Pre-test discussion aims to provide the individual with the information, ability and opportunity to give informed consent to the BBV test.

At first test	At subsequent tests	
Essential <sup>1</sup>	Essential <sup>1</sup>	Negotiable <sup>2</sup>
<p><b>Provide clinical information about the virus</b></p> <p><b>Assess risk</b> Include exemplars for assessing risk</p> <p><b>Provide information about the test and the possible consequences and benefits of testing including confidentiality and notifiability</b></p> <p><b>Provide additional information about the virus</b> Format and language of information should be appropriate to the person's literacy and language skills.</p> <p><b>Discuss whether the patient is ready and able to give informed consent. Gain informed consent</b></p> <p><b>Identify support available to the patient.</b></p> <p><b>Arrange the post-test discussion</b> Provide option to bring a support person when receiving results.</p>	<p><b>Assess risk</b> Include exemplars for assessing risk</p> <p><b>Provide information about the test and the possible consequences and benefits of testing including confidentiality and notifiability</b></p> <p><b>Discuss whether the patient is ready and able to give informed consent. Gain informed consent</b></p> <p><b>Arrange the post test discussion</b> Provide option to bring a support person when receiving results.</p>	<p><b>Provide clinical information about the virus</b></p> <p><b>Identify support available to the patient.</b></p> <p><b>Provide additional information about the virus</b> Format and language of information should be appropriate to the person's literacy and language skills.</p>

<sup>1</sup>Essential; these guidelines should be included in every pre- and post-test discussion regardless of the person's testing history, relationship with TSP, knowledge of blood borne viruses or current situation.

<sup>2</sup>Negotiable: these guidelines could be negotiated between the person being tested and the test service provider based on the person's testing history, relationship with TSP, knowledge of blood borne viruses or current situation.

**Post-test discussion** should always be in person no matter what the reason for the test or whether the result is positive or negative. The purpose of post-test discussion is to ensure the individual understands the meaning and implications of the test result and is provided with support, information and referral as appropriate.

Negative result	Positive result	
Essential	Essential	Negotiable
<p><b>Facilitate discussion which provides harm reduction information to prevent exposure to the virus. Assist the person to develop skills in remaining infection free.</b></p> <p>Discussion should be based on the pre-test risk assessment.</p>	<p><b>Provide immediate counselling and assess other sources of support</b></p> <p>Incorporate positive result giving into two stages as appropriate. It is recommended that this guideline be addressed at the 1<sup>st</sup> appointment.</p> <ul style="list-style-type: none"> <li><b>Provide support and information to prevent transmission</b></li> </ul> <p>Incorporate positive result giving into two stages as appropriate. It is recommended that this guideline be addressed at the 2<sup>nd</sup> appointment.</p>	<p><b>Refer to external sources of support such as longer-term counselling or a local Hepatitis C Council</b></p> <p>Incorporate positive result giving into two stages as appropriate. It is recommended that this guideline be covered at the 1<sup>st</sup> and/or 2<sup>nd</sup> appointment</p>
<p><b>Indeterminate/Equivocal Result</b></p>		
<p>Discussions in this situation should be couched appropriately according to the individual, their level of risk and the likelihood of a positive or negative result.</p>		



## INTRODUCTION

### BACKGROUND TO THE RESEARCH

Australian injecting drug users are commonly tested for blood borne viruses (BBVs) (hepatitis C, hepatitis B and HIV/AIDS). Thus in the 1994 Australian Study of HIV and Injecting Drug Use (ASHIDU), 79% of 872 injectors had been tested for hepatitis C, 81% had been tested for hepatitis B and 91% had been tested for HIV/AIDS. Even though these results were influenced by age and treatment status, more than half of younger injectors who had never been in treatment and had the lowest testing rates, had been tested for all three viruses (Loxley, Carruthers & Bevan, 1995).

There are an estimated 200 000 hepatitis C infections in Australia; more than 125 000 people have been notified with hepatitis C since antibody testing became available in 1990 and there are now around 18 000 – 20 000 notifications a year (NCHECR, 1999). Eighty percent of infections are considered to be as a result of injecting drugs (Lowe & Cotton, 1999).

Hepatitis B was first identified as a virus in 1965, long before HIV/AIDS and hepatitis C, but, perhaps because of this, seems never to have assumed the same significance in the mind of injectors, the community and, possibly, health professionals. In Australia there are 150 000 – 180 000 infected individuals with an estimated 1 200 deaths per annum (Batey & Bollipo, 1996). Hepatitis B is efficiently transmitted by blood, vertical transmission and sexual contact, and people who inject drugs are at high risk of infection. While it has been overshadowed by the hepatitis C epidemic, this does not decrease its importance as a major cause of severe liver disease, morbidity and mortality (Batey & Bollipo, 1996). In Australia, the National Health and Medical Research Council (NHMRC)'s recommendation of universal vaccination to prevent hepatitis B has been adopted, but the uptake of vaccination by high-risk populations such as people who inject drugs is far from complete.

A considerable literature exists in relation to human factors involved in testing for HIV, but there appears to be little or no literature related to human factors in testing for hepatitis C and B, or vaccinating against hepatitis B. In terms of testing for

HIV/AIDS, Beardsell (1994) pointed out that while national 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.

Phillips and Coates (1995) asserted that research should investigate not only the initial decision to be tested, but also follow-through. Lindan et al. (1994) investigated HIV/AIDS testing among alcoholics and drug users and concluded that there was substantial misunderstanding or misreporting of test results, maintaining that this "underscores the need to improve testing and counselling procedures in this group" (p. 1155).

These studies suggest that being tested is not necessarily a valuable or useful experience for individuals. Research over some years at the National Drug Research Institute (NDRI)<sup>1</sup> into the relationship between injecting drug use and BBVs 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 those tested and her/his community. Particular difficulties we have identified include motivations for being tested that include the desire to maintain current behaviour patterns rather than reduce risk; intimidatory testing processes that deter some (particularly young) injectors from presenting for testing or from collecting test results; failures to understand the meaning of test result which may result from inadequate pre- and post-test counselling; over-testing; and uncertainty about serostatus and hepatitis B vaccination process or status (Loxley, 1991, Loxley, 1998, Loxley et al., 1995).

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<sup>1</sup> Formerly the National Centre for Research into the Prevention of Drug Abuse

## TESTING INJECTORS FOR BBVS – RESEARCH IN PERTH

In 1997 the NHMRC funded NDRI to conduct an investigation of some of the human issues involved in testing injectors for BBVs and vaccinating them against hepatitis B. Issues investigated included the decision to be tested or to test, the test process and test outcomes. Two hundred injectors, stratified for age and experience in drug treatment, were recruited in Perth and interviewed in person, and 39 test service providers (TSPs) from every State and Territory were recruited and interviewed by phone. Data in both sets were qualitative and quantitative. The study has been reported by Loxley, Davidson, Heale and Sullivan (1999).

There were 103 male and 97 female injector respondents. Their ages ranged from 14 to 47 years with a mean of 26.1 and a median of 24 years. The majority were not married or living with sexual partners, and nine out of ten were heterosexual. Five were Indigenous Australians. Most had used alcohol, cannabis, hallucinogens, amphetamines, heroin, ecstasy and benzodiazepines at least once, and just under half had used methadone at least once. 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 at least one BBV one or more times and most of these had been tested for all three. Much of the testing had been undertaken in batteries of all three tests. The average (median) number of tests received was as follows:

Hepatitis C	5.6 (4)
Hepatitis B	5.8 (3)
HIV/AIDS	6.4 (4)

Approximately 7% had received more than 10 tests for each virus.

Twenty four percent of respondents reported that they had been vaccinated against hepatitis B: almost 60% believed that they had not been vaccinated, 9% reported that

they were hepatitis B antibody positive, and 8% did not know whether or not they had been vaccinated.

Thirty nine TSPs were interviewed throughout Australia: half from rural and half from metropolitan areas. One third were community GPs and one third were recruited from sexual health clinics. The remainder worked in drug treatment centres, hospitals, prison medical services, gay and lesbian medical services, community health services, youth health services and/or other agencies including contact tracers. On average, agencies saw 706 clients per month. Test service providers reported that they ordered an average of 40 hepatitis C antibody tests, 51 hepatitis B antibody tests and 52 HIV/AIDS tests a month. They also carried out an average of 19 hepatitis B vaccinations a month.

While almost all the injectors were aware of the risks posed by BBVs, there were three major reasons for being tested:

- the respondent had been exposed to risk in some way
- the test was recommended or required
- the respondent was concerned about the possibility of infecting others.

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

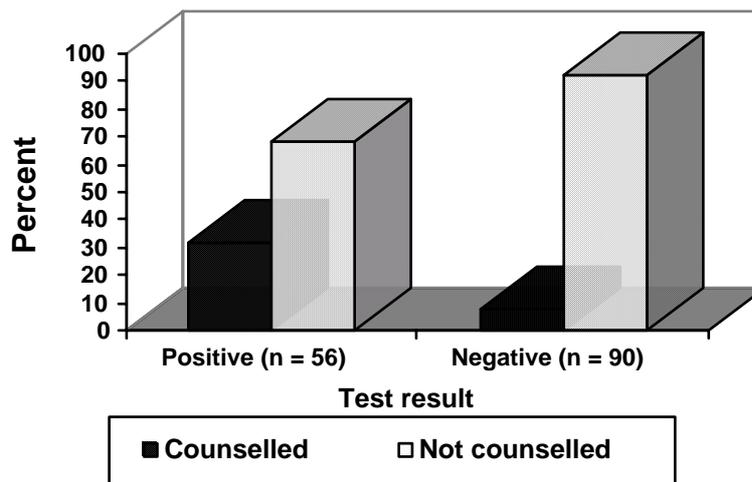
Respondents' reasons for not being tested included the belief that they were not at risk, failure to 'get around to it', and/or being scared or nervous about test outcomes. Some respondents had never heard of a hepatitis B test.

Test service providers reported that their injector 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 injectors 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 TSP informants said they would re-test a client every time a test was requested.

## Testing and Vaccination: Experiences of Injector Respondents

One hundred and fifty testing events were described by injector respondents. Most of these were descriptions of batteries of all three tests and only 17% described a first test experience. Most tests had been instigated by the injector and 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, such that GPs and hospitals were reported as being less likely to have provided counselling than medical, sexual health and drug treatment clinics.

Respondents reported that they had received their test result in a personal interview with their TSP 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. They reported that no post-test counselling was given on 81% of described test occasions, and that whether post-test counselling occurred related to the test result. Clients who received post-test counselling were more likely to be seropositive for at least one test than clients who were not counselled. It should, however, be noted that post-test counselling was reported to have been received on only approximately 30% of test events resulting in at least one positive result, as shown in Figure 1:



**Figure 1: Test outcome by post-test counselling: most recent testing occasion (n = 146) (Loxley *et al.*, 1999)**

Injectors tended to subscribe to the view that the major role of post-test counselling was to follow up positive results, and many of those who described post-test counselling reported it in terms of medical advice given if they were hepatitis C positive. Only four respondents described post-test counselling which contained preventative advice. Respondents reported only nine test occasions which resulted in referral to other medical or community agencies, 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.

Injector respondents reported that on almost 40% of occasions they experienced some anxiety particularly while waiting for results. While most 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.

Those 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 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.

### **Testing and Vaccination: Views of Test Service Providers**

All TSP 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. The majority also reported that they always gave all BBV results face to face but a few said that they were less stringent with hepatitis C and B than with HIV/AIDS results, and were prepared to give these results over the phone. Test service providers' main explanation for injectors' failure to collect results was that the population was transient and mobile.

Almost all TSP informants said they used post-test counselling after negative results to discuss prevention. Most said they used post-test counselling for positive results to suggest follow-up and monitoring, including further testing and referral to specialists, and to discuss transmission and prevention issues. One in three mentioned referring patients to alcohol and drug services, sexual health clinics, and support services.

They described observing a wide range of emotional states, but predominantly anxiety, in their BBV tested clients. Most said they dealt with these reactions with counselling but one in three said they provided more information and some referred these clients.

All TSP informants believed that injectors needed to be advised to be vaccinated. Half said that vaccination came about mainly as a result of their recommendation. Some thought that hepatitis B vaccination needed to be promoted more.

### **Implications of the Data**

The study showed that the process of testing, as reported by the injectors, was, in many cases, far from satisfactory. Test service providers ordered many tests each

month, and tested injectors had typically had more than one test, but in many cases injectors were not motivated to make behaviour changes as an outcome of testing, with some being more concerned to use testing as a way of proving themselves uninfected. Moreover, many TSPs were willing to test whenever they were requested to do so without questioning whether there was any behavioural outcome. All of this suggests that the only purpose served by much of the testing was the diagnosis of infection and the implementation of appropriate medical interventions. This falls well short of what is intended for hepatitis C testing according to the NHMRC Guidelines for TSPs when testing for hepatitis C (NHMRC, 1997). These provide standards for pre- and post-test counselling which 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. The data suggested 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 rarely used except as a medical intervention after positive results. While a range of emotional experiences related to being tested was described by both clients and TSPs, very few clients said they were referred to local support agencies such as the Hepatitis C Council. In general, the testing process, as described by injector respondents, did not actively encourage seronegative injectors to initiate behavioural change, nor seropositive injectors to regard their normal injecting behaviour as behaviour which might transmit infection to others.

Reported low levels of vaccination were also a concern. Most of the respondents in this study had been tested for hepatitis B because they were injectors, but few had been vaccinated, even though many of them had received negative results.

## THE PRESENT STUDY

BBV testing is a common way in which injectors make contact with health and medical services. It therefore presents an ideal opportunity for health promotion and harm minimisation interventions. This is in keeping with the tradition of testing for HIV/AIDS which, from the earliest stages of the epidemic, was seen as an opportunity to prevent as well as diagnose disease: pre-test counselling was designed to inform about the test and obtain informed consent, and post-test counselling was understood

as a ‘key element in the medical and psychological management of infection ...[and]... for people who returned negative tests, to reinforce their continuation in a negative condition” (DCSH, 1989, p. 5).

The NHMRC Hepatitis C Testing Guidelines recognise the potential of testing as a brief intervention. However, the first study demonstrated that more information was needed from doctors, injectors and other key informants about limitations and difficulties with Guidelines such as these. The present study is an examination of clinical and practical difficulties with the NHMRC Guidelines. The report concludes with proposals for modified guidelines for pre- and post-test discussions when testing injectors for blood borne viruses, and specific recommendations to maximise the efficacy of the testing process as an intervention which can prevent and limit the spread of blood borne viruses among injecting drug users in Australia.

