

## "My blood is always dark red": Research Reportback Forum and Hepatitis C Health Promotion Plan Discussion

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**“dark  
My blood is always red”**

**Research Reportback Forum and Hepatitis C  
Health Promotion Plan Discussion**

**REPORT**

National Centre in HIV Social Research  
University of New South Wales

**JULY 2003**

# **“dark My blood is always red”**

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## Acknowledgements and thanks

Thank you to all who participated in this evaluation for providing such candid and open responses.

### Steering committee

Norman Booker  
Catriona Elek  
Ronald Govers  
Stuart Loveday  
Susan McGuckin  
Chris Shipway  
Sharon Valks  
Rob Wilkins  
Carla Treloar

### Funders

NSW Health

### Rapporteurs

Trish Bullen  
Gary Gahan

### Facilitator

Aldo Spina

## 1 Introduction

The National Centre in HIV Social Research (NCHSR), in partnership with The Hepatitis C Council of NSW and the NSW Users and AIDS Association hosted a two day forum, for hepatitis C health promotion and education workers from across NSW. The forum was funded by NSW Health.

The forum served the dual purpose of disseminating and discussing key research findings in relation to the prevention of blood borne viruses among injecting drug users, and reviewing this information with regard to the development of the NSW Health Hepatitis C Health Promotion Plan.

A steering committee oversaw the development and implementation of the forum. The committee consisted of representatives from:

- AIDS Council of NSW (ACON);
- AIDS/Infectious Diseases Branch, NSW Department of Health;
- Drug Programs Bureau, NSW Department of Health
- Hepatitis C Council of NSW;
- National Centre in HIV Social Research (NCHSR);
- NSW Users and AIDS Association; and
- Workforce Development Program.

The Centre for Health Promotion at the Department of Health were invited participate in the steering committee but were unable to do so.

Invitations were forwarded to hepatitis C Coordinators at all 17 area health services, Corrections Health and to a number of other targeted government services requesting that they nominate two individuals to attend the forum. All hepatitis C related non-government organisations were also sent invitation letters. In addition members of the steering committee, and the organisations they represented, were invited and also asked to nominate any other staff within their organisations who should be invited to attend.

The travel and accommodation costs of attendees from outside of Sydney were covered by the forum organisers. Participants were not required to pay a registration fee.

All invited participants were requested to bring to the forum a selection of materials or strategies which they routinely use in their work. These resources were utilised on the first day (see agenda).

The forum was held in Sydney on 6 and 7 May, 2003 at the University of NSW, and was facilitated by Aldo Spina.

### Forum aims

The aims of the forum were to:

- disseminate findings of the “Blood Awareness” project;
- initiate discussion of emerging hepatitis C prevention messages for both primary and secondary prevention;
- to provide a forum for networking among key government and non-government groups in hepatitis C prevention;
- contribute to the development of the NSW Hepatitis C Health Promotion Strategy; and
- document this process for wider distribution.

### Attendance

Over 90 people registered to attend the forum. A variety of organisations and workplaces were represented. The appendix includes a full list of attendees.

## Evaluation

All forum participants were provided with an information kit upon arrival. Included within the kit was an evaluation form. The evaluation form invited participants to provide their name and contact details to the forum organisers if they wished to participate in an approximately 20 minute telephone interview a few weeks after the forum. The evaluation aims to discuss the potential impact of the forum on activities, and was conducted by an NCHSR staff member not directly involved with the project.

### Report

This report includes:

- forum agenda;
- summary of key issues that emerged;
- powerpoint presentations;
- outcomes from small group discussions; and
- list of attendees.

## 2 Agenda

### Tuesday May 6

<b>1</b>	9.00am	Welcome, Review Aims Relating Research, Practice, Policy Expectations	Aldo Spina
<b>2</b>	9.20	Overview Of Hepatitis C Epidemiology In Australia	Matthew Law
<b>3</b>	9.45	Qualitative Research – Brief Introduction	Carla Treloar
<b>4</b>	10.00	Qualitative Research – Example	Aldo Spina
	10.30	Morning Tea	
<b>5</b>	11.00	Present Research Discuss hypotheses emerging from research about new, alternative messages and strategies for delivering prevention education.	Carla Treloar
	12.30	Lunch	
<b>6</b>	1.30	Research and education Small group work	Aldo Spina
	2.45	Afternoon tea	
<b>7</b>	3.15	Panel – Considering Diversity 3 Speakers to present (1) their work (2) reflect on research results and implications for education	Tadgh McMahon, Rosemaree Dowling, Annette Slater
<b>8</b>	4.30	Feedback from Rapporteurs on session 6 and comments from the floor	Trish Bullen Gary Gahan
	5.15	Close	

### Wednesday May 7

<b>9</b>	9.00	Recap day 1, setting agenda for day 2	Aldo Spina
<b>10</b>	9.15	Health Promotion Forum – policy, examples, moving from education to strategy	John Wiggers
	10.30	Morning tea	
<b>11</b>	11.00	Research and health promotion Small group work	Aldo Spina
	12.00	Lunch	
<b>12</b>	1.00	Introduction To Hepatitis C Health Promotion Plan	Ronald Govers
<b>13</b>	1.20	Reviewing health promotion plan Small group work	Aldo Spina
	2.20	Afternoon Tea	
<b>14</b>	2.40	Aspects Of Prevention Practice, Research Or Policy Not Previously Mentioned	Aldo Spina
<b>15</b>	3.00	Rapporteurs' report from session 11 and 13 and comments form the floor	Trish Bullen Gary Gahan
	4.00	Close	

#### Presenters, rapporteurs, facilitators:

**Trish Bullen** Macquarie Area Health Service  
**Rosemaree Dowling** New England Area Health Service  
**Gary Gahan** Northern Sydney Area Health Service  
**Ronald Govers** AIDS and Infectious Diseases Branch,  
 NSW Health  
**Matthew Law** National Centre in HIV Epidemiology  
 and Clinical Research, UNSW

**Tadgh McMahon** NSW Multicultural HIV/AIDS  
 & Hepatitis C Service  
**Annette Slater** New England Area Health Service  
**Aldo Spina** Aldo Spina Consultancy  
**Carla Treloar** National Centre in HIV Social Research, UNSW  
**John Wiggers** Hunter Centre for Health Advancement,  
 Hunter Area Health Service



### 3 Key issues emerging from group discussions

At the end of each day, the rapporteurs presented a summary of their impressions of some of the key issues that had arisen during small group discussion.

Below is a summary of their end of day presentations and of the notes they made of the group discussions that occurred during sessions 6, 11 and 13.

#### Session 6: Research and education

The following questions were discussed in small groups:

- Select an 'idea for intervention' you would like to discuss further;
- Select a resource to examine; and
- Select an education activity to examine.

Then

- How is the 'idea for intervention' currently related to the activity being examined? and
- How might the resource be changed in light of the 'idea for intervention'?

#### Session 6: Rapporteur summary

##### *General feedback*

There was great value in having many hepatitis C related practitioners in one room. The opportunity to network and meet other colleagues face-to-face was seen as invaluable.

The presentation on qualitative research was seen as providing a useful introduction on the limitations and value of both quantitative and qualitative methods, particularly as it didn't assume that all practitioners have a detailed understanding of research. The presentation helped promote common ground and understanding between researchers and practitioners about research methods.

##### *Small group discussion on research and education*

The small groups were asked to discuss the 'ideas for intervention' and then examine how the idea might apply to an existing hepatitis C education resource. The groups found this to be a difficult and challenging task, and some felt that they needed more time to undertake the task. Others felt they hit a brick wall in their discussion, while others felt their groups generated great ideas.

In undertaking the task many questions arose about the education resources that are produced and the messages they contain. Some of the questions included:

- who are we targeting?
- what are we trying to change?
- will the resource work in isolation? (to which there was a strong *no*); and
- does everyone see/read/hear/perceive the same message?

Can one resource be expected to cover the needs of different audiences, and particularly those from different cultures? This raised further questions about the skills of health practitioners to undertake social marketing/advertising. Are we actually good at it? Perhaps we need to explore partnerships with private sector advertisers and social marketers.

There was discussion about the negative aspects of many of the current education resources and messages. There was discussion about the negative and scary messages that many convey and how the subtext is that you are a 'bad' person if you don't do things safely. There was a perception that many resources are aimed at individuals despite the fact risk behaviour occurs in pairs or groups – 'sharing' means that at least two people are involved.

While the groups were examining education resources broader questions were raised about the need to *not* see resources as stand alone activities. For example resources should be seen as a useful tool for peer education or more in-depth discussion.

Health education also needs to be placed in the broader context of health promotion. An important component of this discussion was acknowledging that individuals do not necessarily have complete control over all aspects of their well-being. For example individuals don't have control over policing of illicit drug use, they don't have control over where an NSP is located or its opening hours, they don't have control over the behaviour of their tattooist. It was felt that the focus on individuals often leads to individuals being 'blamed' for becoming infected rather than acknowledging the other factors that may impact on their health over which they have no control.

A number of groups examined the issue of mindlessness versus mindfulness. It was considered a challenge to intervene in behaviour that is automatic or carried about by habit. Groups discussed the need to change strategies to target specific groups, for example at the point of initiation. They also talked about recognising the complex confounders of the process is not just about equipment but where, who with, when, etc. It was noted that factors that may influence mindfulness are literacy levels and optimism.

The mindfulness discussion raised questions about self awareness. The disparity between actual practices and what people perceive or report as their behaviour. How does substance use and intoxication impact upon insight and self-awareness when injecting?

Discussion of 'ideas for intervention' led to some groups examining blood messages. There was a sense that the current blood message is that blood is taboo, stay away from it, it's life-threatening. The research indicated that greater emphasis could be placed on blood as a life-force and as something that is universal and positive: 'blood is good'.

Discussion of the 'ideas for intervention' also led to talk about complex messages versus simple messages, reflection versus direction, and conditional messages versus non-conditional messages. These questions then raised the issue of whether some drug users, for example cocaine users, would want and be able to retain more directional messages rather than conditional messages. The question was also posed about what can be learnt from the HIV health promotion experience where some of these same questions have been debated.

The discussion about hepatitis C messages led some to discuss whether we are assuming education messages have failed. Is it simplistic to believe that the messages have failed or that health workers have missed the mark?

#### Session 11: Research and health promotion

The following questions were discussed in small groups:

- How might the 'ideas for intervention' inform health promotion activities? Think about all areas of health promotion action; and
- How might such activities be supported (eg. workforce development, partnerships)?

#### Session 11: Rapporteur summary

Collaboration and partnerships were emphasised as an important part of hepatitis C health promotion throughout the two days. So too was consumer involvement, though many felt it shouldn't just be lip-service but based on a genuine two-way communication process between workers and consumers.

Theory needs to inform practice. The importance of the Ottawa Charter for Health was emphasised and the need to focus on a broad range of actions and not just education.

Public policy/NSP, prison, drug reform were seen as important as were social isolation and mental health issues. Addressing environmental and social contexts was seen as very relevant.

At the same time it was noted that we need to be aware of our limitations. What do we **need** to get across! We can't necessarily do everything. We need to be brave and address some tough issues such as reform of drug laws. We need to refocus school based education and incorporate skin integrity and blood awareness into education curriculum. Blood needs to be normalised.

Health promotion always emphasises equity. Equity was seen as an important issue that should underpin our work. Access and equity issues were raised in relation to rural and regional areas. A question was posed as to whether health promotion was middle class and relevant to particular sub-populations? There was discussion about the involvement of Aboriginal and Torres Strait Islanders in research and practice. This opened an important, useful and challenging conversation about 'special communities' but highlighted the lack of suitable forums in which these issues could be explored in a more comprehensive way.

There was discussion on the balance between being outcome based or process focused. Some felt we need to focus more on process and not just outcomes, others stated we should be more outcome focused. We need to do both. For some it was important that 'engagement' – with consumers, partners, stakeholders – was incorporated into the planning process.

Peer involvement has been an important approach to working with drug users. For some it was a sustainability issue due to the often tenuous nature of 'peer', others thought that complex health promotion/education issues need to be addressed beyond the notion of individual 'peer'. How do we introduce information into the system and among peers? What are the vectors of information?

As in previous sessions the issue of developing education resources arose and the need to work with professional advertising people and develop visual messages that are effective for people with low literacy or from non-English speaking backgrounds. Are our resources saturated with 'health speak'?

A suggestion was put forward on the need for a database that allowed access to critical project reports on what health promotion activities have worked and which ones haven't, and that also includes an outline of resources have been developed and what resources are currently being developed. Another suggestion was on the need for best practice guidelines to be developed and disseminated.

The difficulties of adopting a whole of health sector approach were also discussed, particularly when training in all social issues for many health care professionals might be no more than a four hour session. That makes it hard to tackle stigma and discrimination against drug users and people with hepatitis C.

For some there was a need to learn from other sectors, and not just those working in health, the example of Department of Community Services was mentioned.

Health education and health promotion needs to be creative. We should use theatre, art, world wide web and we need to use the media more effectively. And we need a national patron to raise awareness of hepatitis C. Where is our hepatitis C poster boy or girl?

