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Presenter: Skye Jewell, Education Project Officer

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Title: Testing and Diagnosis: Injecting Drug User Experience
Compared to National Policy.

My name is Skye Jewell; I work as an Education Project Officer at AIVL, the Australian Injecting & Illicit Drug Users League. For those of you who may not be familiar with AIVL, AIVL is the national peak organisation for the State and Territory Drug User Organisations and represents issues of national significance for injecting and illicit drug users. You heard from our Executive Officer, Annie Madden at the opening ceremony.

Today I am looking at "The National Hepatitis C Testing Policy" released in August 2003 from the Australian National Council on AIDS, Hepatitis C and Related Diseases (or ANCAHRD). Specifically I will look at the guiding principles on Hepatitis C Testing and how this compares to the experiences of injecting drug users (or IDU's).

I have drawn from the data in The C-Change Report of the enquiry into hepatitis C related discrimination, put out by The Anti Discrimination Board of New South Wales, in November 2001.

I obtained the personal quotes used in this paper from injecting drug users, via our member organisations and their networks of peers, and from my own colleagues and IDU peers who've experienced the Australian Hep C testing process.

Firstly I will go through what the guiding principles are, the implications of these guidelines and what this translates to in practice. I will finish up by presenting some recommendations on how the testing process can be improved to better meet the health needs of injecting drug users.

The Guiding Principles for Hepatitis C Testing are that:

1. Testing is voluntary and should be accompanied by test discussion, post-test counselling and specific informed consent.
2. Testing should be of benefit, either directly or indirectly, to the person being tested.
3. Test results should remain confidential at the clinical level, in data management, and during the notification process.
4. Testing should be accessible to all who are or have been at risk of infection.
5. Appropriate standards must be applied by laboratories carrying out testing, to ensure a high level of accuracy in test results.
6. People with hepatitis C infection should have access to continued monitoring of their health status and to appropriate treatment.
7. Testing and notification are critical to determine the extent and location of hepatitis C infection in the community.

The Implications of these principles:

The following points amplify the guiding principles:

- *Test discussion and post-test counselling.* Appropriate test discussion and post-test counselling should be an integral part of all: voluntary, mandatory and compulsory

testing. People with antibody-positive results will need continuing support and information, which may involve referral to community agencies such as hepatitis C councils and drug user organisations.

Overall people experience a range of levels of pre and post test counselling. It seems to be a common misconception that post test counselling is only necessary if you get a positive result. This doesn't take into consideration that if someone has a negative result, they may then need to be told how to keep themselves safe. So depending on their risks, the doctor or health care worker needs to go through safer injecting practices or refer them to a drug user group for this information.

Here's an anonymous quote from a young male injecting drug user who works in this area in Victoria:

*"I have been tested (for Hep C) a number of times, the virus has **not** been detected and I have received close to **nothing** in the way of harm reduction information and **nothing** in terms of pre-test counselling. I personally didn't mind this, because I feel readily equipped, but I shudder to think what else goes on."*

Pre and post test counselling can be particularly overlooked when it is undertaken within another service, for example at detox, rehabilitation services, entering goal etc.

This is an anonymous quote from a worker at a HCV/HIV service in Tasmania:

"Very little, if any pre and post test counselling takes place (here in Tasmania) especially if they were tested whilst in detox."

- *Informed consent.* Particular care should be taken to obtain specific informed consent from marginalised groups. The process of obtaining that consent may need to take account of cultural and language barriers and matters associated with discrimination.

In regard to informed consent, most GP's and other health care workers seem to have an understanding of this and mostly do get informed consent before testing for Hep C. However, again where it can break down is when the person is entering a rehabilitation or treatment service, and they are asked to provide a blood test. Often this test is optional but at times it is implied that if you say no to the test you won't get your treatment etc.

The timing of these tests is very important in this way, obviously when someone is trying to get on the methadone program for instance and they're hanging out for drugs, they're likely to agree to do any sort of test in order to get their dose of methadone. It would be preferable to get the person sorted with their methadone first and then possibly in a few weeks get the person to come back for a pre test discussion, and then once 'informed consent' has been given, carry out the required blood tests.

Also, when people go for operations or other medical procedures, this can be when their Hep C status can come up without informed consent. For example:

Quote: *"Recently I had me gall bladder removed, as I was about to go into surgery the surgeon told me I was Hep C positive, then I was put under. At the time I thought this was an inappropriate time to be telling someone this. I did not know they were testing me for Hep C"* Anonymous (49 year old injecting drug user from South Australia).

- *Confidentiality.* If people who have been tested or are contemplating testing are to have confidence in the health system it is essential that adequate mechanisms exist to ensure the confidentiality of test results at all levels—clinical, data management, and the notification process. People who are considering testing are entitled to be told about how notification to health authorities of confirmed positive tests results occurs and the confidentiality safeguards that apply.

Confidentiality is a real issue, particularly in health care settings. Often people feel obliged to tell professionals like dentists their Hepatitis status, but when the consequences of disclosing their status are traumatic this can result in the person not seeking medical treatment.