## **METHOD**

### **AIMS AND OBJECTIVES**

This project aimed to deepen knowledge about the process of testing injectors for hepatitis C and other blood borne viral infections and to develop concrete recommendations for changes to the testing process.

Specific objectives were:

To use the data gathered in the first testing study (Loxley, Davidson, Heale & Sullivan, 1999) as a basis for a more in depth investigation of the NHMRC Hepatitis C Testing Guidelines.

To investigate clinical and practical difficulties experienced by tested injectors, and TSPs with these Guidelines

To recommend ways to improve the structure, content and implementation of BBV testing guidelines in order to increase the efficacy of BBV testing for Australian injectors.

To make recommendations available to relevant bodies through appropriate publications and presentations.

### **CONSULTANTS**

The project was informed at every stage by consultants drawn from a range of relevant organisations (Appendix I). Some of these consultants met with the Project Officer as a Steering Group five times in the 6 month period of project design and implementation and again in finalising the conclusions of the study, while others were consulted independently. Consultants were asked to assist the research by:

Identifying the specific issues to be covered in the study

Providing initial advice in relation to methodological issues

Having input into establishing methodology and recruitment strategies

Assisting with the development of questions and themes for focus groups and/or interviews

Providing feedback on the analysis of relevant data

Providing input into recommendations

Commenting on the report

Donations were made to the Western Australian Substance Users Association (WASUA) and the Hepatitis C Council of WA (HCCWA) in recognition of their significant contribution as consultants to the study.

## RECRUITMENT

It was intended to recruit approximately 20 injectors, and 20 health professionals including test service providers (TSPs) and key informants (KIs) to the study. The following were start points for recruitment:

Nominations from consultants and snowballing.

The HCCWA and the WASUA promoted interviews and focus groups to their members.

Youth organisations (Trinity Youth Options, the Perth Inner City Youth Service and the Hills Youth Centre) promoted interviews to their client group.

Newsletter of the HCCWA

Information to delegates at the 1999 Annual Conference of the Australasian Society for HIV Medicine

The HCCWA Shared Care project

Inclusion criteria for respondents were as follows:

### Injectors

Tested for hepatitis C in the past 2 years

Never tested positive for HIV (people who have tested positive for HIV were not interviewed as part of the study as the post test counselling they may have received at this time may have contraindicated counselling for other blood borne viruses.)

Aged 18 and above.

### Health Professionals

GPs with an interest in BBV (TSPs)

GPs who do not currently practice much in the area of BBVs (TSPs)

Representatives from organisations who provide BBV testing (TSPs)

Representatives of agencies who have a professional interest in BBV testing (KIs)

## DATA COLLECTION

### Overview

The data collection methodology was primarily qualitative, using a number of different techniques (interviews, focus groups, and consultations) to develop a total data set upon which conclusions and recommendations were based. The approach was loosely based on some elements of Grounded Theory (Strauss & Corbin, 1990) in that it did not aim to prove or disprove a pre-existing theory, but to allow relevant theories to emerge from the studied phenomenon. It was also collaborative, with researchers, practitioners and representatives of the population of interest working together in the belief that valuable knowledge about ways to overcome the barriers to effective pre- and post-test counselling would be held by all those who participated in the research. The analysis was flexible and reflective, with each stage of the research process incorporating opportunities for analysis and consideration of where data collection should proceed in subsequent stages.

### Interview Guides

The major issues to be considered by the research were drawn from questions posed at the conclusion of the first study (Loxley et al., 1999).

How appropriate are the current Guidelines for either hepatitis C or HIV/AIDS testing, when most injectors undertake these tests in batteries?

How relevant are the Guidelines to injectors 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 TSPs to implement the Guidelines given the cost recovery structures of most practices?

What are the barriers to the vaccination of injectors against hepatitis B? How can these best be overcome?

The specific issues raised in the Interview Guides were as follows<sup>2</sup>:

### ***Injectors***

Demographics

Drug use

Serostatus

Testing experience

Reaction to NHMRC Hepatitis C Testing Guidelines

Comments on pre- and post-test counselling

Comments on hepatitis B vaccination

### ***Health Professionals***

Demographics

BBV testing scenarios (for TSPs only)

BBV testing amongst relevant client group (for KIs only)

Reaction to the NHMRC Hepatitis C Testing Guidelines

Implementing the NHMRC Hepatitis C Testing Guidelines

Comments on hepatitis B vaccination

### ***Focus Group Guide***

Introduction to the study

Introduction to the NHMRC Hepatitis C Testing Guidelines

Implementing pre- and post-test counselling

Alternative models for pre- and post-test counselling

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<sup>2</sup> Copies of the Guides can be seen in Appendix II

## **Stages of Preparation, Data Collection and Analysis**

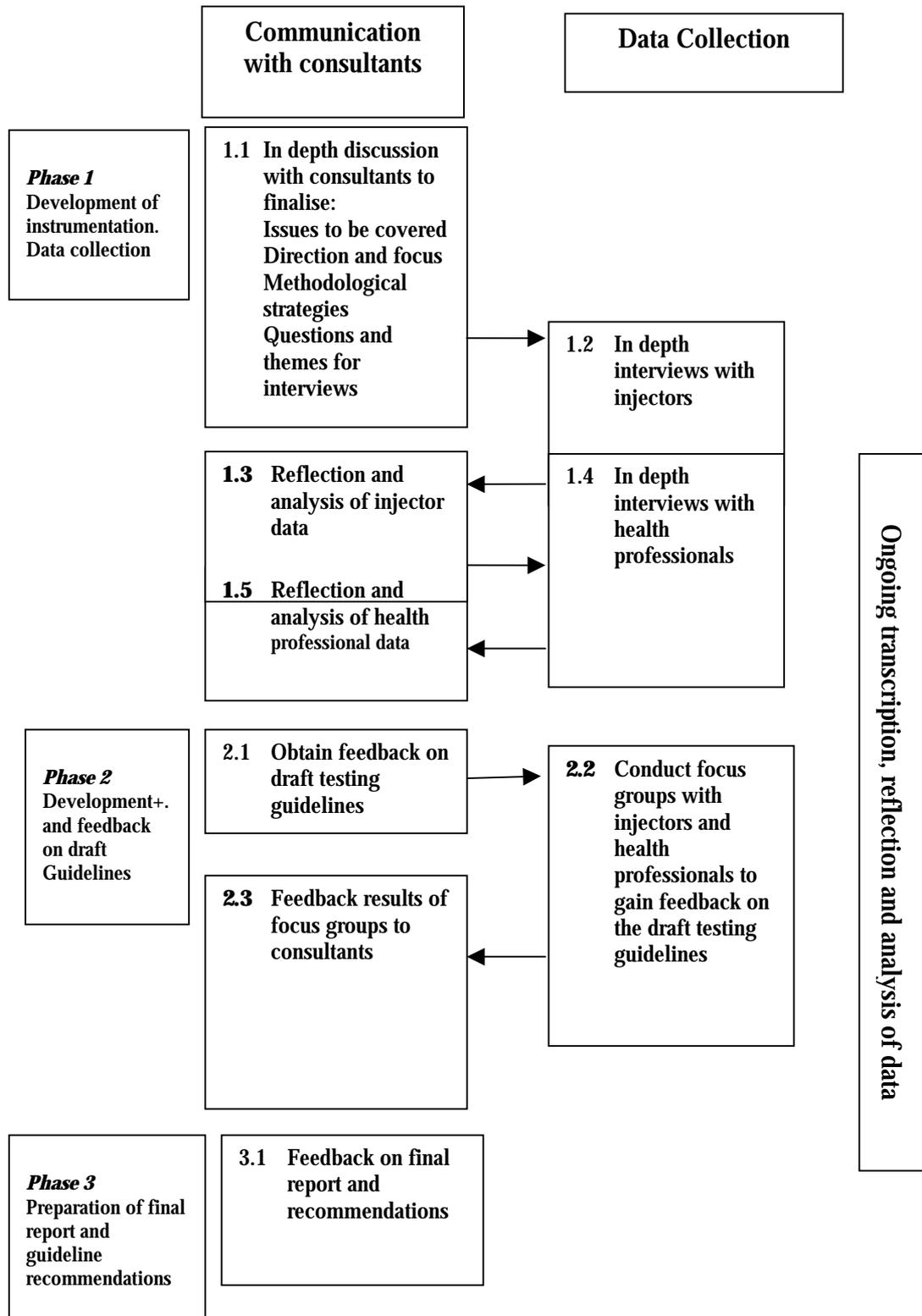
The phases of the study are depicted in Figure 1. It will be seen that the process was iterative, with consultation and communication with consultants occurring at every stage.

### **Data Collection Procedures**

Interviews with injectors and health professionals were tape recorded and transcribed. The majority of interviews with injectors took place at cafes in inner city Perth, with some interviews being conducted at youth organisations. Interviews with injectors were conducted between June and August 2000. Injector respondents were paid \$30 for participation in interviews.

The majority of health professionals were interviewed at their workplace. Interviews with health professionals were conducted between July and September 2000. Health professionals were not paid for participating in the study.

The focus group for health professionals took place at the Annual Conference of the Australian Professional Society on Alcohol and Other Drugs (APSAD) in November 2000. The focus group for injectors and user representatives was held at NDRI in April 2001. Injectors were paid \$30 to take part. The focus groups lasted approximately one and a half hours each. It was not necessary to tape record the focus groups.



**Figure 2: Stages of data collection, communication and analysis**

### **Ethical Issues: Privacy and Confidentiality**

This study was approved by the Curtin University Human Research Ethics Committee. No identifying information about respondents was collected and results are presented anonymously. All research questionnaires, audio tapes and any other recordings of focus groups or interviews were kept in a locked cabinet. Clerical staff responsible for transcribing interview tapes signed a confidentiality agreement at the commencement of their contract.

Respondents were informed of the privacy and confidentiality issues at the commencement of interviews and/or focus groups by way of a Respondent Information Sheet. Participants in the focus groups were reminded by the convenor of the group of the confidential nature of the study and asked not to breach the confidentiality of other focus group participants.

## RESULTS

### PHASE 1 DEVELOPMENT OF INSTRUMENTATION AND DATA COLLECTION

The Interview guides (Appendix II) were developed in consultation with the consultants. There were two major rounds of data collection in this phase with injectors and health professionals.

#### In-depth Interviews with Injectors

##### *Demographics*

There were 19 respondents, almost equally divided between males and females. Half were aged 31 or over, and three were under 20. Almost all lived in the Perth metropolitan area. There were three homo- or bi-sexual respondents. No respondent identified as an Indigenous Australian. Most of the sample described themselves as Australian, with two coming from the UK and four from other countries.

##### *Drug use and drug treatment: access to services*

Fourteen respondents were primary heroin injectors; three were primary amphetamine injectors and two were polydrug injectors (heroin, amphetamines, temazepam). Half had first injected between the ages of 16 and 20, and almost half had been injecting for 11+ years. Half of the sample were in treatment at the time of interview. Between them, respondents had experienced 48 different treatment modalities at some time (they could also have experienced more than one episode of each modality).

The majority of respondents had seen a GP at least six times (range 12 – 50) in the previous 12 months. Almost half (47%) had a single regular GP, 16% saw 2 – 3 GPs on a regular basis, and the remainder did not have a regular GP. Some respondents reported that they had a good relationship with their GP, describing them as role models or friends but some appeared to have a more mechanistic view of appointments with their GP, stating that the purpose of visits was to “fix” particular problems. Some suggested that their GP did not care, or did not have time for them.

Respondents were asked about the frequency of their visits to WASUA, the Western Australian Substance Users Association. Based in inner city Perth, WASUA provides needle and syringe exchange, medical services, BBV testing and HBV vaccination, information, support and treatment referral for injectors. Half had visited WASUA at least once a week; six visited once a month or less and three had never been to WASUA. Almost all had accessed the needle exchange; eight had been in contact with the nurse in relation to BBV testing and/or HBV vaccination; five had sought information and two had been referred to treatment.

### ***Blood Borne Virus status and testing***

All respondents had been tested at least once within the last two years, as this was one of the inclusion criteria for the study. The average number of times respondents had been tested was 16.1 (range 1 – 100+). When the 100+ response was removed the average was 9.6 times. Of those tested regularly, the most commonly nominated interval for testing/retesting was 6 months (range from 2 – 3 weekly to annually).

Six respondents (31.5%) reported that they were hepatitis C positive; 12 reported that they were negative, and one was unsure. No respondent reported hepatitis B infection: 10 reported that they were hepatitis B negative, and five that they had had previous exposure to the virus, but had now cleared it. Four reported that they did not know or were unsure of their HBV status. Seven reported that they had been vaccinated; seven that they had not; three had not completed a vaccination course, and two did not know or were unsure of whether they had been vaccinated.

### ***Comments about Blood Borne Virus testing***

This section introduced the qualitative section of the interview. Respondents were guided through a series of discussion points with open-ended questions.

The majority of respondents did not understand the terms pre-test counselling<sup>3</sup>/post-test counselling, or know what might be involved. Some confused them with therapeutic counselling. A few, however, had a good understanding:

I understand pre-test counselling to be whoever is testing you, to go through what the outcomes may be. I would expect someone to ask me what would my reaction be to the outcomes, being negative or positive. I guess reassurance for pre-testing and I would expect the same thing from post-testing as well, like support.

Most respondents were tested more than once a year. A number of incidents and events occasioned testing: wanting to be tested regularly; going into treatment or other medical intervention; engaging in risky behaviour and/or being anxious about their infection status. Most did not believe that regular testing offered protection against unsafe behaviour, but saw it more in terms of 'peace of mind' and 'protection for others'. A minority believed that testing offered an opportunity to learn about transmission avoidance, or motivated those with negative tests to be more careful in the future:

If you know you're clean you want to keep it that way, whereas if you don't, you're sort of like, well you know, you don't really sort of care. ... Now I know that [I'm negative] I'm never ever going to do the same thing again after that test. 'Cause I'm clean and I want to keep it that way.

Respondents were asked whether they felt they needed pre- and post-test counselling at each test. This question was asked prior to an explanation of how such counselling is described in the Guidelines, and was asked again after that. The majority of respondents did not believe they needed full pre- and post-test counselling on each occasion. Many believed that the extent of counselling needed would depend on the individual and the circumstances at the time:

Not every time, it depends on how I'm feeling. Sometimes I have been clean for a couple of months and feel really good within myself, but sometimes I feel like everything is really full on and chaotic. Sometimes I say to my

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<sup>3</sup> It is appreciated that the terms "pre-test counselling" and "post-test counselling" may not be the most appropriate terms for these interactions. This issue is raised more fully in the Discussion. The terms are

doctor, look if I am diagnosed with HIV I am going to kill myself. ... So therefore sometimes I do think I need to, to prepare myself.