Resourcing is also an important priority. The need for a national bi-partisan approach and the need to ensure hepatitis C prevention funding in all area health services was a priority.

Finally there is an ongoing need to be responsive to the changing drug scene. Should we be attempting to address current levels of injecting? Are we as health professionals really in touch with drug scenes?

### Session 13: Reviewing health promotion plan

The following questions were discussed in small groups:

Priority issues and infrastructure:

- Are there other key issues/challenges that should be identified?

Then for priority issues listed:

- What should be achieved?
- How should this be achieved? and
- Who should achieve it?

### Session 13: Rapporteur summary

The plan needs to embrace and articulate a health promotion framework. The suggestion was made that chapters could be broken up using Ottawa Charter headings.

As mentioned in other sessions, the plan needs to place an emphasis on partnerships, collaboration and a whole-of-government approach. It should look towards developing partnerships with services that we haven't traditionally worked with. Examples put forward included early childhood services, Family First initiative, First Step, health promotion. It should also look at raising the profile of some partnerships, particularly with drug and alcohol services. The development of partnerships should lead to solid outcomes such as police not interfering with NSP/Methadone Program.

The development of the plan needs to involve real community participation.

In identifying target groups, the plan needs to recognise not just traditional groups such as people from a non-English speaking background and Aboriginal and Torres Strait Islanders, but should target *different* cultures that exist among injecting drug users. For example there are differences between Moree vs. Tamworth, Leichhardt vs. Penrith. It was felt an important target group was pre-initiates to injecting drug use. The plan should endorse targeted education of injecting drug users.

Addressing discrimination and acting on the C-Change report should be an important part of the plan. Addressing broader issues such as housing and relationships needs to be considered as they also impact on the health of people with hepatitis C.

The plan needs to endorse evidence-based grass-roots approaches and build on existing infrastructure such as heplink and workforce development.

Some other important components include:

- looking at specialist bodies and their vested interest/knowledge base/imposing restrictions (eg. funereal/forensic);
- expanding role of NSPs;
- expanding role of GPs;
- involving families and other support networks;
- reintroducing methadone injecting equipment; and
- developing a comprehensive media strategy.

Apart from developing a good plan, a good dissemination and implementation strategy must be developed. And the plan should have a purple cover!

## 4 Presentations

### 4.1 Overview of hepatitis C epidemiology in Australia – Matthew Law, NCHECR

#### Slide 1: Estimates and projections of the hepatitis C epidemic in Australia

Matthew Law, National Centre in HIV Epidemiology and Clinical Research on behalf of the Hepatitis C Virus Projections Working Group

#### Slide 2: HCV Projections Working Group

Formed under the auspices of ANCAHRD Hepatitis C Subcommittee

**Chair:** Dr Alex Wodak

**Epidemiologists:** Dr Nick Crofts, Prof John Kaldor, Dr Greg Dore

**Clinicians:** Dr Paul Gow, Dr Elizabeth Powell

**Statisticians:** Dr Matthew Law

**Commonwealth:** Dr Jenean Spencer

**State/Territory:** Dr Sandra Thompson, Wendy Giles

**Hepatitis C Council NSW:** Stuart Loveday

**AIVL:** Nicky Bath

**Drug researcher:** Dr Kate Dolan

#### Slide 3: Epidemiology of HCV in Australia

Risk Factors

- 80–85% of HCV exposures through injecting drugs
- 5–10% through receipt of blood
- 7–13% sporadic

Notifications of newly acquired HCV since 1995

- 91% HCV exposures through injecting drugs

HCV prevalence in IDUs

- 50% to 70% since early 1970s

#### Slide 4: Epidemiology of HCV in Australia

HCV incidence in IDUs

- Around 15% since mid-1980s
- Some evidence of decline in late-1980s
- Continued incidence during 1990s

HCV prevalence in people aged less than 20 years attending NSPs (MacDonald et al)

- 32% in 1998, 44% in 2000

HCV incidence in people attending Kirketon Road Centre (Gilmour et al)

- ~15–20% per annum over 1992–2000

#### Slide 5: HCV notifications

~180,000 HCV notifications in Australia to end 2001

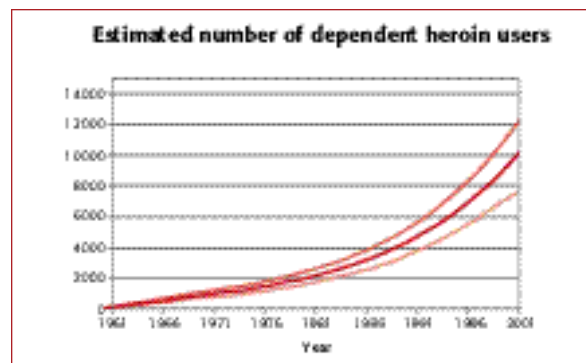
- 65% male
- 65% aged 20–39 years
- Around 20,000 new notifications annually
- ?duplicate reports between States

#### Slide 6: Modelling

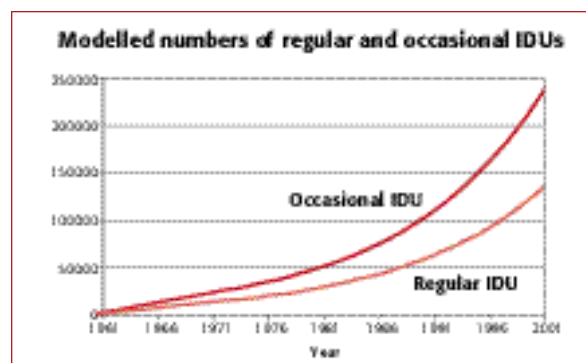
General approach:

- Base models on assumed pattern of injecting drug use
- Inflate estimates of HCV incidence for other risk group

#### Slide 7: Estimated number of dependent heroin users



#### Slide 8: Modelled numbers of regular and occasional IDUs

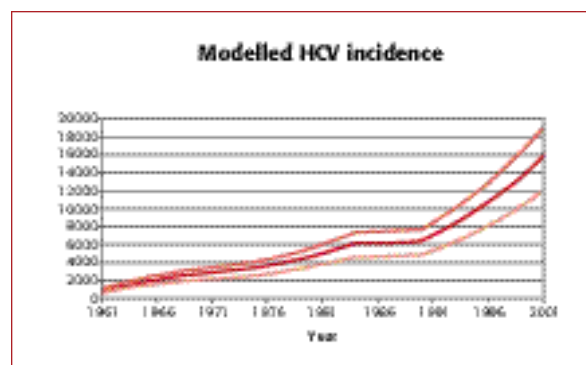


#### Slide 9: Modelling assumptions

HCV incidence in uninfected regular IDUs:

- 18% to 1985
- Linear decrease to 13% in 1989 and thereafter
- Incidence in occasional IDUs taken to be 20% of rates in regular IDUs
- 5% of IDUs cease injecting annually
- Mortality of IDUs is 1% per annum
- Mortality of former IDUs reverts to general population, with an average age at infection of 25 years
- Upper and lower limits on estimates based on upper and lower limits on numbers of IDUs

#### Slide 10: Modelled HCV incidence



#### Slide 11: Modelled estimates

- 210,000 (157,000 to 252,000) people living with HCV in Australia to end 2001
- 16,000 (11,000 to 19,000) new HCV infections during 2001

## Slide 12: Modelling progression rates

**Not chronic HCV** (25%)

**Chronic HCV, normal ALT** (25%)

**Chronic HCV, abnormal ALT** (25%)

**Chronic HCV, abnormal ALT** (25%)

**and further cofactors**

**Annual progression rates from:**  
**Stage 0/1 to Stage 2/3**      **Stage 2/3 to cirrhosis**

0%

0%

1%

1%

2%

2%

3%

3%

**Note:** Stage 0 = no hepatic fibrosis; Stage 1 = minimal hepatic fibrosis;  
 Stage 2 = moderate hepatic fibrosis; Stage 3 = severe hepatic fibrosis; Stage 4 = cirrhosis.

## Slide 13: Modelling progression

Rate of progression to cirrhosis in chronically HCV infected patients:

- 7% at 20 years following HCV infection
- 20% at 40 years

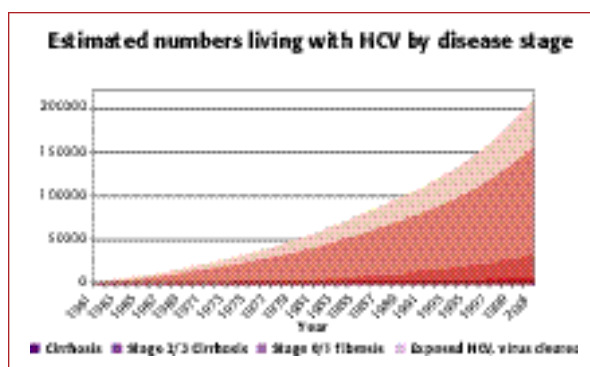
Consistent with recent systematic review by Freeman et al (2001)

- Liver failure taken to be 4% per annum following cirrhosis
- Hepatocellular carcinoma (HCC) 1% per annum
- HCV-related deaths 1.5% per annum

Composite indicator taken as simple average

- NSW = 39.7%
- HCV incidence in 2001 = 6,400
- 83,000 people living with HCV
- 20,000 people cleared HCV, 49,000 people with early liver disease, 11,000 moderate liver disease, 2,600 with cirrhosis

## Slide 14: Estimated numbers living with HCV by disease stage



## Slide 15: Estimated numbers living with HCV

These models estimate that, in 2001, of all people living with HCV:

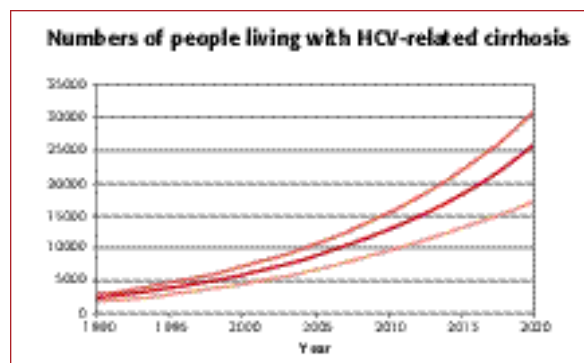
- 53,000 (39,000 to 64,000) had cleared infection
- 124,000 (92,000 to 149,000) had chronic HCV and stage 0/1 liver disease
- 27,000 (20,000 to 32,000) had chronic HCV and stage 2/3 liver disease
- 6,500 (5,000 to 8,000) were living with HCV-related cirrhosis
- 175 (130 to 210) people developed HCV-related liver failure
- 50 (40 to 60) HCV-related HCC
- To end 2001, there had been a total of 1,000 (750 to 1,200) HCV-related deaths

## Slide 16: Estimates by State

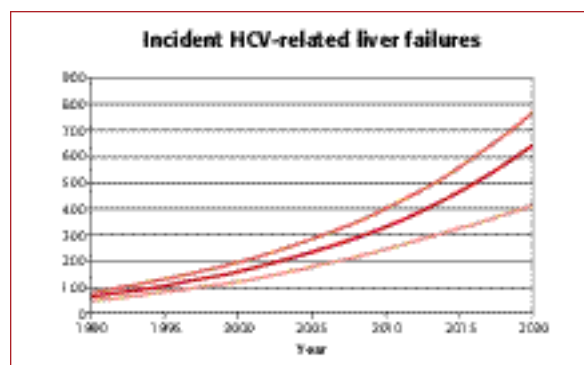
Three indicators of relative sizes used:

- HCV notifications 1995–2000 (CDHA, 2002)
- Opioid overdose deaths 1988–2000 (NDARC, 2002)
- Arrests for heroin, amphetamine or cocaine (ABCI, 2002)

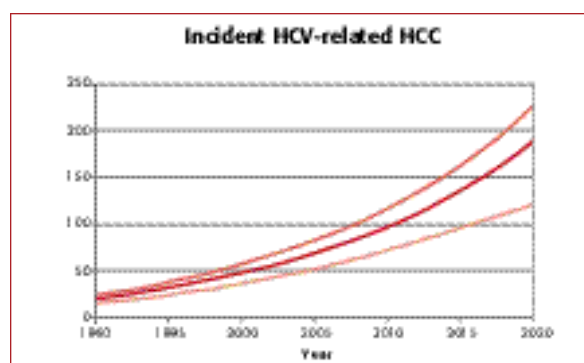
## Slide 17: Numbers of people living with HCV-related cirrhosis



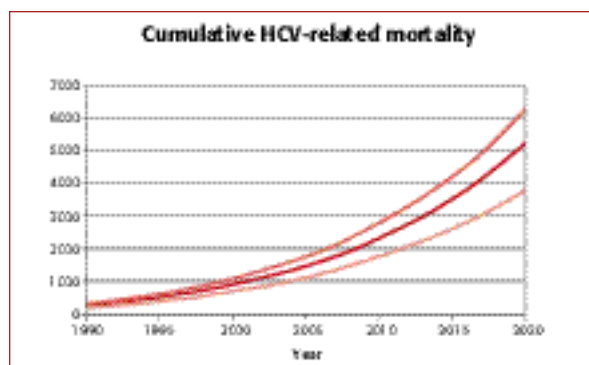
## Slide 18: Incident HCV-related liver failures