People have had their positive status disclosed in a variety of ways at hospitals. Often the patient has a large obvious label placed on their file or even their bedpost stating things like "Hazard - Hep C Positive." In one instance where a woman and her baby were labelled inappropriately in this manner, when she complained she was told "It doesn't matter, you are a drug user, so everyone knows you are Hep C positive anyway."

This is an anonymous quote from an injecting drug user in Sydney, NSW: *"the last liver biopsy I had the nurse did my assessment on the ward with the other patients around. She asked me personal questions like 'how did I get Hep C' and when did I last use (drugs)."*

- *Access.* People who have been at risk of exposure to hepatitis C infection should have ready access to testing. Where barriers to testing exist—especially for marginalised groups—special provisions may need to be made to facilitate

access. Funding arrangements should be such that the cost of testing does not discourage people at risk of infection from being tested.

The issue of access is very important; especially within the context of many general practices no longer bulk billing patients. Although more and more drug user organisations are picking up the slack by providing access to doctors and testing facilities, there's still a significant gap that exists.

Given that injecting drug users are the 'at risk' people that really need to monitor their Hepatitis status, along with other blood borne viruses, it's important to note that many of this target group do not have the funds to have to pay up front for a consult in order to get access to Hep C testing.

At times injecting drug users are being tested for Hep C within services where HIV or other issues are their primary focus. This can lead to the person only getting adequate information about HIV.

"Because my HIV results came back negative, counselling was not re-offered even though my HCV results were positive...While the nurse was taking my bloods, she mentioned the reason for and importance of counselling and also offered me pamphlets about HIV but not HCV until I asked for some info..." This is an anonymous quote from an injecting drug using member from NUAA, our member organisation in NSW.

- *Anonymous testing.* To facilitate access for people who might be reluctant to seek hepatitis C testing, anonymous testing should be available from a number of health care settings in each jurisdiction.

There are some services now offering anonymous testing, although at times it is limited to certain target groups like youth etc. This can be an issue particularly for young people because they often need to provide a Medicare number.

Some young people are still listed on their parent's Medicare card. This will then show up if their parents' request reports on where and when their Medicare card is used. Therefore it is necessary to ensure a service is totally anonymous, that it doesn't rely on Medicare.

This also comes up under the issue of testing in prisons and within mandatory testing. There have reported cases where Hep C blood tests are given by a nurse when the results are negative and by a doctor if they're positive, to allow for post test counselling etc. This is obviously a flawed system, in that it's obvious who's Hep C positive to all prisoners and guards watching when the doctor comes calling.

- *Monitoring and treatment.* Continuous monitoring of their health status should be available to all people infected with hepatitis C, with assessment for treatment occurring in accordance with current eligibility guidelines.

This aspect is also becoming difficult for many injecting drug users, within the diminishing bulk billing system. As many users don't always suffer symptoms from their Hep C, it's easy for it to slip off the agenda. However, doctors need to regularly monitor their liver function and for those who are in need of treatment and who meet the criteria for treatment, talk to them about their treatment options.

In most states and territories in Australia, there are specialist liver clinics. This is where the 'shared care' approach needs to be implemented.

Here's an anonymous quote from a worker at a combined HCV and HIV service in Tasmania:

"Down here in Tassie, not a lot of G.P's are offering PCR testing to those who have been antibody positive for over 12 months, some are not even aware of clearing the virus, or what PCR testing means. Others have been telling people after normal liver function tests that their Hep C is now 'dormant'..."

There are several other implications mentioned in the National Hepatitis C Testing Policy that I have chosen not to go into today due to time constraints.

I'd just like to wrap up now by highlighting some recommendations for improving the testing process. There are many more recommendations also mentioned in the report, which highlight some important issues.

AIVL Recommends:

- That all drug and alcohol treatment services doing Hep C testing, have clear policies to guide their staff in informed consent, ensuring the timing is appropriate (as I mentioned earlier), and that pre test discussion and post test counselling occurs every time and no assumptions are made of anyone's understanding of Hep C and transmission.
- To continue to conduct and encourage health care professionals to attend education training programs about Hepatitis C testing. In particular, these programs should be designed to develop professionals' skills in undertaking exposure assessments of drug use and should

encourage appropriate attitudes to people who inject illicit drugs.

- To ensure **no** results of blood tests are **ever** given over the phone. Alarming many people are still given test results over the phone. This leaves the person very vulnerable, with nowhere to turn for reassurance or just simply information about what it actually means to have a positive result. As Annie mentioned in her opening speech, this is particularly an issue for young people who have reported feeling suicidal after a positive result notification.
- More funding is needed to do **free, anonymous, easily accessible, and non-judgemental Hepatitis C testing.**

I'd just like to finish up today by saying that the key message here is that these recommendations are all very well on paper, but what we need to do is seriously adopt these and put them into practice on the ground.

I will finish with a quote, from an injecting drug user in the Northern Territory:

"...The result was negative. I didn't get pre or post test counselling – I thought that was just something they wrote in policy papers to keep people like you and me happy. I have never heard of it being done for Hepatitis C."