In terms of perceptions of the TSPs' role in the decision to test and the provision of risk reduction support, most believed that the decision to be tested should rest with the patient rather than the doctor, but there was a degree of support for compulsory testing under some circumstances or for some people. Most believed that TSPs could help or support in risk reduction. However, just over half cited negative experiences with medical staff, particularly with GPs, which were mainly related to the perception that doctors did not like drug users. On the other hand, a large minority liked and trusted their GP. Some had experienced alcohol and drug doctors (eg at treatment agencies) as more sympathetic and understanding than GPs.

### ***The NHMRC Guidelines for Pre- and post-test Counselling***

Figures 3 and 4 show the NHMRC Guidelines for pre-test counselling and post-test counselling for hepatitis C testing.

<p>According to the guidelines, <b>pre-test counselling</b> should:</p>
<ol style="list-style-type: none"> <li>1.1. Assess risk</li> <li>1.2. Provide clinical information about the virus</li> <li>1.3. Enable the patient to decide whether they should be tested</li> <li>1.4. Provide information about the test and the possible consequences of testing, including confidentiality and notifiability</li> <li>1.5. Provide information on testing benefits</li> <li>1.6. Establish the ability to give informed consent</li> <li>1.7. Identify support available to the patient.</li> <li>1.8. Provide a written summary of the information covered in the pre test counselling preferably in the testee's native language</li> <li>1.9. Make arrangements for a post test counselling appointment</li> </ol>

**Figure 3: NHMRC Guidelines for Pre-test counselling**

used here because they were the terms used in the research.

<p style="text-align: center;"><b>Post test counselling should:</b></p> <p>2.1 Always be in person no matter what the reason for the test or whether the result is positive or negative</p> <p>2.2 Ensure that the patient understands the meaning and implications of the test result</p> <p>2.3 Ensure that appropriate referrals and psychosocial interventions occur if required</p> <p style="text-align: center;"><b>If patient is negative:</b></p> <p>3.1 Counselling should provide information to prevent exposure to the virus</p> <p>3.2 The individual should be assisted to adopt relevant skills to remain infection free</p> <p style="text-align: center;"><b>If patient is positive:</b></p> <p>4.1. Immediate counselling should be provided</p> <p>4.2 Support and information to prevent transmission to others should be provided</p> <p>4.3 The extent of personal support should be assessed</p> <p>4.4 Referral to external sources of support such as longer-term counselling or a local Hepatitis C Council should occur</p>
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**Figure 4: NHMRC Guidelines for Post-test counselling**

In this section respondents were asked whether they were aware that Guidelines existed and then asked to comment on each. Almost no-one had heard about the Guidelines. For each Guideline that follows we asked: Did your GP/TSP do this at your last test? If no, why not? If yes, how did you feel about it? Not all Guidelines were discussed by respondents, and in some cases Guidelines were amalgamated in discussion. Responses are categorised according to the Guideline number(s).

### **1.1 Pre-test: Assess risk**

The majority said this had happened but few details were given. Where they were, the assessment appeared to have mainly related to a discussion of sharing needles with

little detailed assessment of the specific behaviours which put the individual at risk. Where risk was not assessed, the respondent said that the doctor “knew” they were at risk (because they injected). In some cases, risk had previously been discussed/assessed.

### **1.2 Pre-test: Provide clinical information about the virus**

Most respondents did not receive clinical information at their last test and around half thought it would be a good idea. They stressed, however, that the information should be new and not repetitive and that injectors should have the option of saying “I know that – let’s move on”.

### **1.3 Pre-test: Enable the patient to decide whether they should be tested.**

### **1.6 Establish the ability to give informed consent.**

These two Guidelines related to the same issue: who made the decision for the test? Respondents were almost equally divided between those who asked for the test, those who felt they had no choice, and those who felt that there was some interaction with the TSP relating to consent. There were also strongly held views that a) doctors should not refuse to test anyone who asked for it or b) that some injectors should be compulsorily tested:

They shouldn't ask you, do you want to be tested. If someone asked to be tested, they asked to be tested, whether or not they've got a chance of catching it or not. It's their own peace of mind. The doctor shouldn't be able to say, no I'm sorry I don't want to give you a blood test because you're in the no risk category, because that's just plain stupidity. The doctor's not there twenty four hours a day, doesn't see ... I mean especially blood borne, you know, you can sit there and touch someone who's got blood and stuff like that, you don't know. The doctor shouldn't tell you. If you want to have a test, you should go and have a test.

Well I reckon if that you are an IV user, you should just get tested. I think it is good that GPs automatically seem to do it, rather than you deciding yourself, because quite often you're not in a state to decide yourself.

One respondent thought that a formal consent process, whatever the motivation for the test, was a good idea:

Yes, I can see the benefits of having something like that. The contract at the beginning, 'do you have any questions before we proceed to get your blood taken?' I think that would be a good idea actually.

#### **1.4 Pre-test: Provide information about the test and the possible consequences of testing, including confidentiality and notifiability**

About half of the respondents were not told about the notifiability of positive results, and a similar number thought that they should be.

They've got nothing to hide, they should tell everyone. That's like if they don't tell them, it's like they got something to hide. I'm hiding this from you, that you're going to be on this list, you know?

Some concern was expressed, however, about the possibility that those who were notified as hepatitis C positive would have their names placed on the list of registered addicts held by the Heath Department.

But you don't want to scare people away either, because it does in a way. Like I think, 'oh my god, what if I am positive, I would be on the list', but it should all still be free choice and nothing should be hidden, to come as a surprise later.

The majority had been informed about confidentiality at their last test and believed that this was appropriate.

#### **1.5 Pre-Test: Provide information on testing benefits**

Almost no-one was told about the benefits and consequences of testing (eg in terms of insurance, discrimination etc) apart from the clinical aspects. Most did not see this as vital and some thought it might deter some injectors from being tested.

#### **1.7 Pre-test: Identify support available to the patient.**

This question asked whether TSPs established prior to the test that the patient had access to support in the event of a positive result. Respondents were almost equally

divided between those who said this had, and those who said it had not been established. Some felt that their TSP did not need to ask because he/she knew them well enough to know what levels of support they had. Almost all believed that identifying support was important. Some of those whose TSP did not ask about support, felt that this was because TSPs did not care, did not understand or had other priorities for the patient (eg drug treatment).

I feel if I hadn't been a drug user, and it was some other patient, he would've dealt with it completely differently ... would've probably been a bit more compassionate about what the result would've been and my effect on the result.

### **1.8 Pre-test: Provide a written summary of the information covered in the pre-test counselling preferably in the client's native language**

About half were given access to some written material, usually pamphlets, at their last test. These did not appear to have been specific to the doctor or sometimes even the virus for which the test was ordered. No-one was given a written summary of all the information conveyed in the pre-test counselling. Not everyone thought written material was a good idea: some did not like reading, and some thought pamphlets were a waste of time. Some were concerned in case written material was used as an alternative to face to face discussion.

### **3.1 Post-test for a negative result: Counselling should provide information to prevent exposure to the virus.**

### **3.2 The individual should be assisted to adopt relevant skills to remain infection free**

There was strong support for the notion that TSPs could use post-test counselling to help them to remain free of BBVs. Comments indicated that harm reduction was complex and that injectors could always use more help. Testing was seen as a good opportunity to do this because patients were motivated to avoid risk. Some also realised that previously unknown risk behaviour might be exposed and then discussed:

Yes, because a lot of things I didn't even realise. Like seriously, one of the things that I realised only a short while ago ... A little while before that, if

someone has a dirty fit and I have a clean one and we are sharing the same spoon, that I could still get infected. I had no idea. I wish I had found that out a lot earlier you know. I am sure there are a lot of people like me.

However, there was a strong sense that responsibility for ensuring that prevention counselling was useful rested with the TSP. A number commented on GPs apparent lack of time for long consultations, and were concerned that many TSPs would not have enough time for these discussions.

#### **4.1 Post-test for a positive result: Immediate counselling should be provided**

It is unclear whether those respondents whose last test was positive had received immediate support. Almost all thought that a positive diagnosis was sufficiently serious for this to be an important Guideline. One described how devastating a positive result could be:

No-one was aware, my friend, you know girlfriend, thought I was gonna die, I thought I was gonna die, my mum thought I was gonna die, we all sort of yeah, thought this was it.

#### **4.2 Post-test for a positive result: Support and information to prevent transmission to others should be provided**

Some respondents who had received positive results had had discussions with their TSP about blood awareness, tattooing etc. Most thought that it was important although perhaps not at the first post-test appointment:

I think with the first one [appointment] I would try and just make sure that the patient was okay, emotionally and mentally, like okay to be actually leaving that building and so they are not going to go out and maybe fuck someone because they have got HIV and they are really angry or Hepatitis C and they are really angry, because that happens. It should be the doctor's main concern that the person is leaving in a really safe environment and then the follow-up about transmission.

Some thought this could be better done through referral to organisations like the Hepatitis C Council or User Group because of the need for support from like others:

Sitting down with all of those other people, you hear from them and you don't feel alone.

#### **4.3 Post-test for a positive result: The extent of personal support should be assessed**

Three quarters of those who had received positive results said that there was no discussion with their TSP about immediate support. All respondents thought that it was important:

Yes, I think that should be asked. You know, leaving the office and going home to somebody or having somebody close by, and that kind of thing, you should have somebody there for you. I think it is a doctor or whoever is giving the post-test counselling afterwards that should check with that person if they have got support.

#### **4.4 Post-test for a positive result: Referral to external sources of support such as longer-term counselling or a local Hepatitis C Council should occur**

A majority of respondents thought that referral to support agencies was a good idea, although many stressed that these should be optional. A few had had such referrals and found them useful:

I didn't, you know, do anything straight away because I was so shocked. But, yeah, it was helpful. I rang a few of the numbers and stuff and it was alright.

#### ***Implementing the NHMRC Guidelines for Pre- and post-test Counselling***

Respondents were almost equally divided between those who thought that the Guidelines for pre- and post-test counselling should be administered in full on every occasion with every injector, and those who believed that injectors who were tested regularly did not need all the Guidelines on every test occasion. Most respondents thought that they, personally, would not need full counselling on each occasion, but that it depended on the individual, their relationship with their doctor, the frequency of testing and the rate of change of information. Most thought that they would be most in need of pre- and post-test counselling at their first test, if they were positive or likely to be positive and/or if they were worried or anxious. There was a strong feeling that at the very least, pre- and post-test counselling at the first test should cover all the material in the Guidelines, but that at subsequent tests, injectors could be given

options about what should be covered. All information should be up to date and some aspects (like confidentiality) should perhaps be stressed on each test occasion.

As long as they keep updating and letting us know the information that they have available or they've uncovered, great. But if it's going to be the same old, same old ... and just a waste of time, effort and resources, let's not do it and spend that money in finding a cure.

I would want them to ask me why I want the test done and what makes me feel that I am at risk. I would like questions like that, and I would also like him to tell me how to prevent them. Like people come and leave their syringes there and what I should do, and stuff like that. I think the GP should at least teach things like that.

While there was strong support for the Guidelines to be flexible for those who were tested regularly, some things were seen to be important on every occasion: obtaining informed consent, reminders about confidentiality and notifiability and discussion about prevention of transmission to others if positive, or remaining uninfected if negative.

Some thought that all Guidelines should be used on all occasions with all injectors:

If I go and get tested every six months I know that I'm going to have to listen to all this stuff, but that's just something that I have to wear because it's for the benefit of someone else who's going to another GP that just sort of goes: 'you know about hep C don't ya? Yeah. Ok well let's just get on with it. You know?

Other comments related to the implementation of the Guidelines. Some respondents felt that more effort should be made to ensure that the Guidelines were implemented, and one suggested that a Handbook should be prepared for injectors, so they would know what a test could, or should, entail.

Respondents were almost equally divided between saying that the TSP or a User Group/Hepatitis C Council, should do pre- and post-test counselling. Concern was expressed about GPs having enough time to do a thorough job:

That would depend on the time limit I suppose of the GP, whether they are running two hours behind and really want to move on and whether they make any recommendations I suppose.

Many stressed that the relationship between the injector and their TSP was the critical factor, although some were clear that they would prefer counselling from someone in a User Group or other user-friendly organisation who would understand drug use. Most felt that the TSP should be the person to give results, and couched this in terms of an on-going relationship, although some believed that referral to a support agency was also important. But at least one person felt that it could be difficult to be honest with a GP:

In my head anyway, that is like, 'what is this person thinking about me, I've shared a needle' ... what happens before I even get there, is, 'I can't tell him this, I can't tell him that'. So even the honesty part is really hard, and being honest with your doctor has been a hard part of that. Because that fear of being judged about what you are doing, and your lifestyle and expectations – sometimes it is much easier just to have the blood taken and no questions asked.

Almost half of the respondents admitted to some anxiety while waiting for test results, but most felt that this was normal, and little could be done to alleviate it, perhaps other than reduce the waiting time between test and results as much as possible.

There were strong comments, however, about phlebotomy. Many injectors expressed considerable sensitivity about blood taking, some because they felt they could do a better job than a phlebotomist, and others because they were embarrassed by their track marks. Two respondents talked about these concerns in relation to their addiction to needles:

I'm trying to get off drugs, and needles make me nervous: It was a lot easier to go for tests, because I was using as well, but like now trying to stay away from it, but knowing that I am going to get a needle, the rush and all that kind of stuff for me, my arms go stupid when I see a needle. And the whole thing of going in there and having it, which now even thinking about it, the needle part of it is hard.

There were few suggestions for ways to alleviate these problems, other than a plea for understanding and sensitivity on the part of the TSP and a preference for not being sent to commercial pathology centres for blood taking.

Eleven of these 19 respondents said that their injecting practices had become safer as an outcome of testing. For some, this was a direct result of the information and counselling they received at the test; others because testing sensitised them to the disease, or they received a positive result:

I tend to be more careful, more aware. Having BBV tests reminds me that catching it is a possibility, so I'm more careful.

While they expressed interest in a range of sources of information including videos, pamphlets, books and Internet, some felt that there was no substitution for personal interaction with a knowledgeable professional.