## Slide 19: Incident HCV-related HCC



## Slide 20: Cumulative HCV-related mortality



## Slide 21: Projections

Projecting HCV prevalence:

- If recent trends in injecting drug use continue, models estimate 836,000 people living with HCV in 2020
- If we assume injecting drug use remains at lower limit of 2001 levels, models estimate 321,000 people living with HCV in 2020

These scenarios reflect plausible upper and lower limits – truth likely to be in between HCV prevalence likely to be below this range in 2020 only if:

- HCV-vaccine becomes available
- HCV transmission among IDUs markedly reduced, possibly through anti-HCV treatment

## Slide 22: HCV quality of life adjustments

		Percent QALY	
Mild chronic	undiagnosed	40%	0.94
	diagnosed	60%	0.82
Moderate chronic	undiagnosed	25%	0.94
	diagnosed	75%	0.82
Compensated cirrhosis	undiagnosed	20%	0.84
	diagnosed	80%	0.74
Liver failure	diagnosed	100%	0.32
HCC	diagnosed	100%	0.10

## Slide 23: QALYs lost to HCV

	QALYs lost	
Mild chronic HCV	16,400	(12,100 to 19,600)
Moderate chronic HCV	4,000	(3,000 to 4,800)
Compensated cirrhosis	1,200	(900 to 1,500)
Liver failure	880	(680 to 1,100)
HCC	45	(35 to 55)
<b>Total</b>	<b>22,500</b>	<b>(17,000 to 27,000)</b>

## Slide 24: Summary

Models estimate that there were:

- 210,000 people in Australia at end of 2001 living with HCV, the majority with early stage disease
- 16,000 new HCV infections occurred in 2001
- NSW estimated to be 39.7% of national figures
- 6,500 people living with cirrhosis in 2001, 175 liver failures and 50 HCC
- 1,000 HCV-related deaths cumulative to end 2001
- 22,500 QALYs lost to HCV in 2001, 77% in people with stage 0/1 disease
- Long-term sequelae of HCV-infection – cirrhosis, liver failure, HCC – will at least triple by 2020

- If recent trends in injecting drug use continue there will be of the order of 500,000 people living with HCV in Australia by 2020

## Slide 25: Websites

Estimates and Projections of the Hepatitis C Virus Epidemic in Australia – Hepatitis C Virus Projections Working Group

<http://www.health.gov.au/pubhlth/publicat/hac.htm>

Returns on Investment in NSPs in Australia – DoHA

HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2002 – Ed NCHECR

<http://www.med.unsw.edu.au/nchechr>

## Notes



## 4.2 Qualitative Research – Carla Treloar, NCHSR

### Slide 1: Qualitative Research

Some introductory points ...

### Slide 2: Ways of knowing

- Counting                      Measuring
- Describing                    Observing
- Analysing                    Talking
- Reading

→ is there one right way of knowing?

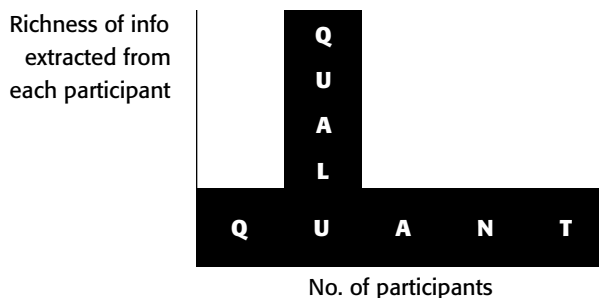
→ chosen for purpose?

### Slide 3: What type of inquiry?

Degree of imposition of constraints on possible outputs	High		Scientific Inquiry
	Low	Naturalistic Inquiry	
		<i>Ideal</i>	<i>Ideal</i>
		Low	High
Degree of imposition of constraints on antecedent variables			

### Slide 4: Qualitative research

- One type of naturalistic inquiry
- Not quantification
- "Flesh on numbers"
- Meaning, process, understanding
- Complexity and context
- "Vertical"



### Slide 5: Vertical vs horizontal approach

### Slide 6: Qualitative research

- Describe and analyse from point of view of those being studied
- Emphasise the comprehensive/holistic understanding of social settings
- Research strategy = flexible & interactive

### Slide 7: Purposes of qualitative research

- Illustrate phenomena being addressed in larger project
- Not fully investigated
- Theory building
- Unexplored, sensitive, personal experiences
- Within small, difficult to access groups
- Culturally defined experiences
- Perspectives which researcher does not share

### Slide 8: Qualitative research – the big questions

Are the findings

- Reliable?
- Valid?

Other terms/concepts

- Trustworthy
- Authentic
- Credible
- Transferable

### Slide 9: Validity – our approaches

- Homogeneous sample
- Do not generalise beyond limits of data
- Triangulation
- Data collector – who, what training, how involved
- Check transcripts for accuracy
- Check transcripts for interviewer style

### Slide 10: Reliability – our approaches

- Contact with other researchers/stakeholders
- Literature
- Record methodology
- 2/more people for analysis and interpretation
- Pilot test

### Slide 11: Examples

- How is information about reproductive decisions effected by translation process with CALD clients?  
Key informant interviews with translators working with several CALD communities
- What are influences on uptake of new medical technologies?  
Interviews with medical professionals, researchers, consumer groups, manufacturers, government, media

### Slide 12: Examples

- Barriers to progress: experiences of "mainstream", international and indigenous students in undergraduate medical program  
Focus group discussions with students
- What are the needs of GP-hospital liaison in a specific location?  
Focus groups with GPs, hospital medical staff, consumers

### Slide 13: Examples – mixed designs

- Why do first degree relatives of people with colorectal cancer not attend for screening?  
Surveys of relatives, focus group discussion  
→ intervention
- What are QoL experiences of men with prostate cancer?  
Focus groups, questionnaire → screening tool
- Why do interns not attend resident round training programs?  
Interviews, questionnaire → intervention

### 4.3 Research presentation – Carla Treloar, NCHSR

#### Slide 1: Hepatitis C Prevention Education

Feedback of Main Research Findings

#### Slide 2: Purpose in feedback of research findings

Often there is a gulf between research findings, practice and policy  
Lack of understanding of how each process works  
This forum – opportunity to look at new research findings, current practices and potential policy implications

#### Slide 3: Purpose in feedback of research findings

No one sector has all the answers  
Hepatitis C prevention education seems to have limited capacity to prevent infection  
? Existing messages provide only part of response needed  
Possible new strategies indicated by research  
Possible new structures to support implementation of new or “tweaked” prevention strategies

#### Slide 4: What we want to do

Present some of the main findings of our research  
Pose some suggestions for new, different ideas to prevention education

#### Slide 5: What we want to do as a group

Take a critical look at hepatitis C prevention education  
Ask: Are there ways we can improve existing messages, resources, strategies?  
Ask: Are there new ways to present these?  
Ask: What would we need to implement these improved or new messages etc?

#### Slide 6: How to do this?

Presentation of research and ideas for prevention education  
Discuss these ideas with reference to what is currently done  
Think about new, different prevention education  
Think about what is needed to support this

#### Slide 7: But wait, there’s more

Research doesn’t have all the answers  
Especially for marginalised people/groups  
Three people will talk about how they have considered these research findings in their own work:

1. Tadgh McMahon, NSW Multicultural HIV and Hepatitis C Service
2. Rosemaree Dowling, New England Area Health Service
3. Annette Slater, New England Area Health Service

#### Slide 8: What we don’t want to do

Annoy anybody  
Pretend that we have all the answers  
Make any personal statements or judgments about individual’s work

#### Slide 9: Background & General Aims

Research funded by NHMRC

Contribute to the development of HCV prevention and education through an assessment of the health promotional possibilities of “blood awareness”

Contribute to the prevention of other blood borne diseases ie. HIV/AIDS, other viral hepatitis

Provide a theorised account of the social meaning of blood for health promotion

#### Slide 10: Specific Aims

- to identify the **different ways** in which individuals and communities of individuals relate to their **own blood and the blood of others**
- to determine the extent to which **understandings of blood play a role in HCV transmission** and thus its prevention
- to produce a typology of the ways in which **blood can be characterised for effective health promotion**

#### Slide 11: Researchers

- Carla Treloar, NCHSR
- Suzanne Fraser, NCHSR
- Susan Kippax, NCHSR
- Marsha Rosengarten, University College London, UK
- Cathy Waldby, Brunel University UK
- Kylie Valentine, NCHSR

#### Slide 12: Associate Investigators

- Hung Yang, Australian Red Cross Blood Service
- Catriona Elek, Hepatitis C Council of NSW
- Chris Hardy, Thalassemia Centre of NSW
- Leola Farnell, Haemophilia Social Worker, RPAH
- Beth Harvey, AIVL
- Ingrid van Beek, Kirkeaton Road Centre
- Michael Flynn, Ambulance Service of NSW
- Maria Romaniw, TRAIDS

#### Slide 13: Background

- Avoid further stigmatising
  - Blood
  - People who use injecting drugs
  - People who have hepatitis C
- Reverse assumptions on difference
  - That IDU are different from other people
  - IDU at risk from blood as well as risk to others
- Reverse assumption of sameness
  - That all IDU have same experiences, perspectives and needs

#### Slide 14: Interview Schedule

- Broaden traditional research on IDU
- Focus on blood in numerous settings
  - Injecting, transfusion, donation, in daily life (accidents, shaving, menstruation, media)
- Emotions associated with blood
- Differences in perceptions, experiences, emotions and constructions of blood

### Slide 15: Methods

- Semi-structured interviews with
- 32 people who are current or ex injectors
- 6 people with thalassemia
- 7 people with haemophilia
- 11 people who have donated blood
- 13 people who have received blood transfusion
- 6 people who are ambulance officers
- 6 people have undertaken body modification

### Slide 16: Focus on target group

- 32 ex or current injectors
- Recruited from:
  - Hep C review
  - Private methadone clinic
  - NSPs
  - snowballing
- Male, female
- Hep C +

### Slide 17: Awareness of blood different times, situations

- Mid 1980s
  - “no sense of hygiene around blood”
  - Difficulty in accessing equipment
- Advent of HIV prevention messages
  - Awareness of safety increased
  - Not all changed straight away
  - “I didn’t change my practices until someone I knew got HIV, then I was more careful. Though if it ‘came to the crunch’ I’d still share.”

### Slide 18: Current practices 1

“Super safe” statements

“Yeah I would never use someone else’s fit. I would even, even if I’m in a place where I’m an hour and a half from my place, I prefer to run back to my place and actually tell them to have a shot there instead. And travel by cab or whatever, even if I don’t have enough money, just to go and get fits. Or run around anywhere.” (Lana)

### Slide 19: Current practices 2

“Improved safety” statements

After they became aware of risks

“better to wait and have a shot than lose your liver”

“safety compromise” statements

Compromise when “desperate”

### Slide 20: Current Practices 3

“Disregard” for safety

Less careful after hep C diagnosis

“I thought, ‘what’s the use?’” (Bugsy)

### Slide 21: Other safety concerns

Injecting in public

Urgency of injecting while in withdrawal

Doubts about physical safety if injecting alone

→ Encourage people “to cut corners and lose track of whose equipment is whose.” (David)

### Slide 22: Other impacts on safety

- Unable to find a vein → spilling a lot of blood
- Variation in awareness of risks of small amounts of blood
- Difficult to believe transmission in small amounts of blood

### Slide 23: Individual and interpersonal factors

Individual responsibility is paramount

“It’s just up to the person to actually do it, you can’t put brains into a statue.” (Christine)

Caring for others

Injecting others in difficulty

Reminding others to clean up

Giving new equipment to others

Not allowing others to reuse equipment

### Slide 24: Highly aware, but on automatic pilot

High level of awareness of blood safety messages

Blood becomes invisible

“I’ve been doing it for so long, its part of the procedure ... you get desensitised from it all. Most people just think of the whole thing. When you’ve been using drugs and that its something that you do every day, so you sort of switch off.” (David)

### Slide 25: Accidental Blood

- Concerned about risk but willing to assist
- Those without hep C:
  - their blood is “pure” and clean”
- Those with hep c:
  - “I have hep C, I don’t want anything else.”
- Stranger versus family
  - “You know where [family] have been.”