Almost all respondents thought that those with a positive diagnosis would need at least two appointments with their TSP: one for reassurance and support, and the second to deal with medical and other issues. A few felt that they would be so shocked they would need some 'monitoring' in the first few days after diagnosis.

Yes, you have to go away and come to grips with the fact that you have it, then you should come back and find out what this really means now. You can't come to terms with that straight away.

There were few other suggestions for improvement to the Guidelines. There were, however, a range of comments about implementation: many felt that there was little point in having well developed Guidelines if these were not followed by TSPs.

### ***Hepatitis B vaccination***

Almost all respondents thought that vaccination was a good idea, although only seven had been vaccinated and three had incomplete vaccinations. One went so far as to say that all those who had had a negative hepatitis B test should be compulsorily vaccinated. However, one vaccinated respondent understood that this might not be a priority for some injectors:

You're so preoccupied with getting the next hit, that what's the point of going to the doctor? It is only going to waste time and money. I may as well just go out and get on, then I can relax and watch some telly. It is a completely different lifestyle when you are using every day. It is very hard core.

The various reasons for not being vaccinated related to “not getting round to it”; not knowing much about it; not being sure it was available for free; and having some concerns about vaccination as a medical procedure.

When respondents were asked what they considered to be the ideal service for vaccination for injectors, a number of different models were proposed. Most responses specified, however, that the service should be free. Other suggestions were that the service should be well advertised, the regime should be accelerated, and patients should be reminded to return. Generally, the service attached to the local Needle and Syringe Program (WASUA) was considered to be the most attractive by most respondents.

### **In-depth Interviews with Health Professionals**

The injector data were used by the investigators and consultants in the development of the interview guide for health professionals (Appendix II).

Twenty one interviews were conducted with TSPs and key informants. Twelve TSPs were interviewed. For the purposes of this study, TSPs were defined as people who conducted and/or ordered blood borne virus tests for injectors. Test service providers were recruited from a range of areas, including treatment agencies (50%), needle and syringe exchange programs (17%) and general practitioners (33%). Nine key informants (KIs) were interviewed. For the purposes of this study, KIs were defined as people who had a professional opinion about the efficacy of pre- and post-test counselling for BBV testing. Key informants were recruited from a range of areas, including peak bodies representing the interests of injectors, (56%) hospital based liver clinics (22%), one sexual health clinic (11%) and one drug and alcohol information service. (11%).

Respondents from this phase of the study are referred to collectively as “health professionals”. Some questions were asked only of TSPs or KIs, and their responses are attributed accordingly.

### ***Experience and involvement in BBV testing***

Six health professionals had been working in area of BBVs for less than 2 years, four for 3 – 5 years, four for 6 – 10 years and seven for more than 11 years. Test service providers with special work related interests nominated illicit drug use or issues related to illicit drug use such as BBVs and methadone. Sexually transmitted diseases, psychological medicine and working with young people or children were also nominated. Most had first conducted or ordered a BBV test within the last 10 years. The number of BBV tests which TSPs estimated they had ordered/conducted in the past year ranged from 5 – 1 000 (average 253). The majority of TSPs conducted their own pre- and post-test counselling and some of these also conducted phlebotomy for tests. Other BBV involvement included providing education about BBVs in a context other than pre- and post-test counselling.

Health professionals were asked what sort of BBV training, if any, they had received in their work. The majority had learned on the job, with half of these receiving specific training related to BBVs. Of those who learned on the job, most people learned by talking to colleagues, accessing resources and/or attending conferences. One had received specific training and another non-specific training relating to BBVs outside of their workplace.

### ***Scenarios***

Test service providers were presented with two scenarios relating to hypothetical requests for BBV tests and asked what they would do in each situation. Scenarios were adapted slightly to suit the type of agency represented by each TSP. Responses to the scenarios have been categorised in terms of the NHMRC Guidelines (Figs 3 and 4).

KIs were not asked to respond to the scenarios but were given a copy of the NHMRC Guidelines and asked to provide feedback on them.

The responses from TSPs and KIs are summarised below. In interpreting these data, it is important to note that TSPs did not have a copy of the NHMRC Guidelines to refer to whilst responding to the scenarios. Test service providers were prompted by the interviewer about confidentiality and notifiability, as this was identified as a key issue

by injectors in the first phase of the study, but were not prompted about any other part of the Guidelines.

**Scenario A****Rebecca****17 year old female****New patient****Says she has been injecting speed for about 6 months****Very anxious about her speed use****Her boyfriend is 24 and has been injecting drugs for about 5 years****Has never been tested for BBVs****Presents with lethargy****Scenario B****Steve****35 year old male****A regular patient of yours for the past 2 years.****He has been injecting heroin on a regular basis since he was 19.****Steve has a BBV test approximately once every 6 months.****For the past 2 years, you have been the sole provider of Steve's BBV tests.****To date, all of Steve's BBV test results have been negative****Presents saying that he's due for his 6 monthly BBV test**

**Figure 5: Scenarios for TSPs**



***Test Service Providers' and Key Informants' responses in relation to NHMRC Guidelines (see Figs 3 and 4, pp. 24-25).***

**NHMRC Guideline 1.1: Pre-test counselling should assess risk**

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>Many TSPs indicated that they would assess Rebecca's risk for BBVs before commencing testing. The majority indicated that they would ask about sharing injecting equipment. Most of these TSPs did not specify what type of equipment they would ask her about but several indicated that they would specify whether she shared fits, filters, spoons or water.</p> <p>A similar number of TSPs indicated that they would ask whether she practiced safe sex. However, a significant percentage indicated that they would not conduct any risk assessment at all or that they would assume that Rebecca was at risk of BBVs because of her injecting drug use.</p> <p>Several TSPs indicated that they would ask Rebecca to describe her injecting technique and would also ask her about other forms of blood exposure such as household exposure. A small number of TSPs indicated that they would attempt to establish rapport with Rebecca at this stage</p>	<p>Most indicated that they would assess risk by asking whether Steve shared injecting equipment. Approximately half of these specified that they would ask whether he shared needles and half did not specify what type of equipment they would ask him about. Several TSPs indicated that they would question Steve about his continuing drug use and his continued exposure to risk.</p> <p style="padding-left: 40px;">“Of course...it's very rare for people to sort of cross their heart and say they're at absolutely no risk. So ... coming regularly for testing every six months isn't actually responsible. It is in one way, but it isn't really in the long term. The long term thing is not to have put yourself at risk in the first place.”</p> <p>A common theme amongst TSPs was that they would be less thorough with an assessment of risk for Steve.</p> <p>Several TSPs indicated that they would “touch base” with Steve and ask whether anything had changed since his last test.</p> <p style="padding-left: 40px;">“Well I'd probably be a bit slack about the interview, if I was being really honest.”</p> <p>One TSP indicated that they would provide new and up-to-date information about hepatitis C at this time. Only one TSP indicated that that would be more thorough with a scenario such as Steve's than they would be with a naive user such as Rebecca.</p> <p style="padding-left: 40px;">“I'd be a bit more ... firm with him and say... 'you keep using and why are you having a BBV test, are you doing some unsafe practices.' I'd be a lot more thorough I suppose.”</p> <p>Other topics that TSPs indicated they would mention as part of an assessment of risk for Steve included his sexuality, lifestyle, whether he practiced safe sex, whether he had experienced any symptoms of hepatitis C and his drug use.</p>	<p>Key informants indicated that assessing risk was of primary importance, particularly in terms of providing relevant harm reduction information post-test. In order for risk assessment to be successful, some key informants indicated that this needed to be carried out in an observably non judgmental way with attention to language detail and without using simple slogans such as "sharing a fit," which could be misleading or stigmatising</p>

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**NHMRC Guideline 1.2: Pre-test counselling should provide clinical information about the virus**


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Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>All TSPs indicated that they would provide some sort of clinical information about BBVs to Rebecca. This information ranged from details of how the viruses are transmitted and how to reduce the risk of contracting them to information about treatment and the nature and symptoms of the diseases.</p> <p>Some TSPs indicated that they would phrase the clinical information based on what the injector already knew about BBVs and aim to dispel myths about them. One TSP indicated that the clinical information they provided was based on the risk assessment which they had conducted with the injector.</p> <p>A minority of TSPs indicated that they would only provide limited clinical information and that they would provide more detail if the result were positive.</p>	<p>The majority of TSPs indicated that they would not provide much clinical information about the borne viruses because Steve would have already heard this at previous tests.</p> <p style="padding-left: 40px;">“I wouldn't tell him anything about the viruses because I would have already said that 3 million times.”</p> <p>Other responses included finding out what Steve already knew about BBVs and dispelling myths or giving up to date or new information.</p>	<p>In terms of providing clinical information, key informants felt that this was an important part of pre-test counselling, particularly in terms of information about transmission.</p>
<p style="padding-left: 40px;">“I say that it's a risk and that it's a liver disease and that it can have quite serious complications. But I wouldn't go into great detail. Not until I got some positive result.”</p>		

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### NHMRC Guideline 1.3 Pre-test counselling should provide information about the test and the possible consequences of testing, including confidentiality and notifiability

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>A significant number of TSPs indicated that they did not provide information, or did not always provide information, about notifiability. Several of these indicated that they did not tell injectors about notifiability prior to the test because they had no choice about notifying the results to the Health Department and the information was statistical and confidential. Other TSPs indicated that they would talk about notifiability with the injector once their result was positive or if they believed that there a high risk of a positive result.</p> <p>“Notifiability? I’m really slack with that...’cause we do it with a closed system. We don’t get names and addresses.”</p> <p>Very few TSPs indicated that they always informed injectors about the confidentiality of the testing process. Some believed that injectors assumed confidentiality and it was therefore not necessary to state this. Only one asked clients to sign a consent form which included information about confidentiality, notifiability and the implications of a positive or negative test result.</p> <p>In terms of the information provided about the test itself, some TSPs indicated that they always told injectors about the type of test and the window periods for returning a positive result for BBVs. Other information which was given at this point included information about false positives, how long it takes for results come back, that results would be given face-to-face and who they needed to inform (if anyone) if they returned a positive result.</p>	<p>As per Scenario A in terms of the types of information that would be covered.</p> <p>However a number of TSPs indicated that they would not spend much time talking about these issues at this test because they would have been covered during previous tests.</p> <p>“The usual things... I’d be a little less careful, because I’d assume we’ve discussed it with him before.”</p>	<p>Key informants indicated very clearly that information about confidentiality and notifiability should always be stated before each blood borne virus test. This was seen as critical in establishing informed consent.</p>

### NHMRC Guideline 1.4 Pre-test counselling should provide information on testing benefits

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>No TSPs indicated that they would discuss this issue with Rebecca.</p>	<p>No TSPs indicated that they would discuss this issue with Steve.</p>	<p>KIs’ opinion was divided about the merits of this guideline and the earlier guideline about enabling the patient to decide whether to be tested. Some felt that these guidelines duplicated each other’s meaning or that their meaning was not clear.</p>

### NHMRC Guideline 1.5 Pre-test counselling should establish the ability to give informed consent

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>TSPs were asked whether Rebecca's age (17 years) would be an issue in deciding whether to conduct her BBV tests. Most indicated that her age would not be an issue but that they would make more of an effort to check that she understood the concept of informed consent and that she was stable enough to receive the results. Some TSPs indicated that they would check how independent she was from her parents and would encourage her to tell her parents what was happening.</p> <p>In terms of the form of consent required, some TSPs asked for specific verbal consent and one asked injectors to sign a consent form. In one case, injectors signed a form for release of information about the test from the testing doctor to the treatment agency but not for the test itself.</p> <p>One TSP indicated that consent was implied when the injector accepted the written referral form for the test. One TSP indicated that injectors were sometimes intoxicated when being tested and/or giving consent for testing.</p>	<p>The majority of TSPs indicated that this type of issue would have been covered at previous tests, though this was not always specified. Several indicated that they would ask for verbal consent and one indicated that they would ask him to sign a written consent form.</p>	<p>Key informants clearly indicated that health professionals have a responsibility to provide patients with sufficient information to decide whether to be tested, that is, to facilitate informed consent</p>

### NHMRC Guideline 1.6 Pre-test counselling should enable the patient to decide whether they should be tested

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>No TSPs indicated that they would discuss this issue with Rebecca.</p>	<p>No TSPs indicated that they would discuss this issue with Steve.</p>	<p>KIs' opinion was divided about the merits of this guideline and the guideline about providing information about testing benefits. Some felt that these guidelines duplicated each other's meaning or that their meaning was not clear. Other key informants felt that this guideline represented a forgone conclusion.</p>

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**NHMRC Guideline 1.7      Pre-test counselling should identify support available to the patient**


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**Scenario A and B: TSPs****Key Informants**

The majority of TSPs did not mention identifying support as one of the activities that they would undertake during pre-test counselling.

Of the few TSPs who indicated that they would identify support, some indicated that they would only do this if the injector were at high risk of a positive result.

Other TSPs indicated that they would identify support in a general way and in the case of Rebecca would assess her relationship with her boyfriend or encourage her to tell her parents what was happening.

While key informants recognized that identifying sources of support was an important part of the testing process, they also recognized that this could sometimes be a complex issue which may be difficult to discuss with a TSP. It was also recognized that additional support might be needed between pre- and post-test counselling sessions.

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**NHMRC Guideline 1.8      A written summary of the information covered in the pre-test counselling should be given, preferably in their native language**


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**Scenarios A and B: TSPs****Key Informants**

The majority of TSPs indicated that they provided some form of information, usually in the form of the hepatitis C pamphlets or other BBV pamphlets published by the Health Department of WA and the Hepatitis C Council of W.A. Several TSPs indicated that it was often difficult to find the pamphlets when they wanted to give them to an injector. Only one TSP indicated that they went through the pamphlets with the client. Some TSPs expressed concern that injectors would not read written information which was given to them.

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A significant percentage of key informants indicated that written information in the form of pamphlets was a good way to provide information.

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**NHMRC Guideline 1.9 Arrangement for a post-test counselling appointment should be made during pre-test counselling**


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Scenario A: TSPs	B: TSPs	Key Informants
<p>TSPs spoke of a wide range of practices in relation to giving test results and setting up appointments to receive results. Several indicated that they would give the results of the blood tests at the injector's next appointment, which would take place regardless of the test result in relation to receiving ongoing treatment or a second hepatitis B vaccination.</p> <p>Some indicated that they would give results over the phone on occasions but preferred injectors to come in and receive results face to face. Other practices included giving all results for all types of blood tests and all types of results over the phone, or sending a letter to people who had received a positive result asking them to return to the agency to receive their results.</p> <p>“Actually I give all results over the phone, especially for patients I know. I’ve never had [an HIV result] so I’d be very hesitant about giving them over the phone. Hep C, well I wouldn’t hesitate about giving over the phone. ...I think its better to give them the results as soon as you’ve got them, rather than tell them that you’ve got the results, come and make a new appointment. And then they get themselves all worried.”</p> <p>One TSP indicated that if they perceived the person was at high risk of receiving a positive result they would set up a face-to-face appointment to receive results, but this would not necessarily occur if they considered the person was at low risk of returning a positive result.</p> <p>A small number of TSPs stated that they would not give results over the phone in any situation and that clients were always informed during pre-test counselling that results were given face-to-face regardless of the result.</p>	<p>As per Scenario A.</p> <p>One TSP indicated that it was unlikely that an appointment for Steve to come back and receive results would be made, because a negative result would be assumed.</p>	<p>Key informants indicated that results should be given face-to-face in the majority of cases, but that there should be some discretion for the test service provider to divert from this if absolutely necessary.</p>

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- NHMRC Guideline 2.1 Post-test: Counselling should always be in person no matter what the reason for the test or whether the result is positive or negative. Refer. 1.9**
- NHMRC Guideline 2.2 Post-test :Ensure that the patient understands the meaning and implications of the test result. Refer to Post-test counselling, positive/negative result. Refer 3.1, 4.1, 4.2**
- NHMRC Guideline 2.3 Post-test: ensure that appropriate referrals and psychosocial interventions occur if required. Refer to Post-test counselling, positive/negative result. Refer 3.1, 4.3, 4.4**

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**NHMRC Guideline 3.1 Post-test for a negative result: Counselling should provide information to prevent exposure to the virus.**

**3.2 The individual should be assisted to adopt relevant skills to remain infection free.**

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Scenarios A and B: TSPs	Key Informants
<p>Responses for both scenarios were quite similar, with TSPs indicating that they would be most likely to talk about how to reduce the risk of contracting BBVs in the future. More TSPs indicated that they would provide this information for Scenario A, with the assumption being that Steve would already know much of this information from previous tests.</p>	<p>Key informants recognized the importance of post-test counselling in providing harm reduction information. They recognized that people might be more open to change in a crisis. However some key informants also expressed the view that the way in which this information was provided was critical and that test service providers should use a problem-solving approach and avoid giving an insensitive lecture or asking patients to justify themselves or their actions.</p>
<p>Other responses made by TSPs in this section included the fact that they would stress to injectors that it is better to be risk free than to keep getting tested. In the case of Rebecca, several TSPs indicated that they would also encourage her boyfriend to be tested for BBVs.</p>	
<p>“A lot of people think that a negative test condones their behaviour, but I would take pains to say that she’s been very lucky and ... [would] go through the safe injecting etc, spoons and injecting talk.”</p>	
<p>No TSPs indicated that they would refer either Rebecca or Steve for further information or support following a negative result.</p>	
<p>A minority of TSPs indicated that they would explain the meaning of a negative test.</p>	
<p>Several TSPs indicated that follow-up of negative results was often problematic, particularly due to limited resources at the agency. Several TSPs indicated that they would spend less time counselling Steve for a negative result than they would Rebecca.</p>	
<p>“He knows the risks. I don’t think he’d want you to make too much of a song and dance about it.”</p>	

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**NHMRC Guideline 4.1 Post-test for a positive result: Immediate counselling should be provided.**

Scenario A: TSPs	Scenario B: TSPs	Key Informants
<p>Several TSPs recognised that a diagnosis of hepatitis C can be devastating to some people and that it is difficult to take in information immediately after learning of the diagnosis.</p> <p>Other TSPs indicated that in their experience injectors were often not surprised or distressed at receiving a positive diagnosis.</p> <p>“I’ve never known anyone who’s terribly reactive about knowing that they’ve got hep C.”</p>	<p>Several TSPs indicated that after two years they would have good rapport with Steve and that there would not be much else that they needed to say at this point.</p> <p>“I wouldn’t have thought that there’d be that much left to say to be perfectly honest. You can try and break the news and see how he takes that.”</p>	<p>Key informants felt that immediate counselling was one of the most important factors in post-test counselling for the positive patient.</p> <p>Key informants acknowledged the shock that many people experience when learning of a positive result.</p>

**NHMRC Guideline 4.2 Post-test for a positive result: Support and information to prevent transmission should be provided.**

Scenarios A and B: TSPs	Key Informants
<p>TSPs demonstrated that they would approach a positive result for Rebecca or Steve in similar ways. In both cases, a majority of TSPs indicated that they would provide clinical information about the virus, information about transmission, further blood tests and a follow-up appointment. Other likely topics for post-test counselling included information about lifestyle changes and possibly written information.</p> <p>TSPs were more likely to explain the results to Rebecca than they were to Steve and TSPs indicated that they would address a wider range of information topics with Rebecca than they would with Steve.</p>	<p>Key informants acknowledged that the TSPs lack of time and the patient’s shock at learning of a positive result could reduce the effectiveness of providing this information.</p>

**NHMRC Guideline 4.3 Post-test for a positive result: The extent of personal support should be assessed.**

Scenarios A and B: TSPs	Key Informants
<p>Several TSPs indicated that they would help Rebecca and Steve to identify possible forms of support.</p>	<p>Key informants did not comment specifically on this area of the guidelines.</p>

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**NHMRC Guideline 4.4    Post-test for a positive result: Referral to external sources of support such as longer term counselling or a local hepatitis C Council should occur.**

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**Scenarios A and B: TSPs**

**Key Informants**

TSPs were likely to refer the person to the Hepatitis C Council of WA for further information or support.

Opinion about referring for counselling was divided. Some TSPs indicated that they would refer for further counselling and support if they considered this necessary while others indicated that although they might refer for treatment or further information they preferred to conduct their own counselling.

Several TSPs indicated that they would refer Rebecca and Steve for hepatitis C treatment.

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Key informants acknowledged that referral was one of the most important functions of post-test counselling for a positive result.

### ***Implementing the NHMRC Guidelines for Pre- and post-test Counselling***

Following discussion of the scenarios, TSPs were given a copy of the NHMRC Guidelines to consider. Both TSPs and KIs were asked to comment on the implementation of the Guidelines and more general issues about BBV testing with injectors, as below.

Most agreed with the content and intent of the Guidelines. Very few said they felt it was necessary to refer to the Guidelines every time a test was ordered, as they felt they had a good knowledge of their content.

I'm aware in a very big way of the usual suggestions as to pre- and post-test counselling, but I suspect it has become a little routine for me, because I'm not perhaps discussing it too much with the patient.

Many health professionals indicated that the Guidelines did not need to be, and should not be, followed in detail for every BBV test. The main barrier to carrying out effective pre- and post-test counselling was felt to be the lack of time, with the length of the average appointment ranging from 15 - 60 minutes.

Basically ... some of it you miss with them and there's some that you overdo with them, but I think it's like seeing the person and about what's happening for them.

Opinion varied about the use of the word "counselling" in the Guidelines. Some felt it was appropriate, some preferred terms like "pre-test information" and some felt that it was not an issue.

It's almost getting into the therapy side of counselling a bit, there's a bit of an overlap and the problem is that there isn't the time for the therapy side.

The majority of BBV tests ordered by TSPs were simultaneous tests for hepatitis C, hepatitis B and HIV/AIDS. Most TSPs said they felt they were doing all that they could in relation to BBV testing.

In terms of the physical form of the Guidelines, health professionals indicated a wide range of preferences, from CD ROM or web based designs to laminated charts or posters or the existing paper based form. Several indicated that a variety of forms would be

needed to meet the different needs of TSPs. Some also commented that the TSPs who were likely to conduct thorough pre- and post-test counselling would do so regardless of the form of the Guidelines and that TSPs who were not going to conduct thorough pre- and post-test counselling would not change their practices if the Guidelines were presented in a different format.

### ***BBV testing and the role of the TSP***

Test service providers were asked when they were most likely to suggest testing to an injector. The most common response related to the level of perceived or actual risk of the injector contracting BBVs. A significant number of TSPs indicated that they always suggested BBV testing, particularly when working with people who injected drugs. Other reasons for suggesting BBV testing related to the person's testing history, their level of knowledge about hepatitis C and admission to a residential treatment program.

Test service providers were asked how they would respond in a situation where somebody repeatedly requested testing when it was not deemed clinically necessary. Most TSPs indicated that they would agree to test the injector. Some of their reasoning included the fact that it was an opportunity for harm reduction information to be given, it was an important means of maintaining rapport and /or that someone asking for test was a good enough reason for it to be carried out. A number, however, indicated that they would try to dissuade the person from being tested and/or explore the reasons why the person wanted to be tested. Other responses included assessing the individual situation, not retesting, and testing for free once but then charging for subsequent tests if not at risk. Reasons given for not retesting somebody in this situation included issues related to agency resources and a belief that retesting was unlikely to result in any change to long established risk practices.

In regard to retesting, one test service provider expressed the dilemma which many TSPs experienced in relation to retesting.

I probably would [retest]. I could feel a little bit guilty about it because it's costing the taxpayer a certain amount of money. I think it's very important that I maintain a good rapport with him and I might discuss why he thinks he needs a test at the moment. It's difficult enough to get people to come for tests and if they're asking for a test then it makes sense to give it to them.

Another TSP talked about the need to find out why an injector continued to request testing.

I think you've got to explore that, you've certainly got to find out what's behind his fears. There may be something else behind his anxiety, not necessarily having hepatitis, the danger of hepatitis C or HIV... You can sort of fob somebody off all the time to have this done. But then you think, well I'm actually missing an opportunity here.

Health professionals were also asked how often injectors should be tested for BBVs. For hepatitis C, opinion ranged from three months-12 months, with the majority believing that hepatitis C testing should occur once every six months. Not all health professionals commented about testing for hepatitis B and HIV, but those who did indicated that testing should occur once every three months. Several health professionals thought that the BBV testing interval should depend on the injector's current level of risk while others felt that it should occur on an individual basis. Other options included testing on commencement and completion of a residential treatment, an interval of approximately eight weeks.

Factors which affected health professionals' decision about how often injectors should be tested for BBVs included considerations about window periods, working with clients who were sometimes transient, the level of risk currently being experienced by the injector, the cost of testing and the wishes of the person being tested.

One health professional summarised his view about HCV testing thus.

Six monthly is not unreasonable for someone who's injecting on a regular basis. I think 6 months is probably a reasonable compromise between frequency, cost and likelihood of getting a positive.

Health professionals were asked about the role of BBV testing particularly in preventing the transmission of BBVs. They were asked to indicate whether they felt that BBV testing was a medical-psychosocial issue or whether it was a medical issue only. The majority of health professionals thought it was a medical- psychosocial issue.

There were a number of positive associations with BBV testing. The most commonly mentioned were factors relating to information, education and awareness about BBVs.

Blood borne virus testing was seen as an opportunity to provide information and education and to raise awareness about the transmission of BBVs.

Approximately one quarter of health professionals stated explicitly that BBV testing was a good vehicle for prevention. The opportunity for harm or risk reduction was commonly mentioned. Health professionals also indicated that BBV testing was an opportunity to talk about risk, to identify triggers or situational contributors to risk and to develop strategies with the injector for avoiding risk in the future.

A smaller number of health professionals believed that BBV testing was an opportunity to achieve changes in attitude, particularly in terms of breaking down blasé attitudes about transmission of BBVs or beliefs about re-infection and co-infection. A similar number of health professionals also talked about the results of a BBV test changing people's risk behaviour. This could take the form of the anxiety experienced while waiting for results motivating the person to reduce risk behaviour in the future or the injector being keen to remain negative for BBVs after receiving a negative result.

Several health professionals indicated that they felt testing had a role in providing reassurance to people who injected drugs about their BBV status. Several also suggested that pre- and post-test counselling had the potential to help establish rapport between TSPs and those being tested. One suggested a link between establishing rapport and pre- and post-test counselling as a tool for prevention.

If testing can encourage doctors to talk to people who inject drugs like human beings that's an effective prevention tool.

Interestingly, only one health professional talked about the role of BBV testing in terms of detecting viruses and initiating treatment.

There were a similar number of negative or cautious associations with BBV testing. Health professionals recognized that BBV testing was not always a priority for injectors and although it might present an opportunity for psychosocial intervention this might not be what the injector wanted at that time. Some concern was expressed that TSPs might attempt to provide more information than the injector was willing to receive.

You can't expect the education if they're not interested in hearing the message.

Some health professionals were of the opinion that while BBV testing was a vehicle for prevention it was not necessarily the best vehicle. This related to the different settings in which BBV testing might take place and the variation which this might cause in the efficacy of pre- and post-test counselling.

Some health professionals also recognized that although there might be good intentions to change behaviour immediately after receiving a negative result, achieving and maintaining long-term change was more difficult.

My experience has been that... In theory people... have got a negative... and there's this huge relief and they perhaps change their behaviour ... perhaps for a short time. And then gradually... they step backwards again.

Another view was that being tested for BBVs too often (for example more frequently than once every three months) could actually increase risk behaviour.

Some health professionals were more negative in their perceptions of BBV testing as a vehicle for prevention. Several felt that BBV testing was too late in the process to have any real impact and others indicated that information from users' organisations and information in "Fit-packs" would work better than the pre- and post-test counselling associated with BBV testing. Another health professional made the point that testing injectors for BBVs was not the only opportunity to talk to them about ways to reduce their risk of contracting BBVs.

Several health professionals did not believe there was a strong link between BBV testing and behaviour change. Some felt that access to clean injecting equipment was a much more effective prevention tool than BBV testing or pre- and post-test counselling.

The behaviour is more about I reckon being in the wrong place at the wrong time without the right piece of equipment. You know what you're supposed to do, most people, but at the time if you haven't got access to it [then] the only option is 'OK I'll take the risk' and then do it and afterwards they panic and think 'oh shit, shouldn't have done that.' It's more about that than actually in the future, change, you know, but you can't have a fit pack with you 24 hours a day really, can you?

Another group of health professionals felt that it was more important to look at the broader issues around illicit drug use such as social, legal and psychological issues than it

was to focus on BBV testing as a means for prevention. One expressed the opinion that BBV testing was merely "a sop to the community."

Health professionals were well aware of the need for hepatitis C prevention. Several expressed the view that hepatitis C was an epidemic which had huge consequences for the public health system in the future although a number also suggested that HIV/AIDS was still seen as more of an issue by people who injected drugs than hepatitis C.