### Slide 26: Blood as life saving

- “Oh not it’s life sustaining. No matter which way you look at it. Whether it is diseased or not. Without it you are dead. It’s as simple as that. Don’t get me wrong. I’m diseased at the moment. I’ve got this virus running through me 24 hours a day. But it’s there. Without my blood I wouldn’t be here. So as far as I’m concerned it is essential to life, no matter where it is diseased or not. Put it this way, I’ve haven’t yet heard any medical report saying that blood is detrimental.” (Wolfe)
- Threat – own of structure or function in the blood as a threat to others

### Slide 27: Blood

- Changes with drug use or hep C infection
- “My blood is always dark red, a shade darker than it should be.” (Raymond)
- Described in mainly biomedical terms
- Non-biomedical ideas of blood – not apparent
- But little knowledge body functions of blood

### Slide 28: Blood & Emotions

- Strong emotions – not common
  - Imagining large volumes of blood
  - Different colours of blood
  - Injury
  - Imagining blood donation
  - feeling “queasy” when blood taken
- “dirtiness” of own blood because of hep C



### Slide 29: Blood ownership

- Does blood remain yours when it leaves your body?
  - Does blood become yours when it enters your body?
  - Range of responses:
    - Temporary, permanent ownership
    - “something in your body that doesn’t belong to you”
    - “hospital substance”
- 

### Slide 30: Devaluing of blood

- Unconcerned about other disease
  - Own blood characterised as tainted – ‘bad’, ‘dirty’ or ‘useless’
    - “My blood has potential, um, sickness you know. Someone else could catch it, I mean, in that way bad. Well I can’t give blood, my blood is useless for anyone else except me.” (Sandra)
- 

### Slide 31: Devaluing of blood

- HCV+ blood is devalued → complacency about contracting other diseases?
  - Speculative conclusions:

This devaluation may be exacerbated by:

    1. many participants’ apparently scant knowledge of the role of blood in the body and
    2. confusion about blood’s uniqueness to the individual or otherwise
- 

### Slide 32: Levels of responsibility

- In interviews – people speak primarily from personal responsibility levels
  - Nothing can change until individual “comes good” by taking responsibility for self
  - Also – strong theme of responsibility to others
- 

### Slide 33: Levels of responsibility

- Reflection on past practice
    - Unsafe, uninformed
    - Gulf between old self and current self
    - “I didn’t have a cent. There was nowhere to get a fit. I had to get one off the street and clean it out and use it. I mean how stupid is that? I can’t believe I’ve done it. But I did.” (Daniel)
- 

### Slide 34: Levels of responsibility

- Responsible current practice, like “super safe” statements
  - “I’m very safe I’m very safe with everything I do. Like even using myself, I use everything brand new ... Any bit of blood on it I’m not touching it, I’m not going anywhere near it. Like one thing I’ve learnt with using, is as soon as you pull the needle out you pull it to the side the skin covers over so that it doesn’t bleed also. Like some people just ... like they’re jabbing it all through their hand and they’re blood’s pouring out of their arm, it’s like phhhh, I don’t want nothing to do with it, I’m right away from it. (Sasha)
- 

### Slide 35: Levels of responsibility

- The irresponsible other
  - Contrast poor practices of other injectors with proper practice of self
    - Unsafe injecting practices
    - Hep C → moral retribution for bad behaviour
    - “no respect for themselves and other people”
    - Moral taxonomy: drug user, drug addict, junkie
- 

### Slide 36: Levels of responsibility

Caring for others:

- Other injectors and community at large
  - Impart knowledge
  - Discourage others from reusing equipment
  - Risk disapproval and physical harm by refusing to pass on equipment
  - Cast self as volunteer “mummy” to inexperienced
  - Won’t inject with “young people”
  - Distribute syringes to others
- 

### Slide 37: Levels of responsibility

- Resisting responsibility of self – Jill
  - Describes current equipment sharing
  - Does not critically reflect on behaviour of others to make self appear responsible
- 

### Slide 38: Prevention messages, strategies

- Any **one** message or strategy limited
    - By relevance in terms of personal attitudes, experiences
    - By stage of experience with hep C
    - By system or culture around the message
  - Aim today – to suggest new, different ways to maximise to achieve prevention aims
- 

### Slide 39: Ideas for intervention 1

#### **Mindlessness/Mindfulness**

- ML = focus on whole process of injecting, rather than on smaller components
  - Rigid definition (I am safe)
  - Lack of conscious awareness (even though I’ve sat in pools of my own blood)
- 

### Slide 40: Ideas for Intervention 1

#### **Automatic Pilot = Mindlessness**

- Over-reliant on categories and distinctions drawn in the past
  - Oblivious to novel or alternative aspects of the situation
  - Rigid or invariant behaviour with little or no conscious awareness
  - Issue for experts not novices
- 

### Slide 41: Ideas for intervention 1

#### **Mindlessness/Mindfulness**

Mindfulness:

- Open to novelty
  - Alert to distinction
  - Sensitive to different contexts
  - Aware of multiple perspectives
  - Oriented in the present
-

## Slide 42: Ideas for intervention

### Mindlessness/Mindfulness

- Conditional learning → mindfulness
- This *is* a pen — This *could* be a pen
- This *is* a safe way to inject
- This *could* be a way to inject safely
- Acknowledge issue of expertise, automatic behaviour

## Slide 43: Ideas for intervention 2

Knowledge of blood limited

Blood is seen as what hepatitis C “is”

Eg. liver first

Hepatitis C is not a blood disease

Function/quality of blood not affected by hepatitis C

## Slide 44: Ideas for intervention 3

IDU can talk about and relate to blood in ways beyond injecting

To get beyond “public health veneer”

Other ways to talk about blood in peer education

Challenge assumption of IDU as outsider to “normal” society

→ destigmatise IDU

## Slide 45: Ideas for intervention 4

Blood bank as a metaphor for sharing

Rigorous process for accepting, cleaning, storing blood

Blood = resource we all may have to share

Sharing = positive human value

Sharers = contribute much to society

Various levels of responsibility

Society decided = what is good to share and protects that

## Slide 46: Ideas for intervention 4

Blood bank as a metaphor – injecting

Various levels of responsibility

Societal – individual

Blood – we all have a stake

Rejects portrayal of IDU blood as bad or dirty

All people party to processes of protection and care for blood

Acknowledges IDU role in broader society

## Slide 47: Ideas for intervention 5

### Levels of responsibility

- Focus on individual – problems
- Individual becomes target of blame as well as advice or aid
- Evoke weariness among those who are continually targeted
- Risk bypassing others for whom transmission could be relevant
- Already infected – failed to have behaved responsibly
- Individuals held responsible for issue – more justly understood as network of responsibilities

## Slide 48: Ideas for intervention 5

### Levels of responsibility

- Problematic
- Structural supports for individuals (to be responsible) are vulnerable to politics
  - Eg. closure of NSPs

- Ignore/not considered
  - Social attitudes to IDU
  - Legal status of IDU
  - Availability of appropriate, timely, approachable care
- Close off other options

## Slide 49: Ideas for intervention 5

### Levels of responsibility

- Does health promotion take for granted autonomous, rational decision-maker who can resolve complex dilemmas?
  - Safe injecting = common sense???
  - Easy to follow??? Acknowledge difficulty in adherence
- Incorporate more messages of distributed responsibility
- Acknowledge contribution of political, legislative and social determinants of drug use
  - Social and economic status of IDU, availability of NSPs, detox, state of medical research into hep C, levels of funding for this ...

## Slide 50: Ideas for intervention 6

- Devaluing blood and risk for “secondary” infection, reinfection
- Recognising prevention messages (ie. hepatitis C is a serious, life threatening disease) carried into living with hepatitis C
- Efforts at testing, follow-up, treatment for prevention

## Slide 51: Summary

- No one intervention/message/strategy can be totally effective
- Ideas presented as hypotheses
- Ideas relate to each other
- Impact on materials, strategies, advocacy, systems

## Notes

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## 4.4 Hepatitis C and CALD – Tadhg McMahon, MHAHS

### Slide 1: There's no word for it

Hepatitis C prevention among people from Culturally and Linguistically Diverse Backgrounds (CALD)  
Multicultural HIV/AIDS and Hepatitis C Service

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### Slide 2: There's no word for it

- Overview of CALD communities and hep C in NSW
  - Overview of some multicultural hep C prevention initiatives we have implemented
  - Research of HCV prevention issues among CALD communities
  - Suggestions for policy and practice
- 

### Slide 3: Overview of CALD communities in NSW

From the 2001 census:

- 23% of people living in NSW were born overseas
  - 19% of people living in NSW speak a language other than English in the home
  - In 2000–2001 NSW received 46% of all immigrants to Australia
- 

### Slide 4: Global and Australian Snapshot of Hepatitis C

- Globally 170 million with hepatitis C (WHO, 1999)
  - Prevalence in selected high prevalence countries
    - Egypt, Bolivia > 15%
    - Vietnam, Thailand, Palestinian Self-Rule Areas > 5%
    - China, Brazil, Indonesia, Jordan, Pakistan, Sudan > 3% (WHO, 1997)
  - Guesstimate that between 10–15% of people with hepatitis C in Australia from CALD backgrounds
- 

### Slide 5: Overview of Hepatitis C among CALD communities

- CALD communities are over-represented in those presenting for treatment
  - Evidence of CALD IDUs being at increased risk of HCV infection
  - Evidence of lower levels of knowledge of BBVs
  - Lower levels of health service utilisation among CALD IDUs, including NSPs
    - How do you translate hepatitis C? There's no word for it. A Rapid Assessment of HCV Prevention among CALD IDUs. Sargent, Maher & Cunningham, 2001
- 

### Slide 6: Responding to hepatitis C among CALD communities (1)

Workforce development

- HCV forums for Arabic, Chinese, Italian, Khmer, Spanish and Vietnamese health/welfare workers in partnership with community organisations and HCC of NSW
  - HCV training for Health Care Interpreters in AHS in partnership with NUAA and HCC of NSW
- 

### Slide 7: Responding to hepatitis C among CALD communities (2)

Resource development

- Hepatitis C: the facts in six community languages and English
- Ethnic media component of the 2000 NSW Hep C Awareness Campaign
- 

### Slide 8: Responding to hepatitis C among CALD communities (3)

- Research – A Rapid Assessment of HCV Prevention among CALD IDUs
  - 3 X Focus Groups with Arabic, Spanish-speaking, and Vietnamese IDUs
  - 3 X Focus Groups with Arabic, Spanish speaking and Vietnamese workers
  - 1 X Focus Group with NSP workers and 1 X Focus Group with HCV service managers
- 

### Slide 9: CALD IDU Focus Groups (n=33) (1)

Culture and community

"Very rarely do you ever see a Spanish person going on the nod in the middle of Cabramatta ... and the reason is for respect of your family's name or respect within yourself ... you still do it, don't get me wrong ... but somewhere hidden ..." [Spanish-speaking background]

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### Slide 10: CALD IDU Focus Groups (n=33) (2)

"It's their reputation too, you know the family's reputation that they can lose face with their friends you know. Asian people, their reputation, very important, you know and they don't want to go round hearing their friends saying 'oh, your daughter or your son, you know is on the gear.' It makes the lose face you know". [ Vietnamese participant]

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### Slide 11: CALD IDU Focus Groups (n=33) (3)

Drug use and HCV

- Many participants believed that they could become infected through the reuse of their own syringe/equipment
  - Confusion re the difference between hepatitis B and hepatitis C
  - Confusion with 'positive' and 'negative' in HCV antibody testing
- 

### Slide 12: CALD IDU Focus Groups (n=33) (4)

Poor knowledge of viruses and routes of HCV transmission

"If it's a virus, it has to come from the air, it's an airborne disease ..." [Spanish-speaking background]  
"Well if it [hepatitis C] can't be in food then how it stays in the spoon?" [Arabic]

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### Slide 13: CALD IDU Focus Groups (n=33) (5)

Accessing HCV services and information

- Poor access to testing
- "See I'm scared now, cause I've been with people, they hep C, and sometimes they play with their spoon or something ... since I've been in jail, before jail, two years now, I've never done blood test. I'm just worried." [ Arabic-speaking background]
-

#### Slide 14: CALD IDU Focus Groups (n=33) (6)

- Need for bilingual/bicultural staff in NSP and other IDU health services
- Need for targeted information in English and community languages

"English to us, to our parents Vietnamese ... or could be on top in English and down the bottom in Vietnamese or Chinese." [Vietnamese]

#### Slide 15: Response to the Blood Awareness Research

Little specific response

Re-use of own equipment as a potential transmission route for HCV?

Poor access to HCV testing and confusion with results?

Access to health services, including NSPs?