Health professionals were asked which type of agency or organisation was best placed to provide BBV testing and pre- and post-test counselling. Peer based agencies such as WASUA were clearly the preferred type of agency to provide BBV testing for injectors. General practitioners were the next preferred option. The next most popular option was for drug treatment agencies to provide BBV testing and counselling. Several health professionals indicated that there was a need to develop a specific service or outreach facility to provide BBV testing for injecting drug users. Others indicated that a multi disciplinary approach was most appropriate.

In looking at these results, it is important to take into account that there was a very strong tendency for agencies to nominate their own type as the best place to provide BBV testing and pre- and post-test counselling. All the GPs who responded to this question maintained that GPs were best placed to undertake this counselling. All the health professionals associated with peer based programs suggested peer based programs were best placed to undertake this counselling and all the suggestions of treatment agencies came from health professionals who represented treatment agencies.

As well as nominating which types of agencies were felt to be most appropriate to provide BBV testing, health professionals also indicated what they considered to be most important aspects of the provision of BBV testing. Many thought that people who injected drugs should have a choice about the type of agencies they accessed for BBV testing. Continuity in the agency and the staff member providing BBV testing and counselling was also considered to be an important issue. This was partly because continuing to see the same TSP over a period of time was seen as critical in establishing rapport between the TSP and the injector.

A number of agencies suggested that they currently experienced resource related issues in providing BBV testing and/or counselling, or that they would experience resource related issues if they were to expand into this area. The majority of health professionals who raised resource related issues suggested that more cooperation with other agencies could help them to overcome these problems.

Health professionals expressed a range of opinions about the merits of each type of agency or organisation being involved in BBV testing and counselling. Some indicated that, in their experience, GPs and hospital clinics could be judgmental of people who inject drugs and that GPs did not provide enough counselling in the testing process. Other health professionals had positive perceptions about GPs providing BBV testing and counselling although some felt that GPs required more training in this area.

Although peer based programs were most frequently nominated as the best type to be offering this kind of service, some health professionals were not aware of their existence.

### ***Hepatitis B vaccination***

Test service providers were asked if they would recommend hepatitis B vaccination for Rebecca and Steve, regardless of their BBV test results. The vast majority of TSPs indicated that they would recommend vaccination and one TSP indicated that if Rebecca and Steve were positive for hepatitis C then they would recommend hepatitis B and hepatitis A vaccination. Two TSPs said that their agency did not suggest or provide hepatitis B vaccination.

All health professionals were asked what they considered to be the main barriers preventing the uptake of hepatitis B vaccination amongst injectors. The need to have three vaccinations over a period of time (usually six months) was considered to be a significant barrier for many injectors. A slightly smaller number of health professionals indicated that the cost of the vaccination was also a significant barrier, as was the fear or dislike of the intramuscular injection used for hepatitis B vaccination.

I think the main thing is people's time and the pain of the needle. And they're worried about an immediate reaction after the needle.

Other responses included the perception that injectors were in too much of a hurry at the time of the appointment to have the vaccination done and misconceptions about universal

hepatitis B testing. Several TSPs indicated that they did not suggest or offer hepatitis B vaccination through their clinic and others said that they did not think there were any real barriers to hepatitis B vaccination.

## **PHASE 2 DEVELOPMENT OF AND FEEDBACK ON DRAFT GUIDELINES**

### **Development of Modifications to NHMRC Guidelines**

The data from Phase I were discussed by the consultants and investigators in the development of proposed modifications to the Guidelines. These modifications, which are described below, take the form of flexible guidelines, with some elements that are considered essential (part of a minimal set) and some negotiable. Essential guidelines are defined as those which should be included in every pre- and post-test counselling session regardless of the person's testing history, relationship with the TSP, knowledge of blood borne viruses or current situation. Negotiable guidelines are defined as those which are not essential for every patient. Whether or not they would be included in a particular test could be negotiated between the person being tested and the test service provider and would depend on the person's testing history and knowledge of blood borne viruses.

In the following section, considerations which were used in the development of the modified guidelines are described.

#### **1. Pre-test counselling should:**

##### **1.1 Assess risk**

Injectors and TSPs agreed that assessing risk was an important part of pre-test counselling. However, there was significant variation reported in the depth of risk assessment, from "do you share fits?" to detailed discussion of injecting technique. This indicated the need for some standardisation. The consultants were somewhat divided about the value of this, given the resulting increase in length of the guidelines. It was recognised by the majority of respondents, however, that risk practices and knowledge about BBV transmission alter over time. Thus it was felt that assessing risk needed to be part of the essential set of guidelines, regardless of the number of times someone had been tested.

### 1.2 Provide clinical information about the virus

Whilst providing clinical information was considered by injectors and health professionals to be an important part of the testing process, the majority of respondents recognised that it was not appropriate to deliver the same clinical information at every test. Injectors expressed a desire to hear new information, but not to receive the same information at every test. Consultants also recognised that some flexibility was required in order for the guidelines to be workable. Thus it was suggested that this guideline be negotiated in terms of the injector's testing history and their knowledge of BBVs.

### 1.3 Enable the patient to decide whether they should be tested

Injectors and TSPs had difficulty in understanding how this guideline differed from other guidelines such as 1.4 and 1.5. Test service providers did not volunteer this topic as one which they would include. The fact that many injectors ask to be tested complicates the application of this type of guideline. The intent of this guideline is probably to ensure that the injector has sufficient information and opportunity to provide informed consent for a BBV test. Informed consent was considered by many respondents to be the key goal of pre-test counselling. Thus, while this guideline represents an important stage in pre- and post-test counselling, the research indicated that it might be more effective if it was incorporated with guideline 1.6 to form a new guideline which represented the gaining of informed consent. This new guideline would be part of the essential set of guidelines.

### 1.4 Provide information about the test and the possible consequences of testing, including confidentiality and notifiability

All respondents tended to be unclear as to what "information about the test" might include. Thus there would be some value in specifying what this information should cover. The provision of information about confidentiality was relatively uncontroversial, with the majority of respondents indicating that this part of the guidelines was currently followed and should continue to be followed in the future.

The provision of information about notifiability was more controversial. A significant percentage of injectors indicated that they were not aware of notifiability arrangements and that they would have liked to be informed of them. The majority of injectors saw this as a courtesy and as part of giving informed consent. No injectors indicated that they

would have refused a BBV test if they had known about notifiability - most were reassured once they were informed that the information was confidential and anonymous. Regardless of this, they still preferred to be informed about notifiability before giving consent. Health professionals were divided in their response to this element of the guidelines. Several TSPs expressed doubts about the wisdom of informing injectors about notifiability, given that the information was essentially statistical and confidential and that notifiability was mandatory. These doubts appeared to contribute to a belief that injectors might refuse to be tested if they knew about notifiability and/or that there was nothing to be gained by telling them because it could cause them to be concerned by something over which they had no control. Other health professionals believed that it was important to inform injectors about notifiability in order to give them all the information they needed to provide informed consent. Consultants were also divided about the value of informing injectors about notifiability.

In considering these opposing points of view, three factors were taken into account. The first of these was that no injectors indicated they would have refused to be tested if they had known about notifiability. The second was that BBV testing is usually not urgent. If an injector had concerns about notifiability, there would normally be the option for them to consider the issue at their leisure before deciding whether or not to be tested. The third was that facilitating informed consent was clearly seen by all respondents as a key goal of pre-test counselling. In order to achieve "true" informed consent we felt it was necessary to inform injectors about notifiability.

All respondents (and some consultants) had difficulty in distinguishing between this guideline and guideline 1.5. In order to avoid ambiguity and repetition, it was recommended that this guideline be incorporated with 1.5 to create one which represented the provision of necessary information prior to gaining informed consent. This new guideline would be part of the essential set.

### 1.5 Provide information on testing benefits

Respondents and consultants had difficulty identifying what this guideline actually meant. No TSPs indicated that they would "provide information on testing benefits" in either scenario. It was considered that merging this guideline with 1.4 would clarify and simplify the pre-test counselling process and create a guideline which represented the

provision of necessary information prior to gaining informed consent. This new guideline would be part of the essential set.

#### 1.6 Establish the ability to give informed consent

Respondents and consultants agreed that informed consent was a key aim of pre-test counselling, so much so that some respondents suggested that pre-test counselling should be called "obtaining informed consent". Health professionals indicated that they would cover this issue, although more attention was paid to it in Scenario A, which related to the first BBV test of a girl aged under 18 than in Scenario B which involved testing an experienced injector. Most health professionals indicated that the most appropriate way to gain informed consent was verbally. Written consent was seen by both health professionals and injectors as potentially compromising of confidentiality and/or anonymity. Confusion arose around whether somebody who was requesting a test still needed to give informed consent; an issue which should be clarified in the guidelines. It was recommended that this guideline be incorporated with guideline 1.3 to form a guideline which represented the gaining of informed consent. This new guideline would be part of the essential set.

#### 1.7 Identify support available to the patient.

Some respondents, particularly injectors, recognised that determining a person's level of support prior to a BBV test was a critical part of managing a positive result. A significant percentage of TSPs, however, did not include identifying support as one of the activities they would undertake in responding to the scenarios. Respondents also recognised that assessing a person's level of support could be a complex process which would vary significantly between individuals. Another suggestion was for people to bring a support person to the post-test counselling session, regardless of the result. Another option was only to identify support as part of post-test counselling for a positive result, or only to identify support if somebody was thought to be at high risk of returning a positive result. In discussion with the consultants it was suggested that while assessing a person's level of support was important, in some situations it could be negotiated between the TSP and the injector.

### **1.8 Provide a written summary of the information covered in the pre-test counselling preferably in the patient's native language**

A wide range of opinions about the value of providing written information as part of pre-test counselling was expressed. These opinions related mainly to the literacy of people being tested and the relevance and availability of written information. It was assumed that written information meant pamphlets and brochures about BBVs, such as those published by the Health Department of WA or the HCCWA. The broad range of opinions and the frequency with which some injectors are tested indicated that it would be not be advisable or practical for it to be deemed essential to provide written information on each testing occasion. Some injectors also indicated that they would find information which was presented by means of video or internet easier to access and/or understand and some were concerned that written information should not replace personal interaction. Several consultants raised concerns about the availability and appropriateness of materials which had been translated into other languages and about the provision of information for people with low literacy levels. While not a focus of this study, it is an issue which warrants further attention. Thus it was suggested that the provision of written information be negotiated based on the person's testing history and knowledge about BBVs.

### **1.9 Make arrangements for a post-test counselling appointment**

Respondents expressed a broad range of opinions about the wisdom of always receiving results in person. One of the chief concerns which was raised related to the injector telephoning for test results and being informed that they had to make an appointment to receive results, thus occasioning anxiety. Adhering to this guideline would help to reduce that anxiety because injectors would know that regardless of whether it was negative or positive they would still need to see the TSP to receive the result of their BBV test. It was also recognised that giving BBV test results in person is often facilitated by the injector returning to see the TSP in relation to another matter, for example drug treatment. Some respondents indicated that it was not always possible or desirable to give results face to face. This issue was discussed with the consultants and despite these varying opinions, it was decided that it would be preferable to keep this as part of the essential set of guidelines in order to demonstrate the importance of giving results in person.

## **2. Post-test counselling should:**

### **2.1 Always be in person no matter what the reason for the test or whether the result is positive or negative**

Bearing in mind the difficulties associated with giving results face to face, as discussed in 1.9, it was decided that this guideline should remain as part of the essential set of guidelines.

### **2.2 Ensure that the patient understands the meaning and implications of the test result**

While this guideline was seen by respondents and consultants as being an important part of post-test counselling, it was also considered to be superfluous in some situations, for example where a person had consistently returned negative results over an extended period of time. It was also thought by consultants that it could be addressed by the provision of written information. Consultants also identified potential difficulties for the TSP in recognising whether somebody understood the test result or not. Thus it was considered that this guideline could be negotiated based on the person's testing history, relationship with the TSP and current situation.

### **2.3 Ensure that appropriate referrals and psychosocial interventions occur if required**

This guideline was considered by respondents and consultants to apply only in the case of positive results. We therefore recommended removing it from this position and it is further discussed under 4.3 and 4.4.

## **3. If patient is negative:**

### **3.1 Counselling should provide information to prevent exposure to the virus.**

### **3.2 The individuals should be assisted to adopt relevant skills to remain infection free**

Provided that the information was presented in a non-judgemental and interesting way, the majority of respondents supported the inclusion of this guideline. Most TSPs indicated in responding to the scenarios that they would address this issue, and a significant percentage of injectors indicated that they would find such information useful.

It was suggested that basing this information on the risk assessment which was conducted pre-test would increase its relevance for the injector. It was thought that this guideline should be retained as part of the essential set.

#### **4. If patient is positive:**

##### **4.1 Immediate counselling should be provided**

Providing immediate counselling was seen as the key role of the post-test consultation. The strong reaction of injectors to both actual or hypothetical positive results indicated that immediate counselling would be paramount. Some health professionals also recognised that a diagnosis of hepatitis C could be devastating. The majority of respondents indicated that in the shock of receiving a positive diagnosis it would be difficult to absorb information. Thus it was considered that a two-stage positive result-giving process could be of benefit, with the first stage including immediate counselling and the second stage including medical and other consultations and referral. Whilst this concept had support from most respondents, it was not supported by all consultants some of whom felt that injectors might not return for the second appointment. It was also recognised that many injectors already have a follow up visit to their TSP after a positive result in order to have further blood tests, such as LFTs. We suggested there was sufficient overlap between 4.1 and 4.3 to merge these guidelines into a single statement: "Provide immediate counselling and assess other sources of support". This guideline would be part of the essential set.

##### **4.2 Support and information to prevent transmission to others should be provided**

This guideline was well understood by the majority of respondents. Test service providers indicated that they would always include this type of information when conducting post-test counselling for a positive result, and injectors also recognised its importance, although they indicated that the information might be better received at a 2<sup>nd</sup> appointment or through an organisation such as the HCCWA. It was felt that this information could be incorporated into the suggested two-stage positive result-giving, although this could be negotiated depending on the reaction of the injector to a positive result. It was considered that this guideline should be included as part of the essential set.

### **4.3 The extent of personal support should be assessed**

As outlined in the pre-test counselling, assessing the extent of someone's personal support was considered by most respondents to be an important, if complex, part of the testing process. As discussed previously, it was felt that in order to make the guidelines as simple and unambiguous as possible, it would be of benefit to merge this guideline with guideline 4.1 and to create a new guideline which read "Provide immediate counselling and assess other sources of support." This guideline would be part of the essential set.