#### Slide 16: Response to the Blood Awareness Research (2)

Pre- and post-evaluation of ethnic media component of 2000 NSW Hep C Awareness Campaign (pre- n=150, post- n=98)

- pre- only 4% believed that the risk of HCV from a blood transfusion was 'low'
- post- this had increased to 60 % but still very different to the general population (Chen, J & Bauman, A., *Hep C, understanding is the answer*. Evaluation Report)

#### Slide 17: In the pipeline

- Cultural competency training for NSP workforce
- HCV prevention resource for CALD IDU
- HCV video – *Everybody's Business* – in English and four community languages (late 2003)

#### Slide 18: Suggestions for improved HCV prevention among CALD populations

- Tackle access issues
- Messages will need to be robust
- Translation is not the answer
- Suggestions for a local response (eg. AHS, NSP)
  - Engage with CALD communities
  - Service utilisation data
  - Prioritise CALD in local contexts
  - Bilingual/bicultural recruitment (where appropriate)

#### Slide 19: Multicultural HIV/AIDS and Hepatitis C Service

PO Box M139, Missenden Road, NSW 2050

Tel: (02) 9515 3098 or 1800 108 098 (outside Sydney)

[www.multiculturalhivhepc.net](http://www.multiculturalhivhepc.net)

[info@multiculturalhivhepc.net](mailto:info@multiculturalhivhepc.net)

#### 4.5 A rural perspective – Rosemaree Dowling and Annette Slater, NEAHS

##### Slide 1: A Rural Perspective – HCV

Rosemaree Dowling

Senior Health Education/Promotion Officer

Sexual Health Service

New England Area Health Service

##### Slide 2: Who is doing HEP C Prevention?

- Sexual Health Promotion Officers
- CNC for HIV & HEP C
- The NSP (Secondary Outlets)
  - some direct contact engaging clients
  - information provided (eg. fliers, stickers, *NUAA News*)
- Alcohol & Other Drug Workers?  
(not their primary focus)

##### Slide 3: What work are we doing?

- IDU Peer Education Project – 2000
- GPs & HCW's Forums
- Non Health Agency HEP C Forums
- MSM Worker talking to Gay/MSM IDUs
- Young Injectors Project
- Cultural Sharing is not always Cultural Caring
- Aboriginal NSP Project

##### Slide 4: IDU Behaviour: a rural perspective

Users describe their practices in similar ways as this research

- 'super safe'
- more careful with increased knowledge of HIV & HEP C
- HEP C +ve so disregard for safety 'everyone has it'
- Oblivious to blood being present

##### Slide 5: IDU Behaviour: rural perspective

- Partner /family OK to share
- Sense of responsibility
  - caring for others, cleaning up, 'I've got kids I always shoot up in the bathroom'
  - pick up extra supplies for others

##### Slide 6: Rural Differences

Lower threshold level for being 'desperate'

Increases risk in rural areas

- Small communities – not anonymous
- Distance between NSP greater
- No public transport
- Remote communities limited access

##### Slide 7: Rural Differences

- No or less Primary Outlets
- Sharing in Aboriginal communities high
- Pick up extra supplies
  - being prepared

##### Slide 8: Mindfulness

Safe or safer messages

- Are IDUs, who become oblivious to the presence of blood while using, capable of determining & 'controlling' a safer way to use when the injecting situation changes?

### Slide 9: Blood Bank Model: Blood is good a resource – to be shared

- Blood is associated with trauma, injury accident, pain, death
- Blood is given – blood donors – Gift
- Not a resource

A resource is to be shared:

'Keep your blood clean for others to share'

### Slide 10: Blood Bank Model

Can you share your blood?

- Don't know
- NO

Criteria for donating blood very rigorous

- Reinforces – exclusion, being unhealthy, cannot contribute to this community resource

### Slide 11: Blood Bank Model

Politically would this model be accepted?

- by governments
- by the blood banks
- by the community

### Slide 12: Ottawa Charter

- Develop Personal Skills
- Create Supportive Environments
- Strengthen Community Action
- Reorient Health Services
- Build Healthy Public Policy

### Slide 13: The Great Divide

- Between what IDUs know as 'best practice' and what they actually do
- What they tell you they are doing and what you see happening
- HIV/AIDS Prevention crossed the 'no go zone' of explicit sexual behaviour
- Similar 'no go zone' to speak openly of drug use practices – insulated

### Slide 14: The bridge

- Use peer educators
- Management support innovative peer education programs
- Courage to walk the fine line
- Rural: Secondary Outlets less direct engagement – peer ed vital
- Build bridges between NSPs/Sexual Health and D & A Services
- HEOs also located within D & A Services

### Slide 15: A message for all

Blood bank model suggests +ve messages for IDUs but ...

Can we turn this around??

Why not normalise blood awareness for everyone?

Universal precautions

- Mainstream the messages in the mainstream media for everyone to see read and hear

### Slide 16: Be Alert not alarmed

Lets all

be Blood Aware

### Slide 17: An Aboriginal Perspective

Annette Slater

Aboriginal Sexual Health Promotion Officer

- Cultural Sharing is not always Cultural Caring
- Aboriginal NSP Project

### Notes

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## 4.6 Health promotion – John Wiggers, HAHS

### Slide 1: 'My blood is always dark red'

Health Promotion Forum

### Slide 2: Overview

- Definitions
- Ottawa Charter
- Planning Health promotion action
- Case study: Prevention of Hepatitis C transmission by tattooists and body piercers

### Slide 3: WHO definition of health

'A complete state of physical, mental and social well-being, not merely the absence of disease'

Key points:

well-being not just disease  
social as well as medical

### Slide 4: Primary Health Care – Alma Ata – 1978

Primary Health Care includes:

'promotive, preventive, curative and rehabilitative services, including educational intervention concerned with prevention'

Key point:

health promotion located at the primary care end of the care continuum

### Slide 5: What is health promotion?

"Activities that seek to make life safer and enable individuals to choose health and behave in health-preserving and health enhancing ways." (NHS, 1993)

Key points:

enabling  
'preserving' (prevention) and 'enhancing' (promoting)

### Slide 6: Infant mortality in Great Britain 1800–1986

Year	Rate
1800	100/1,000 births
1970	21/1,000 births
1986	10/1,000 births

### Slide 7: Explanations for improvement

80%–90% due to behaviour, nutrition and environment changes:

- reduced family size
- improved food supply
- improved sanitation/water supply

Medicine has limited contribution to improved health status (McKeown, 1976)

### Slide 8: Scope for further improvements in health status

US Surgeon-General

- behavioural factors contribute:
- 40%-70% of premature mortality
- 33% of acute illness
- 66% of chronic illness

### Slide 9: Modifiable risks

Disease	Modifiable Risks
Neoplasms	Smoking, sun exposure, screening, environmental exposure, alcohol
Circulatory	Smoking, diet, hypertension screening, exercise
Hepatitis C	Needle sharing, needle stick
Injury	Road safety, work safety, home safety, alcohol

### Slide 10: How can we go about changing these risks?

### Slide 11: The Ottawa Charter for Health Promotion

World Health Organisation, 1986



### Slide 12: Build healthy public policy

Putting health on the agenda

- public agencies
- private organisations
- health sector and other sectors

Legislation, fiscal measures, taxation guidelines, policies, enforcement/compliance, organisational processes

### Slide 13: Create supportive environments

Considering how a person's environment affects their choices work environment

- leisure options and environment
- living conditions
- access to goods and services

### Slide 14: Strengthen community action

Choosing health requires support

- political
- social
- access to information
- access to human and funding resources

to empower

- contribution to setting priorities
- the making of decisions
- involvement in implementing health improvement strategies

### Slide 15: Develop personal skills

Enabling people to make decisions conducive to good health

- Information and education
- Skill developing

### Slide 16: Reorient health services

Ensuring that the health care system is as much about promoting good health as it is about treating illness and disease

Continuum of care:

- Primary prevention
- Secondary prevention
- Tertiary prevention

Health care professionals are credible and trusted source of support to the community

### Slide 17: Ottawa Charter – 1986

Healthy Public Policy

RBT, skin penetration guidelines

Supportive Environments

Smoke-free areas, NSP

Community Action

Anti-discrimination

Personal Skill Development

Needle sharing, Hep C campaign

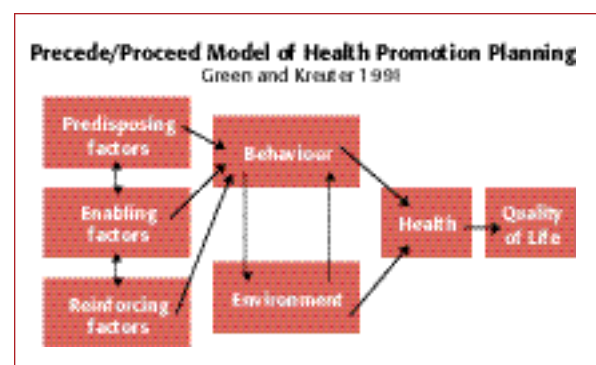
Reorient Health Services

Hep C self management

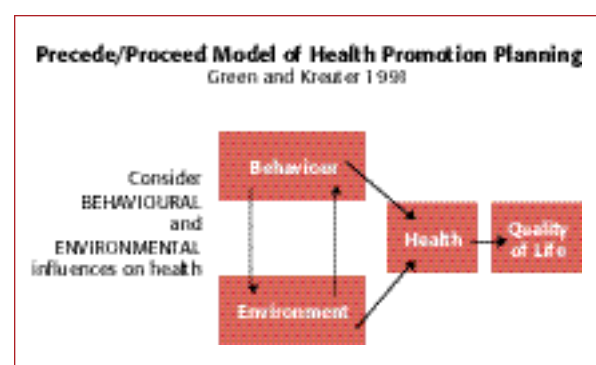
### Slide 18: Selecting the focus of health promotion activity

- What is the health issue?
- What are the determinants?
- What are the contributing factors?

### Slide 19: Precede/Proceed model of health promotion planning – Green and Kreuter 1991



### Slide 20: Precede/Proceed model of health promotion planning – Green and Kreuter 1991



### Slide 21: Precede/Proceed model of health promotion planning – Green and Kreuter 1991

*Behavioural determinants*

risk, protective, health, self care, treatment, organisational

*Environmental determinants*

physical, legislative, social, socio-economic, goods and service

### Slide 22: Hepatitis C

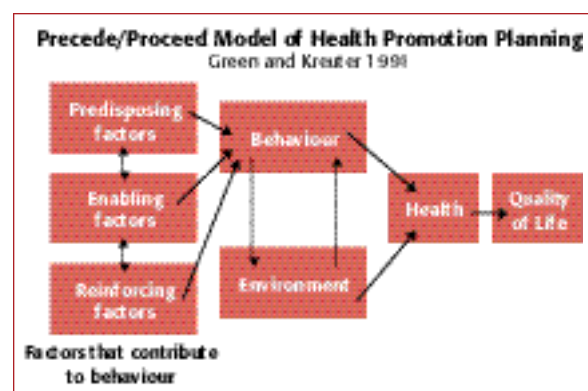
Behaviour:

- Needle sharing
- Health care worker non-compliance with universal precautions
- Tattooists unsafe practices

Environment:

- Blood donor screening
- Needle Syringe Programs
- Inadequate sharps disposal facilities
- Inadequate inspection/training of tattooists

### Slide 23: Precede/Proceed model of health promotion planning – Green and Kreuter 1991



### Slide 24: Factors that contribute to behavioural determinants

**Predisposing factors:**

Opinions, attitudes, beliefs, values, needs, awareness, interest, knowledge, perceived skill, confidence

**Enabling factors:**

Facilitators/barriers to action – access to resources, skills

**Reinforcing factors:**

Rewards/punishment/support that have an influence on behaviour – rewards, punishment, support, models

### Slide 25: Hepatitis C

**Predisposing factors:**

Knowledge of transmission risks

Value/attitudes re blood

Assessment of level of risk

**Enabling factors:**

Cost /availability of clean equipment

Skill level of tattooists

Skill level of EHO inspectors

**Reinforcing factors:**

Pressure from peers to share

Absence of supervisor/organisational support for precautions

### **Slide 26: How important are the determinants and factors, and can they be changed?**

Looking at environmental and behavioural determinants, and the contributing factors – you may have a very long list!

For each determinant/factor, consider:

how IMPORTANT is this within the context of the health issue you are addressing?

How CHANGEABLE is this?

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### **Slide 27: How important are the determinants and factors?**

Relative burden of illness

- epidemiological data – rates, incidence, prevalence
- qualitative data – needs assessments

*Evidence based*

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### **Slide 28: Can the determinants and factors be changed?**

- What is already being done – is it effective?
- Results of research – trials of effectiveness
- Trend data – has prevalence increased or decreased over time

*Evidence based*

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### **Slide 29: Precede/Proceed**

*Predisposing*

- Attitudes, beliefs, values etc
- Knowledge, interest
- Confidence

*Reinforcing*

- Family, friends, peers
- Employers, community leaders
- Fines, punishment
- Cost

*Enabling*

- Material resources
  - Access to health care
  - Laws and policies
  - personal skills
- 

### **Slide 30: Utility of the Precede/Proceed model**

- Multiple factors
    - Individual, social and organisational – ecological
  - Interaction of factors
  - Intervention success dependent on consideration of multiple factors
  - Evidence-based
- 

### **Slide 31: Prevention of Hepatitis C transmission by tattooists and body piercers**

### **Slide 32: Prevention of Hepatitis C transmission by tattooists and body piercers**

- *Problem identification*
  - Risk of transmission
  - Increasing prevalence of tattooing/piercing
  - *Behaviour*: poor operator compliance with infection control guidelines
  - *Contributing factors*: no evidence available
- 

### **Slide 33: Prevention of Hepatitis C transmission by tattooists and body piercers**

Statewide survey – random sample of 874 tattooists, beauty therapists, hairdressers

*Results*

- lack of knowledge, of guideline content
  - positive attitudes: guidelines, compliance, inspections
  - lack of compliance, lack of skills
  - inadequate frequency, content of inspections, and of EHO inspector skill
- 

### **Slide 34: Prevention of Hepatitis C transmission by tattooists and body piercers**

Statewide survey – all Public Health Unit and Council skin penetration EHO's

*Results*

- lack of knowledge
  - positive attitudes: guidelines, compliance, inspections
  - lack of skills re changing operator behaviour
  - inadequate frequency, content and process of inspections
- 

### **Slide 35: Prevention of Hepatitis C transmission by tattooists and body piercers**

Statewide survey – all Public Health Unit/Council skin penetration inspection managers

*Results*

- 15% and 23% of councils do not inspect tattooists/beauty therapists
  - 2/3 conduct annual inspections; av 21.3mins
  - Half provided information; 4% provided demonstrations during inspection
  - 2/3 used checklists – most in-house
- 

### **Slide 36: Prevention of Hepatitis C transmission by tattooists and body piercers**

*Conclusions*

- less than optimal guideline dissemination
  - less than optimal compliance monitoring
  - lack of EHO inspection/compliance aiding skills
  - lack of knowledge/skills among operators
  - acceptance among stakeholders of need for improved monitoring/enforcement process
- 

### **Slide 37: Prevention of Hepatitis C transmission by tattooists and body piercers**

Randomised controlled trial – educational feedback inspection protocol – all tattooists/piercers in Sydney

*Intervention*

Enhanced inspection protocol: demonstration, observation; tailored feedback report; EHO feedback visit – structured education

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### **Slide 38: Prevention of Hepatitis C transmission by tattooists and body piercers**

*Results*

- Increased perception of risk of detection
  - Improved infection control (demonstration and observation) – in areas of greatest deficiency
  - Improved use of guidelines
  - Acceptable to operators
  - Acceptable cost – \$120/premises
-



### Slide 39: Health Promotion

Recognises that:

CONDITIONS AND RESOURCES required for health: these include policies, shelter, education, food, income, resources, social support

It would be unreasonable to expect that people respond to advice on Hepatitis C if they are unable to afford or access the resources, or are not supported to do so

### Slide 40: Health Promotion

Recognises that:

- health promotion includes ADVOCACY;
- health promotion is about ENABLING people to achieve their fullest health potential;
- the capacity to achieve health is not solely dependent on individual actions
- that such actions are mediated through other factors
- that governments, organisations, communities play a role
- the health sector alone cannot achieve these things

### Slide 41: Acknowledgments

*Funding*

- NSW Health – HIV/AIDS Infectious Diseases
- NHMRC
- Hunter Area Health Service

Hunter Centre for Health Advancement

- Peninnah Oberdorfer

### Notes

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## 4.7 Hepatitis C Health Promotion Plan – Ronald Govers, NSW Health

### Slide 1: Road Map

#### NSW Hepatitis C Health Promotion Plan

Ronald Govers

AIDS/Infectious Diseases Branch

NSW Department of Health

rgove@doh.health.nsw.gov.au

### Slide 2: Timeframe

3 March	Present outline & timeline for Plan to MACH
24 April	Establish Advisory Committee with major stakeholders to guide Plan development
7 May	Discussion of outline for Plan at Blood Forum
14 May	Provide first draft Plan to Advisory Committee
15–21 May	Discuss draft Plan with Advisory Committee
22–23 May	Revise draft Plan
26 May	Present draft Plan to MACH

### Slide 3: Timeframe (cont)

27 May–6 June	Revise draft Plan
11–12 June	Present draft Plan to HIV/HCV Coordinators
9 June–18 July	Consultation on draft Plan
21 July–1 August	Redraft Plan
4–8 August	Discuss Plan with Advisory Committee
11–29 August	Final consultation
1 September	Present final draft to MACH
2–19 September	Finalisation Plan

### Slide 4: Outline

- Introduction
- The NSW response to the hepatitis C epidemic
- Identifying priority issues
- Infrastructure issues
- Monitoring and Evaluation
- Action Plan

### Slide 5: Introduction – Rationale

- Foreshadowed in NSW Hepatitis C Strategy
- Choice for health promotion approach acknowledges the importance of supportive policy environments, legislation and related health services needed for effective prevention and education

### Slide 6: Introduction – Objectives Plan

- To improve the quality and efficacy of hepatitis C health promotion interventions in NSW
- To enhance the hepatitis C health promotion infrastructure in NSW

### Slide 7: Introduction – Guiding Principles

- Harm minimisation
- Partnership
- Involvement affected communities
- Non-partisan political support
- Transparency
- Enabling environment

### Slide 8: Introduction – Priority Target Populations

- people who inject drugs
- people with (chronic) hepatitis C
- inmates of correctional facilities
- workers and clients in the skin penetration industry
- health care workers

### Slide 9: The NSW response to the hepatitis C epidemic – Prevalence & Incidence

- Estimated prevalence & incidence in NSW
- Risk factors
- Treatment efficacy is improving, but prevention further spread crucial to controlling epidemic

### Slide 10: The NSW response to the hepatitis C epidemic – Achievements in hepatitis C health promotion

- Strategies aimed at people who inject drugs: NSP, drug treatment services, drug education
- Strategies aimed at people with hepatitis C: clinical management, care and support services, health promotion services
- Programs for inmates of correctional facilities: hepatitis C services provided by CHS, hepatitis C services provided by DCS
- Strategy aimed at health care and other workers potentially at (high) risk of infection: infection control education and training

### Slide 11: Priority Issues

- Access to harm reduction services, incl to education/ information about safe injecting, to sterile injecting equipment, to drug education, to drug treatment
- Access for people with (chronic) hepatitis C to education/ information about health management issues, and to treatment, care and support
- Discrimination and stigmatisation of drug use
- Access to testing/screening

### Slide 12: Infrastructure

- Quality Improvement: identification and implementation of minimum service levels; promoting best practice guidelines
- Research and Surveillance: improving timeliness and reliability of surveillance; improving planning, coordination, dissemination and utilisation of research; improving understanding of effective practice in hepatitis C health promotion

### Slide 13: Infrastructure (cont)

Workforce Development and Capacity Building – NSW Health Workforce Development Program; ASHM Hepatitis C Prescriber Accreditation Program; Annual statewide NSP Workers Meeting  
Planning and Coordination – Implementation Committee; Action Plan

### Slide 14: Monitoring and Evaluation

- To measure performance against objectives & priorities
- To improve accountability of service providers funded by NSW Health
- To review & inform objectives & priorities in view of the available evidence
- To provide timely & accurate information on program performance

### Slide 15: Monitoring & Evaluation (cont)

- Annual report to Minister for Health
- AIDB to provide quarterly progress reports to MACH
- Areas and NGOs to provide quarterly progress reports to AIDB
- Annual Funding Plans to be submitted by Areas & NGOs
- Development of a Annual Performance Audit instrument
- Annual Surveillance reports
- Commissioned evaluation of individual projects/programs
- Independent review at the conclusion of this Plan

### Notes

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## 5 Small group discussion

This section of the report records the outcomes of small group discussions.

### Session 6: Research and education

The following questions were discussed in small groups.

- Select an 'idea for intervention' you would like to discuss further
- Select a resource to examine
- Select an education activity to examine

Then

- How is the 'idea for intervention' currently related to the activity being examined?
- How might the resource be changed in light of the 'idea for intervention'?

#### Group 1

Intervention 2

- Education on blood
- Health promotion – what does blood do
- All blood should be suspicious
- What does blood do
- Other injectors eg. diabetes
- Blood gives life
- Blood gives other things too
- Association of blood with liver
- Hepatitis C information and blood
- Start with blood and then onto hepatitis C
- Need series of pamphlets
- All discussion kept reaching a brick wall

Intervention 1

- Need to reframe focus to unseen blood as well
- Everyone discussing different modes of presentation
- 'New and improved' resources
- 'Blood gives life but' gives other things too
- Not judgmental
- What is blood good for
- Blood gives life but try to give it the right way

#### Group 2

Intervention 1

- Use peer education. Difficult to have resources could be used for treatment options
- Need more context related education more than resources
- Encourage people think – strategies relate to their cultural situation context
- Resources matched with educational intervention
- New fit for every hit (non-conditional statement) become mindful but 'New fit for every fit ...' and get people to complete

#### Group 3

- Stages in injecting cycle
- What can people take on without feeling that they're to blame?
- Problem of talking to individuals while acknowledging community, etc
- Need for new word – replace 'responsibility'
- Peer support – look after your mates
- Responsibility of health workers watch for 'what's the use' feeling
- Encourage responsibility and activism outside injecting

practices – foster sense of community, self esteem among users

- Delivery of message – responsibility of workers
- Consumers educate workers
- Responsibility in injecting – sharing equipment. HCV+, HCV- people softly using – deciding who goes first
- 'I'm new to this, someone needs to be responsible for me'
- Caring/sharing – look after your mates – look after community
- Beware the shifting sands of mateship
- Different kinds of users, different kinds of drugs
- Finger-pointing – users looking down on other users
- Targeting people who don't see themselves as drug users
- Young people – responsibility not important
- Window of responsibility – stages of injecting, intoxication
- Feeling a victim – low self-esteem – more problematic behaviour
- Taking on societal attitudes of not regarding (all) drug use as problematic
- Use methadone program – 'just because you fuck up doesn't mean you've lost your chance' – responsibility – just because you have hepatitis C doesn't mean you have lost your chance

#### Group 4

- Salience to population – meaningful messages – values of peer lead promotion (eg. HIV)
- Gap between science and practical applications – IDU information and work not limited to heroin but also other drugs – eg. steroids
- Need for a variety of resources
- Better stuff of 'actual' practice – real world

Intervention 6

- HCV low priority
- HCV reinforces 'otherness'
- Need more consultation with target groups
- Separate blood from the disease – clarification
- Reframe messages to highlight positive issues
- Give other health protective messages/information
- Focus on chronic users who are HCV+
- Efforts for prevention and testing, follow-up and prevention
- Need for education before testing
- Testing for health maintenance – giving patients ownerships of and understanding of health
- Recognise different priority of needs
- Treatment – blood is good: blood is mode of transmission – not diseased
- Broad education – outside of hep C. Capturing all risks – reduce stigma of injecting
- Can't normalise injecting unless Drug Law Reform occurs first (eg. person brought into accident and emergency for sky diving – extreme sport – present IDU is an extreme sport of the mind)

#### Group 5

Low literacy HCV resource

- May reinforce stereotypes
- General without being preventative
- Tries to do too many things
- Who is the audience? Injectors? New? Experienced?
- Not pithy, but still ... hmmm?

Blood bank

- Blood is good!

- Goes on holidays with you
- Important for living – need to bank on it
- Blood as a resource ... we may all have to share
- What does blood do: nutrition; oxygen; immune system.
- What's in our blood?
- My body is a temple; I don't smoke in church
- What do you put in your blood?
- How can you put things in it?
- Blood care
- (blood) Inside and Outside (body) and (things that you can see)!!
- Our society's blood bank
- People – blood
- Animal – meat
- Be aware and bloody care
- 'If it keeps vampires alive for thousands of years there's got to be something going for it'

### Group 6

#### Intervention 1 – 'Are you injecting' (AIVL)

- Injecting practice already established before the resource has been seen
- Information can vary depending on context
- Red and green lights on resource very closed-ended – does not encourage 'mindfulness'
- Automaticity vs. intensity of focus (the DRUGS!)
- Doesn't cover 'tricky situations'
- Develop strategy/intervention for point of initiations – peer education, likely initiators
- Resource changed to allow discussion of current practice and opportunities for awareness around potential risk/harm
- Raise concept of mindlessness/mindfulness in resource
- Covering all other things that need to happen while injecting as a sequence/process
  - possible interruption/fear/vigilance
  - sharing equitably (more? less?)
  - state of mind (hanging out)
  - injecting procedure
  - blood borne viruses
  - possible overdose/partial 'taste'
- Resources as a discussion point between service provider and 'client'. Resources are also for workers

### Group 7

#### Intervention 1 – 'Old habits are hard to break' (AIVL)

- Addresses 'automaticity' through discussion of 'old habits' (addresses intervention 1)
- Young people – new infections. But messages haven't got to them yet ... therefore this message is good because shifts responsibility to those already with hepatitis C to keep others safe
- Also addresses assessing risk 'could be the most risky'

#### Intervention 2 – 'Old habits are hard to break' (AIVL)

- Very blood focused resource
- Is ok because a short resource

#### Intervention 2 – 'What is hepatitis C' (Hepatitis C Council)

- Starts by mentioning liver, but then says 'blood virus'

#### Intervention 5 – 'What is hepatitis C' (Hepatitis C Council)

- Is very individual responsibility eg. you are responsible for your tattooist using new equipment
- Does it target a group 'weary' of health promotion messages
- Could give the message that its hard to get hepatitis C, so it's your fault that you did

- Could mean more to those with HCV if also mentioned sharing especially p.4 'the most common way to get'
- 'Avoiding hepatitis C' page puts onus on individual. Could use collective pronoun (?) eg. 'If people are doing drugs, the group should take control of each other'. This gives people permission to pull each other up if they think safety is at risk (could be optimistic!)
- Are prevention pamphlets (with no information on HCV+) useful, as those who see this resource probably have HCV. Once person targeted with this information, probably already infected.
- Can the concept of a policy/community response to HCV. Could this resource make a person feel the world is against them – its all up to them to stop HCV.
- Could include a statement about lots of work to make (eg. tattoo parlours) safe and it's a joint effort 'here's what you can do'
- Could have something about the responsibility of the person who initiates you knows what they are doing. This is a hard message to get across
- Could be easier to shift from individual responsibility for IDU (vs. tattoo, razors) message
- A possible individual message is to be organised, but can this be a negative or unlikely message
- Is personal responsibility a negative thing??
- Possible fall out is that broader community then further stigmatise/blame, lead to disempowerment and possible lack of concern for healthy choices?
- Target groups are vital: do we know who we are addressing? IDUs are diverse, yet we need consistent messages? Different messages?
- We are addressing marginalised people, yet not strong advocates. We need to act. Different levels of marginalisation, yet can also be excluded in our research, health promotion

#### Intervention 1 – 'What is hepatitis C' (Hepatitis C Council)

- Conditional messages could be appropriate for some, but not others ... but could diverse messages cause confusion?
- Sharing household items eg. razors can be quite conditional/through provoking eg. 'did you know brushing teeth before sex can cause bleeding gums ...'