### **4.4 Referral to external sources of support such as longer-term counselling or a local Hepatitis C Council should occur**

The majority of injectors indicated that they would welcome referral for further support or information and most health professionals indicated that they also saw this as desirable, particularly in terms of providing further information. Some TSPs, however, expressed reservations about referring people for counselling, believing that this was better achieved "in house." Recognising the wide range of potential reactions to a positive diagnosis, and the varying level of skills which TSPs might have in responding to this, it was considered appropriate for this guideline to be negotiated based on the person's testing history, relationship with the TSP and current situation.

### **Feedback on Suggested Modifications to the Guidelines**

This section summarises the results of the two focus groups which were run to provide feedback on these proposed changes. The focus group results were compiled and given to the consultants for further comments.

The proposed modifications and feedback from the two focus groups and the consultants on these proposals are outlined below.

## Focus Groups' and Consultants' Responses to Proposed Modifications to Guidelines

### NHMRC Guideline 1.1

#### Pre-test counselling should assess risk

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline  Essential: part of the minimal set of guidelines	Need to check whether IV user, whether sharing equipment, what client's knowledge re. BBVs is, what services they have accessed previously.  Ask client why they want a BBV test.	Essential to retain this guideline.  Other suggestions were; include example questions on how to assess risk, encourage self-assessment and suggest how this could be done. Clients should be informed that they don't have to answer questions.	Agree.  There is currently a lack of education for GPs in relation to assessing risk in a non-threatening, non-judgemental way.

### NHMRC Guideline 1.2

#### Pre-test counselling should provide clinical information about the virus

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline.  Negotiate how much clinical information is provided based on the person's testing history and their knowledge of BBVs	Essential for new users.  May need to do this before assessment  Check the need to provide information.	Essential that this guideline be retained while allowing negotiation between client and TSP about how much information is provided based on the person's testing history and their knowledge of BBVs.	No specific feedback on this guideline.

### NHMRC Guidelines 1.4/1.5

**Pre-test counselling should provide information about the test and the possible consequences of testing, including confidentiality and notifiability/ provide information on testing benefits**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Merge guidelines to create a new guideline. “Provide information about the test and the possible consequences and benefits of testing including confidentiality and notifiability.” Essential: part of the minimal set of guidelines.	Provide some information at pre-test but go into more detail later: clients are often more responsive when they know the result of the test.	Should include consequences of testing, i.e. notifiability, social, financial (health insurance), legal  Needs to be retained. No objection to merging guidelines.	It would be good to give injectors information about this so they can ensure their TSP covers it.

### NHMRC Guidelines 1.6/1.3

**Pre-test counselling should establish the ability to give informed consent / enable the patient to decide whether they should be tested**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Merge these guidelines and create a new guideline. “Discuss whether the patient is ready and able to give informed consent. Gain informed consent.” Essential: part of the minimal set of guidelines.	Guidelines could state “Have you obtained informed consent?”	Needs to be retained as essential part of minimum set of guidelines.  GPs probably need information on current informed consent guidelines (not just for BBVs).	Agree.  Another issue to consider is that if results from an LFT are abnormal, the GP can order an additional test from the lab without having to seek further consent from their patient.

### NHMRC Guideline 1.7

**Pre-test counselling should identify support available to the patient**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline. Negotiate whether this guideline is covered based on the person’s testing history, relationship with the TSP and current	This guideline should be retained.  Most important if client expresses poor coping mechanisms.	This is an optional guideline which could be included with the first guideline re. assessing risk  Important to identify third party support options, eg.	Could read “In the event of a positive result, identify support.”

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 situation.

Hepatitis C Council.

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**NHMRC Guideline 1.8**

**A written summary of the information covered in the pre-test counselling should be given, preferably in their native language**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline. Negotiate whether written information is provided based on the person's testing history and knowledge about BBVs.	TSP could go to the relevant web site and give client a copy of information obtained  Could provide a small leaflet which is not too obtrusive	Essential for first test then negotiable	Also important to consider what information about BBVs is available in a translated form and how culturally appropriate the information is .

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**NHMRC Guideline 1.9**

**Arrangement for a post-test counselling appointment should be made during pre-test counselling**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline. Essential part of the "minimal set" of guidelines. Provide option to bring support person to post-test appt.	Yes. Most important.	Essential that the guideline is kept, that it is part of a minimal set of guidelines and that the client be given the option to bring a support person.	Face to face result giving is not always practical in rural and remote areas.

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**NHMRC Guideline 2.1**

**Post-test counselling should always be in person no matter what the reason for the test or whether the result is positive or negative.**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
Keep this guideline. Essential: part of a "minimal set" of guidelines.	Important in order to maintain contact after an indeterminate or negative result, as well as a positive result.	Retain guideline. Appointment to be made at the conclusion of the test appointment	Face to face result giving is not always practical in rural and remote areas.  Delete 2.1. 2.2 and 2.3 and just have positive or negative results.  If 2.1, 2.2 and 2.3 are deleted then consideration needs to be given to counselling for an indeterminate or equivocal result. Counselling in this situation should be couched appropriately

according to the individual, their level of risk and the likelihood of a positive or negative result.

### NHMRC Guideline 2.2

#### Post-test counselling should ensure that the patient understands the meaning and implications of the test result

Suggested Changes (NDRI)	Focus Group 1 Health Professionals	Focus Group 2 Injectors	Consultants
<p>Keep this guideline.</p> <p>Negotiate based on the person's testing history, relationship with the TSP and current situation.</p>	<p>Could be covered in pre-test counselling.</p> <p>TSP needs to have an understanding of client's level of understanding re testing. Could be negotiable, as long as it covered their understanding in the pre-test.</p> <p>This should be less based on TSP's lack of time and more based on the client's level of confidence.</p>	<p>Retain guideline.</p> <p>Should be used to assess level of understanding.</p>	<p>Delete 2.1, 2.2 and 2.3 and just have positive or negative results.</p> <p>If 2.1, 2.2 and 2.3 are deleted then consideration needs to be given to counselling for an indeterminate or equivocal result. Counselling in this situation should be couched appropriately according to the individual, their level of risk and the likelihood of a positive or negative result.</p>

### NHMRC Guideline 2.3

#### Post-test counselling should ensure that appropriate referrals and psychosocial interventions occur if required

Suggested Changes (NDRI)	Focus Group 1 Health Professionals	Focus Group 2 Injectors	Consultants
<p>Keep this guideline.</p> <p>Essential: part of the minimal set of guidelines.</p>	<p>Delete this guideline as it is covered in the guidelines relating specifically to a positive or negative result.</p>	<p>Reword to the following:</p> <p>Ensure that appropriate referrals (eg psychosocial support) occur if requested or deemed necessary.</p> <p>Retain guideline as an essential part of minimum set of guidelines.</p>	<p>Delete 2.1, 2.2 and 2.3 and just have positive or negative results.</p> <p>If 2.1, 2.2 and 2.3 are deleted then consideration needs to be given to counselling for an indeterminate or equivocal result. Counselling in this situation should be couched appropriately according to the individual, their level of risk and the likelihood of a positive or negative result.</p>

**NHMRC Guideline 3.1, 3.2**

**Post-test for a negative result: Counselling should provide information to prevent exposure to the virus.**

**The individual should be assisted to adopt relevant skills to remain infection free.**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
<p>Keep this guideline. Essential: part of the “minimal set” of guidelines.</p> <p>Should the discussion be based on the risk assessment from pre-test discussion?</p>	<p>Discussion should be based on pre-test risk assessment.</p> <p>Documentation of pre-test assessment therefore important.</p> <p>Aim to raise client’s knowledge re risk.</p>	<p>Reword to the following:</p> <p>“Discussion should provide harm reduction information to prevent exposure to the virus and the individual should be assisted to remain infection free.”</p> <p>Retain the guideline.</p> <p>Important to determine why the patient is getting the test. If risk behaviour is to continue then harm reduction practices should be explored.</p>	<p>No specific feedback on this guideline.</p>

**NHMRC Guideline 4.1 /4.3**

**Post-test for a positive result: Immediate counselling should be provided /the extent of personal support should be assessed.**

<b>Suggested Changes (NDRI)</b>	<b>Focus Group 1 Health Professionals</b>	<b>Focus Group 2 Injectors</b>	<b>Consultants</b>
<p>Merge these guidelines and create a new guideline. “Provide immediate support and assess other sources of support.”</p> <p>Essential: part of the “minimal set” of guidelines.</p> <p>Have two stage positive result giving. The first stage would include immediate counselling and second stage would include medical and other consultations and referral.</p>	<p>Use the merged guidelines.</p> <p>The 2 stage positive result giving depends on client.</p> <p>Give brochure and results to consider before next appointment.</p> <p>This guideline could include the last two guidelines re. transmission to others and referral to external sources of support.</p>	<p>Query about the suitability of the word “counselling.”</p> <p>These two guidelines represent two separate issues and should not be merged. Also both should be retained as part of the minimal set of guidelines</p>	<p>Opinion was divided about whether “pre- and post-test discussion” was the best term to replace “pre- and post-test counselling.”</p> <p>In post-test for a positive result, “counselling” could be used in its ‘proper’ term, but this distinction needs to be made clear.</p> <p>2 stage result giving is essential – encourage patients to bring someone to 1st and 2nd appointment, write down questions which occur between appointments and ring the HCCWA between the appointments.</p> <p>2nd appointment would probably happen anyway in</p>

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order to do LFTs etc.

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### NHMRC Guideline 4.2

#### Post-test for a positive result: Support and information to prevent transmission should be provided

Suggested Changes (NDRI)	Focus Group 1 Health Professionals	Focus Group 2 Injectors	Consultants
<p>Keep this guideline. Essential: part of the minimal set of guidelines.</p> <p>Incorporate into two stage positive result giving, though this could be negotiated depending on the reaction/state of the injector.</p>	<p>Could be included under guidelines 4.1 and 4.2.</p>	<p>Reword to the following: 'if positive, support, information and referral to prevent transmission to others should be provided.'</p> <p>Retain Guideline and include as essential.</p>	<p>No specific feedback on this guideline.</p>

### NHMRC Guideline 4.4

#### Post-test for a positive result: Referral to external sources of support such as longer term counselling or a local hepatitis C Council should occur

Suggested Changes (NDRI)	Focus Group 1 Health Professionals	Focus Group 2 Injectors	Consultants
<p>Keep this guideline. Negotiate based on the person's testing history, relationship with the TSP and current situation.</p>	<p>Could be included under guidelines 4.1 and 4.2.</p> <p>The word counselling could be changed to discussion.</p>	<p>Retain the guideline. Guideline should be negotiated based on person's testing history, relationship with TSP and current situation.</p>	<p>No specific feedback on this guideline.</p>

### Summary of Responses to Proposed Modifications

In summarising the responses, it is clear that there is strong agreement about the changes proposed to *pre-test* counselling guidelines, with the exception of the level of detail provided under guidelines 1.4 and 1.5 and some differences about the best placement of guideline 1.7.

In relation to the *post-test* counselling guidelines which apply whether the result is positive or negative both focus groups agreed that guidelines 2.1 and 2.2 should be retained. Differences were expressed about guideline 2.3, with the first focus group indicating that this guideline could be incorporated into other guidelines and the second focus group indicating that it should be retained and reworded. Some consultants felt strongly that there needed to be an additional guideline for use in cases of indeterminate results.

In relation to *post-test counselling for a positive* result, both focus groups agreed that the guidelines need to be retained and reworded. Both groups suggested that this area of the guidelines could be expanded.

Where the focus groups differed most was in relation to *post-test counselling for a negative* result. The first focus group felt that these guidelines could be incorporated into one guideline. The second focus group felt that guidelines 4.1 and 4.3 should be kept separate and that the guidelines for 4.2 and 4.4 should be retained and possibly reworded. The key difference between the focus groups appeared to be that TSPs felt that post-test counselling for a negative result could be accomplished using one guideline, whereas people who injected drugs felt that post-test counselling for negative result required a more in-depth approach.

The consultants agreed with the majority of suggested guideline changes. Most of their comments related to the implications of implementing changes to the guidelines, or ways to extend the suggested changes. The only significant area of difference between consultants was the merit of the term “pre- and post-test discussion” in preference to “pre- and post-test counselling”. We feel that ‘discussion’ is a preferable term, because of the multiple associations of the word counselling. This issue is discussed in more depth later.

We have taken all these points into consideration in our final proposals for modifications to the existing NHMRC Guidelines for hepatitis C testing. Moreover, we consider that the modified guidelines should be generalised to all blood borne virus testing with injectors, since most tests occur in batteries rather than singly. Our proposed guidelines, therefore, relate to BBV testing with injectors.

**Table 1: Proposed Guidelines for BBV Testing with Injectors**

**Pre-test discussion** should always be in person no matter what the reason for the test. Pre-test discussion aims to provide the individual with the information, ability and opportunity to give informed consent to the BBV test.

<b>At first test</b>	<b>At subsequent tests</b>	
<b>Essential<sup>1</sup></b>	<b>Essential<sup>1</sup></b>	<b>Negotiable<sup>2</sup></b>
<p><b>Provide clinical information about the virus</b></p> <p><b>Assess risk</b> Include exemplars for assessing risk</p> <p><b>Provide information about the test and the possible consequences and benefits of testing including confidentiality and notifiability</b></p> <p><b>Provide additional information about the virus</b> Format and language of information should be appropriate to the person's literacy and language skills.</p> <p><b>Discuss whether the patient is ready and able to give informed consent. Gain informed consent</b></p> <p><b>Identify support available to the patient.</b></p> <p><b>Arrange the post-test discussion</b> Provide option to bring a support person when receiving results.</p>	<p><b>Assess risk</b> Include exemplars for assessing risk</p> <p><b>Provide information about the test and the possible consequences and benefits of testing including confidentiality and notifiability</b></p> <p><b>Discuss whether the patient is ready and able to give informed consent. Gain informed consent</b></p> <p><b>Arrange the post test discussion</b> Provide option to bring a support person when receiving results.</p>	<p><b>Provide clinical information about the virus</b></p> <p><b>Identify support available to the patient.</b></p> <p><b>Provide additional information about the virus</b> Format and language of information should be appropriate to the person's literacy and language skills.</p>

<sup>1</sup>Essential; these guidelines should be included in every pre- and post-test discussion regardless of the person's testing history, relationship with TSP, knowledge of blood borne viruses or current situation.