### Group 8

- Levels of responsibility – Kit up – plan ahead – pick up for you and mates
- Checklist – water, tourniquets, etc
- Targeting appropriately – who are you trying to reach
- Challenging rituals – to break bad habits – skill them up, negotiation skills
- Strategies how to break the habits

### Group 9

#### Intervention 5 – SESAHS Fit Pack Stickers

- Resource: Fit pack stickers; Cell Block Youth Health Service focus group; murals commissioned by CSAHS at Marrickville train station; three on individual responsibility; two on broader statements
- Utilised different types of messages that can be interpreted by the individual rather than more traditional 'direct' messages
- Assumption that people know what they are talking about 'be aware' – autopilot
- Liver 'blood sucker' sticker – message not straightforward. Lay person probably will not understand. May be confusing could be more effective for target group that already has some knowledge re hepatitis C
- Different stickers more effective for different targets

- Association of graffiti with health promotion – turning an ‘anti social’ behaviour into a positive. Graffiti versus mural – several layers re: societal values
- Messages need to be layered to be effective
- Peer education an important component – people learn from their friends
- Who are we targeting? First-time vs. long-term users
- How to access peer groups who will generally have first contact with users
- Social attitudes biggest barriers to effective education
- Need to decrease discrimination in society – these murals one step in bringing the issue out into the open
- Range of messages required to reach different target groups
- Confusion generated by linking hepatitis C with HIV re: sexual transmission
- Interesting that hepatitis C hotline and NUAA – lot of contact originated from the telephone book – this raises the question – how to make resources accessible to target group
- Don’t just target individuals – target systems, local government, education, companies, etc., eg. run poster design competition in schools – the process of doing this is just as important as the end product

#### *Group 10*

##### Intervention 3

- Shifting contexts – from injecting to other scenarios eg. domestic, sports, etc. ‘Normalisation’
- Enticing discussion beyond the first person – opening discussion up – overcoming barriers
- Medium as important as the message – range of resources
- Not ‘stand-alone’ resources – to be used in conjunction with discussion/education
- Targeting: events; specific groups; able to be easily understood resources (clear and unambiguous)
- Cross-cultural interventions are possible

### **Session 11: Research and health promotion**

The following questions were discussed in small groups.

How might the ‘ideas for intervention’ inform health promotion activities? Think about all areas of health promotion action.

How might such activities be supported (eg. workforce development, partnerships)?

#### *Group 1*

- Thorough evaluation of the current activities, ensuring Ottawa Charter is the guiding principle
- Not a ‘consulting’ approach but stronger partnership approach eg. working with marginalised groups to develop resources around specific issues such as blood awareness principles
- Developing tools for the communities to use – not ‘use a condom’ but ‘this is how you use a condom’
- Broaden workers’ education roles. Not merely provision of pamphlet, but follow up with tailored information (involves restructured job descriptions and guidelines) – WDP role
- Collaborate with communities to make it ‘culturally’ appropriate, either ‘rural culture’ or ‘CALD’ or ‘inner city IDU’ – NOT TRANSLATION
- Heavy involvement of community members on steering committee and opening the structures to be more ‘community’ friendly eg. language use, inclusively, not tokenistic
- Drug reform laws to enable ex-users to come forward in

public as ‘role models’ eg. doctors, lawyers, politicians and businessmen

- Harm reduction principles as ALL health workers ‘core business’
- Mandatory harm reeducation/drug and alcohol training for all health care workers/or in all orientation programs
- Acknowledge the ‘contradictory’ nature of ALL people to begin inclusive principles
- Supplementing new and existing resources with important and related issues eg. bulk billing for chlamydia tests and transport subsidies
- Revisiting the basics and mechanisms at simple levels eg. not ‘BBV’ but ‘your blood and others blood’

#### *Group 2*

- Mixed messages don’t share – takes out of social context. All comes back to needing more than messages – where is voice of community/network
- Until change policies – messages limited
- Fit bins – lots of people use and need sharps eg. medical
- General messages around self-medication/administration
- Trust (more than just partnerships)
- Increase engagement – sense trust between services and clients/services
- Develop trust not just partnerships. Trust with the individual often rather than service
- Trust/credibility
- How establish trust – terms of referrals to other services
- Trust and community/neighbors
- Collaborative planning
- Ways of relating/engaging with clients (develop credibility and trust)
- Develop workers skills – selling NSP value back to communities
- Need to develop trust internally as well
- We need policy change, we also need to educate community value of NSPs
- Developing partnerships – find often the one key person who will be ally to get ball rolling
- Be opportunistic with partnerships
- Build trust at different levels, develop indicators around this

#### *Group 3*

- Put socks on son’s feet to prevent him getting a cold – that’s a health promotion activity
- Limitations – targeted interventions – what’s the most important message to get across? Rapport and empathy between workers and users
- If hepatitis C isn’t greatest concern, do you speak to their greatest concern? – first point is establishing trust
- One of the most important things is existence of injecting centre
- Acknowledge no piece of paper is going to change anyone
- Visual message of text may have a very good message
- Some clients can’t read
- Engagement one-on-one is sometimes very difficult
- Often not about health, it’s about ideas – what triggers response?
- Adjust focus – campaigns targeted at homeless people not likely to be effective – focus on stability, resources, etc
- Community consultation – constant community engagement – KRC successful NSP because of community support
- Health promotion – NSPs – to people who aren’t clients – target campaigns at community – NSPs need to be seen



more holistic, not associated with just giving out equipment. But needs to be understanding that giving out equipment is a good thing – sell the message that giving out equipment is a good thing

- Everyone knows HIV low here in part because of NSP
- Depends where money going – retractable needles not a good strategy – good example of how to waste \$30 million – not consumer-led
- Knee-jerk reactions – opinions of community trigger politician's responses – need to get community support as well as lobby politicians
- Get yourselves invited to community forums, speak to hostile audiences
- Police closer to issue than community – have greater understanding – partnership issues needs to be reanimated
- Difference in policing activities – lobbying local commanders

#### Group 4

- Indigenous people:
  - acknowledge – cultural/spiritual values should be applied by AHCW
  - Interpretation by elders of community if health care workers unable to interpret
  - rural versus urban indigenous culture
  - tribal beliefs
  - elder influence
- Articulate objectives instead of benefits of process to improve health promotion
- Tribes – not just stickers – look at process of development
- Health promotion relevant to target groups
- Peer education – cheap as one off but sustainability requires funding
- Models often complex: Peer leaders may not be a leader but rather the person who puts their hand up!!!  
Re-think models
- Experiential knowledge
- Network nannies
- Snowballing effect of information – correct, incorrect
- Effectiveness of brief interventions – opportunistic effect of intervention
- Specific to target group ie. KRC different to cohorts attending tertiary setting
- Marketing the promotion – change ... health promotion noticeboard ... This requires health promotion planning: well educated workforce to facilitate; remove incorrect information
- More creative approaches ie. art classes expression of feelings – pain
- Take information/data and make relevant to target groups – NSP figures.
- Legalise drugs – prevent problems. But legislation may not affect hepatitis C epidemic ... pressure of injecting quickly; more availability of needles, etc; may not remove sharing of equipment.
- Illegality: divert resources to law enforcement/punishment; compounds harm – criminal records/incarceration

#### Group 6

- Opportunities
  - Engaging with clients in other ways/around other issues – builds trust and relationship between clients
  - Competence training around NSP for secondary outlets
  - Resources more responsive to varying injecting scenarios (induction, if you have no water, street injecting, etc)

- Two way information flow – worker/client. What works (information). What doesn't work (situation)
- Best practice in brief intervention versus short client interactions
- Decriminalising use of some substances
- Greater involvement of people who inject drugs in development of information
- Local partnerships of/with indigenous and non-indigenous health services
- Continuity of care for clients between NSP and other health care services
- Activism/lobbying
- Expansion of medically supervised injecting centres eliminates problems arising from street-based injecting
- Accommodation for chaotic clients – provides stability and contact point as well as opportunity to implement harm reduction
- Whole of community approach – local priorities, advocacy
- Mainstreaming health promotion
- Heroin trial!

#### ■ Barriers

- Education as brief intervention
- Lack of access to equipment in rural and regional areas
- NSP and injecting marginalised from core business in secondary outlets
- Equipment that can be provided – funding space (vending machine)
- Few opportunities to canvas clients actual practice and occasions of being at risk
- Re-infection not seen as a big issue
- Hepatitis C diagnosis – impact/meaning for client: information given by health care workers can be unclear/confusing
- Legality of keeping used equipment – clients/workers unsure about rule – err on side of caution
- Lack of data on people/clients from CALD backgrounds
- Lack of access to treatments
- Chaotic lifestyles of clients prevents adherence to health nutrition and other optimal health outcomes
- Discrimination against PWID (people who inject drugs)
- Lack of cohesion among PWID as a group – competition for funds, for drugs, not a heterogeneous group apart from common denomination of drug use
- Strategies, yes, but what about media
- Not the messages but the medium/environment of the message: attitudes and values of users; community versus individual
- Problems with political environment
- Start with health sector ... image of MSIC as the face of injecting
- Reality versus practicality: political realities and education; injecting practices and realities; prisons
- Drug use literacy – community and schools
- Leave hepatitis C alone and talk about injecting (with humour)
- “Adventures in drug use”
- Presently: in-service; media campaigns; literatures; anti-discrimination

### *Group 7*

- Pamphlets limited eg. does anyone who is not yet injecting see them? are they any use for HCV+
- Do we need to do an audit of pamphlets? How is this compatible with different needs or perceived needs or target groups
- Interventions is so brief. Little more time for anything but pamphlets; very restricted with what we can do with clients
- SIC Project in Wentworth: came in contact with new injectors and non-injectors; but need extra resources
- Peer interventions – need more of
- Vein Care pamphlets – relevant to all injectors and focuses on whole range of issues of interest for injectors (not just HCV and BBV). Also has other resources that go with it (Qld resource)
- AHC database of education resources much needed
- Peer education – how do we know, and what works
- Need focus our prevention on health promotion on IDU, but tattooing will become more important than currently is
- Health promotion should also target HCV+ health management
- Vaccine will make the biggest difference
- Treatment increase uptake will decrease pool of infection
- Do we need to reduce the amount of injecting (even if not drug use)
- Are the projections of drug use accurate? Or will infection lose favour? Or could drug treatment have an impact?
- Need demystify/decriminalise drug use – accept it's a universal phenomena
- Need political and bipartisan support for NSWP – need promote as a health promotion activity
- Reorienting health dollar
- Cycles in health \$\$, 10 years and then it gets less prominence, but HCV hasn't even had that because on back of HIV
- Not a popular group/media friendly issue
- Will a national spokesperson help? Need a group of cross section of society to 'come out'
- Supportive environment – changing public perception
- School education – skin integrity/blood awareness, along with not sharing straws, washing hands
- Openness in talking about sex – some change might be able to occur in field
- Need to believe that things can change – be optimistic

### *Group 8*

- Improve partnership with key stakeholders e.g. youth, youth workers, department of housing
- Target health care workers as well as the clients – so they support the messages, actions, etc, that they spread to clients
- Leaflets to reflect people's situation e.g. washing hands, etc – street people don't always have access to a sink. Leaflets on hepatitis C often reflect the ideal situation not the realities of people's situation
- 'Grass roots' approach – involve the community in what works best (they have the experience)
- What needs to be developed: partnerships; community involvement; more research/understanding other approaches to improve health well being of other groups considered 'too hard'; political support

### *Group 9*

- Education not getting to those that need it
- Still stigmatisation
- Education needs to be broader – including the concept promotion

- We can learn from other experiences
- How do we develop a promotional activity that is all inclusive – maybe not. May need to do something in chunks – small projects overseen by larger plan
- Message is not getting across
- Do you concentrate on hepatitis C, methadone
- School promotion activities
- Posters do become invisible
- What is effective
- Promote the taking of drugs by other routes other than injecting
- Other ways of sending these messages
- Getting to media (TV, radio)
- What drugs are people taking
- Decriminalise
- Have different projects happening at the same time
- Resources
- Ownership of this issue by services
- Many issues that are at play – why do people start taking drugs?
- Stigma/discrimination
- Research on those that have hepatitis C
- Difference in different ethnic groups
- Target community/schools

### *Group 10*

- Move away from 'tokenistic' one-off activities (eg. World AIDS Day, NAIDOC) but enhance messages more generally and more evenly through year
- Re question 2: Workforce development and partnerships are not OTHER. They are integral to program planning and delivery – should not be seen as adjuncts
- Issue of where stigma and discrimination sit in relation to any training of hepatitis C work done with non IDUs.
- Need to do more work with women especially in maternity settings
- Need to constantly reexamine strategies – refining approaches and methods in light of changes in the community and its context
- Exchanges, visits to other agencies, etc, can help workers share ideas and resources
- Questions of how we as individual practitioners influence the huge systemic structural issues. Need to clarify roles and contribution and not attempt to much
- Validating role of health providers within the system – advocacy achievements and successes – up the line
- Refer to foundation documents (eg. Healthy People 2005 etc.) to advocate that local practice is in line with things like the principles in the Ottawa Charter

## **Session 13: Reviewing health promotion plan**

The following questions were discussed in small groups.