<sup>2</sup>Negotiable: these guidelines could be negotiated between the person being tested and the test service provider based on the person's testing history, relationship with TSP, knowledge of blood borne viruses or current situation.

**Post-test discussion** should always be in person no matter what the reason for the test or whether the result is positive or negative. The purpose of post-test discussion is to ensure the individual understands the meaning and implications of the test result and is provided with support, information and referral as appropriate.

<b>Negative result</b>	<b>Positive result</b>	
<b>Essential</b>	<b>Essential</b>	<b>Negotiable</b>
<p><b>Facilitate discussion which provides harm reduction information to prevent exposure to the virus. Assist the person to develop skills in remaining infection free.</b></p> <p>Discussion should be based on the pre-test risk assessment.</p>	<p><b>Provide immediate counselling and assess other sources of support</b></p> <p>Incorporate positive result giving into two stages as appropriate. It is recommended that this guideline be addressed at the 1<sup>st</sup> appointment.</p> <ul style="list-style-type: none"> <li><b>Provide support and information to prevent transmission</b></li> </ul> <p>Incorporate positive result giving into two stages as appropriate. It is recommended that this guideline be addressed at the 2<sup>nd</sup> appointment.</p>	<p><b>Refer to external sources of support such as longer-term counselling or a local Hepatitis C Council</b></p> <p>Incorporate into two stage positive result giving as appropriate. It is recommended that this guideline be covered at the 1<sup>st</sup> and/or 2<sup>nd</sup> appointment</p>
<b>Indeterminate/Equivocal Result</b>		
Discussions in this situation should be couched appropriately according to the individual, their level of risk and the likelihood of a positive or negative result.		

## Other Issues Relating to NHMRC Guidelines

In addition to providing feedback on specific guidelines, the focus groups and consultants made additional comments about other issues related to pre- and post-test discussion.

Focus group one comprised a number of TSPs from rural areas, and their comments related to the implications in rural areas of limited access to testing facilities, the financial cost of a blood borne virus test, collection and transporting fees for specimens and the confidentiality of results. This was verified by one of the consultants, who indicated that GPs who did not bulk bill tended not to ask laboratories to bulk bill. If there was a higher percentage of GPs in rural areas who did not bulk bill, this could account for the difficulties identified by focus group one.

Comments from focus group two, who represented injectors, were mainly related to the relationship between TSPs and injectors, which was seen as very important. Participants believed that injectors who did not have a regular GP were less likely to receive pre- and post-test discussion according to the Guidelines. They suggested that a checklist for injectors might help remind them which questions they should ask their TSP, although they felt that disseminating such a list could be difficult. The consultants supported this concept, indicating that it would be in accordance with current developments in GP/patient relationships in terms of providing patients with the means to ask more questions of their GP. It was suggested that this checklist could take the form of a poster and/or a pamphlet.

Participants in the second focus group also suggested that TSPs should have a list of Frequently Asked Questions about BBV testing so that they knew what to expect and could have appropriate information on hand.

The consultants had a number of suggestions about the language used in the revised guidelines. It was suggested that the guidelines should be written as action statements, with an additional checklist of exemplars to which TSPs could refer. The consultants also recognised that definitions needed to be included for terms such as “indeterminate

result” and “harm reduction.” The term “counselling” needed to be used clearly and consistently, or be replaced with an alternative term.

## DISCUSSION

The proposed guidelines encapsulate the data that has been gathered in this study. In this section, we take up some issues which we believe warrant further consideration, discuss implementation of the proposed guidelines and make some specific recommendations.

### ISSUES RELATING TO THE MODIFIED GUIDELINES

#### Risk Assessment

As noted above, both injectors and TSPs identified that assessing risk was an important part of pre-test counselling and recognised that risk practices and knowledge about BBV transmission might vary over time. Injectors, however, believed that risk assessment should go beyond merely establishing whether the client was a drug injector. Their specific risk behaviours, occasions of risk, their own assessment of the risk of sharing injecting equipment with close friends and lovers, and the likelihood of domestic transmission in households with at least one positive member could all be discussed.

This risk assessment, if detailed enough, can be an opportunity for occasions of risk to be examined in detail once the test result is known. It is also an opportunity to explore patterns of greatest risk – such as being intoxicated – and discuss ways to reduce risk at these times. Tested injectors said they would value these discussions as long as they were not presented as lectures, and conveyed information that was new. Some TSPs, however, questioned whether they had enough time to conduct these detailed risk assessments – this issue is taken up in more detail below.

#### Repeat Testing

This study shows that much BBV testing of injectors is undertaken at the injector's request and that many injectors and TSPs felt that TSPs should acquiesce to every test request. Test service providers have good reasons for doing so including creating opportunities for harm reduction information dissemination and building and maintaining rapport with their patients. Nevertheless, it is clear both from this and our

earlier study (Loxley et al., 1999) that some injectors request regular testing less to establish whether they have become infected, than to demonstrate that they are 'clean". That this motivation is unlikely to be conducive to behaviour change was demonstrated in the first study. Nevertheless, testing can alter risky behaviour as has been clearly demonstrated in the present study.

Given the public health resources that are involved in testing, we believe that TSPs should make decisions about the frequency of testing on clinical grounds, and negotiate these with individual patients. Injectors should be required to demonstrate that there are sufficient grounds for retesting (eg new episodes of risky behaviour) and if testing does not appear to change behaviour, discussions between the TSP and the patient about the purpose of testing should ensue.

### **Confidentiality and Notifiability**

In the modified guidelines we suggested that establishing whether the patient was ready and able to give informed consent should be the major task of pre-test counselling. This included being given information about the virus, the infection and the test, not only in terms of what test results meant but also what could and would happen to test results. Patients have a right to know what use can be made with information about themselves. This is in line with the NHMRC Ethical Conduct in Research Statement which clarifies that consent should be sought for the disclosure of personal information whenever possible (NHMRC, 1999).

While giving patients information about confidentiality has been found to be hardly contentious because it reassures patients who come for testing, we understand the concerns that some TSPs have that giving information about the notifiability of positive results may unnecessarily worry some patients. Nevertheless, none of the injectors in this study who were told about notifiability for the first time in the research process were inappropriately concerned about it, nor did any of them feel that if they had been told in the testing process it would have discouraged them from being tested. Indeed, some were indignant that they had not been told, indicating that it felt as if health authorities had something to hide.

These matters are best resolved in pre-test discussions between a patient and a TSP who have a good relationship. If the injector is unwilling to give consent to a medical procedure because they do not trust their health professional, referral to an alternative test provider should be considered.

### **Giving Test Results**

The majority of TSPs in this study gave all BBV test results in person, and the majority of injectors received their last results in person. Nevertheless, it is disappointing to note that, despite very clear Guidelines to the contrary, some TSPs gave hepatitis results over the phone, and/or felt that negative results did not warrant return visits.

This goes to the heart of whether a BBV test with an injector is solely a medical intervention, designed to diagnose an infection which, if it is present, can be treated, or whether it is also an effective brief psychosocial intervention to prevent infection. The NHMRC Guidelines make it clear that it should be considered as the latter. We will return to this point later.

There was strong support in this study for the practice of making the follow-up appointment at the pre-test appointment. This obviates the necessity for the medical practice to ring the patient to make a follow-up appointment, with all the anxiety that may engender. Moreover it makes it abundantly clear to the injector that they should expect post-test discussion, whatever the test result. With that expectation, they are more likely to be willing to participate in effective post-test discussions of both negative and positive results.

### **Follow-up with Positive Results**

The discussion of medical options following positive test results is obviously an important consideration, but post-test discussion after a positive result should be more than a medical intervention. Some TSPs may underestimate how devastating a positive hepatitis test result can be. Injectors in both this study and our earlier research graphically demonstrated that a positive result could feel at first like a death sentence. Given this, and the need to intervene both medically, and behaviourally to prevent

further transmission, we strongly recommend that whenever resources allow and the patient is willing, the TSP should schedule a second appointment after a positive result, and devote the first appointment to giving support and reassurance. Moreover, patients should be encouraged to bring their own support people with them to collect results. Referral to other support service such as hepatitis C councils should, wherever possible, be made.

The readiness to refer to other agencies when one cannot provide a service oneself is a fundamental element of clinical practice across many disciplines. Referral does not necessarily mean giving up on a relationship with a client in order to send them off somewhere else: indeed many clinicians note that it can be just as hard to initiate and resource an appropriate referral as it is to provide a service oneself. Clearly, one needs to know who is available as referral sources, how these can be accessed and what they can offer. Good use can be made of the referral sources available to TSPs such as community based drug users' groups and hepatitis C councils. The question of the ability of organisations such as these to support referrals is, however, one that they will have to resolve in consultation with the medical community.

#### **PRE- AND POST-TEST 'COUNSELLING'**

We have used the term 'counselling' consistently through the research and in this report<sup>4</sup>, because it is the standard term that was first used to refer to pre- and post-testing discussion for HIV/AIDS tests and continues to be applied to hepatitis testing.

It may not, however, be the most appropriate term. In our first study we found some confusion on the part of injectors between pre- and post-test 'counselling' and therapeutic counselling and that confusion was also evident in the present study. Of more significance, perhaps, is whether this is the appropriate term to use for interactions which may not seem to either party to be so much counselling as discussion and negotiation.

The recent Draft National Hepatitis C Testing Policy (2001) recommends the term 'test discussion' for the pre-test session because the term counselling is not broad

enough to encompass the various elements: assessment of risk, obtaining of informed consent, arranging follow-up and identification of referral needs. We would concur with this view, but propose that this session be defined as 'pre-test discussion' so that patients are aware that all of this would take place before the test is undertaken. The Draft National Hepatitis C Testing Policy uses the term 'post-test counselling' for all post-test interventions, both for negative and positive tests; again, we feel that 'counselling' is not a broad enough term to cover the elements that will be broached. 'Post-test discussion' is a better descriptor.

Use of the terms 'pre- and post-test discussions' should thus reduce confusion, more accurately reflect the focus of these sessions, and may also defuse any concern or anxiety on the part of either party as to what might be expected from 'counselling'.

The issue of whether or not TSPs have enough time to follow the testing guidelines is one that was raised a number of times by both injectors and TSPs themselves. If the proposed guidelines were followed, a number of discussions would be shorter than they would be with the current NHMRC Guidelines, because some discussion topics would be negotiated and might be omitted.

Finally, we can only reiterate what we have said before. Blood borne virus testing with injectors is an important opportunity for brief interventions to reduce risk to individuals and the community. TSPs who feel unable to offer complete pre- and post-test discussions because of lack of time, should discuss this with their injector patients and negotiate what can be undertaken.

## **IMPLEMENTATION ISSUES**

Our research demonstrates that implementation is a concern: test service providers are busy people who are bombarded with invitations to training exercises, and sent extraordinary amounts of paper resources to consider. Nevertheless, these or any other guidelines will not be effective unless TSPs are aware of them and receive some support in their implementation. How this is to be undertaken will be a matter for medical organisations to determine. Clearly some TSPs, perhaps particularly those in

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<sup>4</sup> Other than in the proposed guidelines

rural and regional areas, will need extra support. It appears that the form of the guidelines – paper, internet, CD etc – may be less important than the usefulness of the guidelines and the preparedness to use them.

A further strategy would be to inform injectors about what they could expect when they request BBV testing. We found that the majority of our injector respondents did not know that guidelines for pre- and post-test counselling existed, and many were impressed with the scope of these when they were so informed. Material which explains the guidelines could be prepared, and made available through the various community based and medical services with which injectors have contact. That way, many injectors could be well prepared for their test: might understand that a BBV test was more than a quick check, and might be more willing to work together with their TSP to negotiate a testing process which was most suited to their individual needs. A checklist for injectors to remind them which questions they should ask their TSP could be appended to those materials. TSPs could have a Frequently Asked Questions list attached to the guidelines to remind them of the issues that are likely to be of most concern to injectors.

The availability and appropriateness of materials which have been translated into other languages and about the provision of information for people with low literacy levels was a more general concern. This is an issue which warrants further attention.

## **SPECIFIC RECOMMENDATIONS**

While most of our recommendations are contained in the proposed guidelines, and the issues discussed above, there are a few specific tasks which we believe should be undertaken:

1. It was suggested that the proposed guidelines should be written as action statements, with an additional checklist of exemplars to which TSPs could refer. This seems like an excellent suggestion, but we believe it could best be undertaken by people with medical qualifications who have full understanding of clinical issues.

2. We have suggested that a manual or brochure for injectors should be developed: this, again, would best be undertaken by peers who understand the particular issues that confront injectors.
3. Sensitivity about phlebotomy has emerged as a somewhat unexpected concern in this study. We recommend that this issue be raised with TSPs in discussions and written material relating to the guidelines.
4. Rates of hepatitis B vaccination apparently increased between the first and second studies in this series. This appears to relate to the greater availability of free vaccine in WA, and the commencement of a free vaccination program at WASUA. Cost is one of the major barriers to vaccination - we recommend that States and Territories consider how they can best offer free vaccination to at-risk populations like drug injectors until universal vaccination programs take effect in the community.

## CONCLUSION

As we noted in the Introduction, hepatitis testing can be used to assist those tested to become aware of the extent of the epidemics, the prognosis of infection, and the realistic likelihood of becoming infected, reflect upon their risk behaviour, and develop strategies to minimise it, thus reducing the risk of infection. Our research generally supports this contention. BBV testing of injectors can be a good opportunity for prevention but it does not automatically follow that it *will* be, or that it currently is. Since the majority of injectors are tested at some point and many have multiple tests and often have multiple contacts with TSPs, testing is an excellent opportunity for brief interventions with a large number of at risk people.

With a clear statement of the value of appropriate pre- and post-test discussions, injectors and TSPs will find the testing experience valuable. The best testing experiences will undoubtedly be those that emerge from a relationship of rapport and mutual respect between the injector and his/her TSP. These relationships will not always be easy to develop, but our research shows that they exist and can be developed.

It is axiomatic, however, that a test event is a not only a medical but also a psychosocial intervention to prevent risk behaviour. Both injectors and TSPs need to

have the expectation that a test event is an opportunity for them to discuss why the injector could be infected and how further risk to the individual and the community could be avoided.

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**APPENDIX I – CONSULTANTS**



<b>Consultants to the Study</b>	
<b>WA Substance Users' Association</b>	Ms. Janet Bradbury
	Mr. Justin Woodruff
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<b>Dr. Lewis Marshall</b> (public health physician)	



**APPENDIX II – INTERVIEW GUIDES**