Priority issues and infrastructure: Are there other key issues/challenges that should be identified?

Then for priority issues listed:

- What should be achieved?
- How should this be achieved?
- Who should achieve it?

### *Group 1*

- Workforce development and training for all AOD workers (especially methadone) around HCV
- Targeted education and support for current IDU who are already living with HCV
- Improved coordination between existing infrastructures eg. NSP, treatment services, AOD, GPs

- Corrections – funding, education of staff and inmates, diet limitations, treatment options, NSP services, drugs policy, peer education
- Broad-based blood awareness strategies, in partnership with Department of Education, Health, Corrections, media and other relevant stakeholders
- HCV supported groups to make the HCV community more politically active and empowered
- Acknowledgment of underlying social issues which lead to drug use, mental health, exclusion of marginalised groups, social isolation. Why is this happening and how can our community involve our neighbours
- Increased social support for HCV+ within health, NGOs, social workers, psychologists, helplines, free counselling!!
- \$\$\$\$

#### Group 2

- Enforcement of public policy
- Empower individuals
- High schools
- Equity
- Continuum of care
- Health promotion data – scope, outcomes, program
- Database of what people are doing
- C-Changes
- ‘Process of developing’ education is important
- Support peer educators

#### Group 3

- Corrections: who’s doing it, what are they doing?
- No health promotion for hepatitis C in some area health services
- Funding
- Who’s going to run programs and projects?
- Political will
- Every area health service should have a hepatitis C officer
- Hepatitis C officers funded by COAG – funding going to run out
- Bring in health infrastructure to be part of hepatitis C response
- E.P.C. – GPs not mentioned in plan
- Differences between HIV and HCV – sizes of epidemics – population groups – discrimination against IDU
- ‘IDU are you’
- Differences between HCV and HIV – differences between health promotion plan
- Experience of living with HCV – silent, unknown effects to populations and individuals
- Separate dedicated response – not piggybacking on HIV
- Partnerships – with Department of Education – training/educating young people
- Legislative change is health promotion
- Decriminalise – easier access to treatment, etc
- MSIC – increase treatment options/facilities

#### Group 4

- Broad education for all fields of medical undergraduate courses: medical students; nurses; dieticians; occupational therapy; dentistry; psychology/social work; pharmacist
- Improve access to NSP/Infrastructure in rural areas
- Changes around privacy
- Discrimination – working with health care workers. Dissemination of information
- Anti-discrimination C-Change report – sustainability of forum and issues relating to discrimination

- Include testing or attractiveness of being tested with risk of discrimination or disclosure
- No testing of deceased for BBV (during autopsy)
- Funeral Directors not enforcing no viewing of body – education of those workers involved in care of deceased
- Testing of patients attending health care for alternative ill health and coincidental testing perhaps because patient attending for surgery has elevated LFTs etc.
- Ensure consent is provided – push for written consent as for HIV

#### Group 5

- Sex workers – should they be included elsewhere or considered as special population??
- Steroid and gym users
- Does not appear to foster ‘supportive environment’
- Dual diagnosis (eg. mental health and drug issues)
- We need information and education before people inject ie. youth (why wait to target people when they became members of groups) ... discuss injecting as a ‘normalised behaviour’
- Something this important will probably be given such little PR and spin – get a PR consultant – go to broad population
- Sexually active communities
- Broader unidentified risks in HCV transmission eg. sexual practice ... not reinforcing stereotypes and broader responsibility
- Use of normal daily press especially *Daily Telegraph* to promote campaign/awareness
- Partnerships – what about police role, eg. in ‘policing’ NSPs
- Methadone injectors – equipment unavailable
- No mention of drug law reform – taking harm minimisation seriously
- Drug treatment – as an outcome?

#### Group 6

- Another priority groups? Target population – ATSI/CALD/friends and family. At least approaches developed are also relevant and appropriate for these people
- In priority issues – point 2 ‘access for people with chronic hepatitis C to education/information’ – education and information should involve and be relevant to these people
- p4, pt4 ‘response to HCV epidemic, achievements in health promotion’ – Strategy aimed at health care and other workers: whole of population approach missing – also high school education program?? Training for teachers to implement this/a package (and it is compulsory!!) – parental permission needed?
- Priority issues focus on access issues – what about equity issues? ‘Specific needs of particular groups are considered separately and acted upon accordingly’ eg. consumer advocacy??
- Implementation of a ‘continuity of care’ plan (eg. Central Coast project) to create stronger links between NSP (workers) and other health care services to improve health sector support for PWID (clients)
- Monitoring and evaluation – health promotion project database for health care services to access – including scope range of projects – successful strategies, links, outcomes and less successful (etc) – not tied to project reporting or funding requirements
- Investigation of education resource for PWID and health care workers as tools for discussion or brief intervention – health care workers should have a forum to feed back which resources work in which contexts – PWID should be able to comment on effectiveness/salience of information and highlight gaps



- Access to drug treatments – investigate other options (heroin trial?), expansion of MSIC program (or other safe injecting program), extra places in rehabilitation and detox services – expansion of supported accommodation and semi-supported accommodation programs include Special Do Housing projects
- Research – national reporting register? to eliminate duplicate reporting?
- Lacking: dissemination of the broad strategies to local levels
- Lacking: to find ‘setting based approaches’
- Lacking: to have reporting mechanisms for the strategies. NEED!
- NSW strategy should be more consistent with the health promotion plan
- References to health promotion theory? NEED
- Look at sexual health promotion guidelines to set up a template that is consistent with theory – principles, implementation
- Need for theory. NEED
- Ottawa Charter template/framework in play?
- NEED a basis of health promotion theory and theories
- Incorporate health promotion in the key stakeholders?
- Community participation – NUAA, HCC, service level
- Incorporate D & A services
- Contact details and description for infrastructure services (concrete)
- Better dissemination of best practice hepatitis C health promotion
- Partnerships between NSP/methadone/police/other HC services to improve support and service. Especially police disinterest towards PWID

#### *Group 10*

- Target groups – should include pre-initiates especially young people, ATSI, CALD
- Outline – doesn’t include anything re health promotion – include Ottawa Charter and adult education
- Strategic partnerships with mental health, youth services, education, community groups
- Guiding principle – bi-partisan support – hopefully this would include discussion on drug law reform, NSP in prison: maybe public policy on these issues
- More on peer support for HCV affected people, eg. networks, GPs, support groups
- More on potential community development activities – especially in IDU networks, HCV+ networks (networks are very important)
- Chapters could be broken up with the Ottawa Charter headings
- In priority issues – should be a section on influencing public policy especially drug law reform and NSPs in prison. Could also include removal of unhelpful policy
- Needs to support initiatives such as MISC, safe houses, prison work – this should be specific not general examples
- Monitoring and evaluation: perhaps an opportunity for feedback on successes and lessons to peer organisations – so far its all about reporting to NSW Health
- Workforce development and capacity building – other examples could include interagencies for HCV workers
- Acknowledge that HCV is responsibility of other agencies such as Department of Corrective Services, ADB, police, AOD, etc
- Inclusion of section on importance of health promotion research and partnerships between community, practitioners and researchers.

## This image shows a full page of blank, lined paper. It features approximately 28 horizontal grey lines spaced evenly apart, typical of notebook paper. The lines extend across the entire width of the page, leaving small margins at the top and bottom. There are no vertical lines, text, or other markings on the page.

# **“dark red”**

My blood is always

## **Research Reportback Forum and Hepatitis C Health Promotion Plan Discussion**

### **EVALUATION REPORT**

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University of New South Wales

**JULY 2003**

## 6 Aims

To conduct evaluation interviews with a cross-section of forum participants to:

1. examine their perceptions of benefits and tensions in attempts to link research, practice and policy generally and in the field of hepatitis C specifically
2. collect their perceptions of the organisation and impact of the forum in the areas of (1) dissemination of NCHSR research (2) networking opportunities (3) discussion of the NSW health promotion plan.

## 7 Summary of main findings

The following are the main findings of the evaluation interviews. The procedure for conducting and analysing the interviews will be described below as well as a full presentation of the results.

- The forum was generally well received by participants.
- Most participants positively regarded the networking opportunities provided by this type of forum.
- Small groups should have been rotated on the second day to provide a variety of interaction and networking opportunities.
- More time should have been allocated to discussion following presentation of research.
- The introduction to qualitative research theory and practice was a useful introduction to the presentation of qualitative research findings.
- The research information presented will have impact on the practices of some participants.
- Efforts to link practice, research and policy in this type of forum are limited even with representatives of each sector involved.
- Opportunities to provide input into the NSW Department of Health Hepatitis C Health Promotion Plan were perceived as limited.
- Links between policy and research (or practice) were seen as less successful than between research and practice.
- A greater diversity of participants (ie. from within the hepatitis C sector and from different sectors) would have contributed to the success of the forum.

## 8 Procedure

Participants were asked to complete a form indicating their interest and permission in being contacted for an evaluation interview. Thirty-two participants completed this form. These participants were classified by type of organisation (eg Area Health Service, other Government service, and Non-Government Organisation), location (eg Sydney versus non-Sydney) and type of position held (eg front-line worker, coordinator). A selection of 20 people was made to include a representation of organisation, location and type of worker. These 20 people were sent an email invitation to arrange an interview with a NCHSR staff member (MH) not involved with the research presented at the forum or with organisation of the forum.

The interview schedule (*see page #*) closely reflected the aims of the evaluation. The interview opened with an examination of the participant's own levels of experience and interest in the three domains of research, practice and policy and a request for them to provide an example of a scenario where they had perceived a strong link between these three domains.

The participant was then asked to comment on the benefits and tensions in linking research, practice and policy generally and in relation to hepatitis C specifically. The interview schedule then focused on the blood forum and asked the participant to comment on the issues outlined in Aim 2. The interview schedule closed with questions about "lowlights" and "highlights" of the forum and an opportunity for the participants to provide any other comment.

## 9 Analysis

The interviews were audio-tape recorded and transcribed. For the purpose of the evaluation report, the interview transcripts were closely read by two NCHSR researchers. The findings presented here relate to specific issues of the forum (*see Aim 2*).

One researcher (CT) compiled summaries of the main points raised by participants under the following headings:

1. Linking Research, Practice and Policy
2. Dissemination of Research
3. Impact of Forum
4. Networking
5. NSW Hepatitis C Health Promotion Plan
6. Overall Organisation of Forum

The second researcher (MH) compared these summaries to the original transcripts to check for completeness and clarity of interpretation. Where relevant, quotes have been selected to highlight issues raised by participants. Quotes were selected on the basis of clarity of expression. Individuals are not identified but indications are given of their organisation (Area Health Service/Department of Health or Non-Government Organisation) and the area in which they work (Sydney or non-Sydney).

## 10 Results

Twelve interviews were conducted each of approximately 20–25 minutes duration. Participants included representatives from three Non-Government Organisations (all based in Sydney) and nine Area Health Service/Department of Health (three based in Sydney, six not based in Sydney) (*see Table 1*).

### 10.1 Linking Research, Practice and Policy

There was a range of opinion expressed in relation to the extent of the linkages made between research, practice and policy. Some participants felt the three domains were well integrated and that the "structure of the forum" (AHS, Sydney) and its "clear stated aim" (AHS, Sydney) assisted in this, that the forum was an opportunity "for a lot of different practices to come together and debate policy" (AHS, non-Sydney) and others felt there was "not enough time to absorb ... discuss the effectiveness of the research and how we can change our practice" (AHS, non-Sydney). Other participants felt that the linkages between these three domains are "poor" and that "the idea of incorporating policy is pretty far fetched" (NGO, Sydney).

Some participants felt that the links between research and practice were well made during the forum, but the links between policy and other sectors were as successful:

*"Rate 10 out of 10 as far as research to practice, but as far as policy goes, I haven't seen any policies that sort of cover that area"* (AHS, non-Sydney)

**Table 1** Evaluation Participant Characteristics

	Area Health Service/Dept of Health	Non-Government Organisation	Total
Sydney	3	3	6
Non-Sydney	6	0	6
<b>Total</b>	<b>9</b>	<b>3</b>	<b>12</b>

*"In terms of practice and research 10 out of 10 – very very well ... In terms of policy, not so successful, 3 out of 10."* (AHS, non-Sydney)

The specific difficulties of linking policy with research and practice were also discussed by participants. For example participants felt that the opportunity to comment and reflect on the specific health promotion plan presented at the forum was limited. Others described the forum as a "step in the right direction" (NGO, Sydney) and acknowledged that the time required in linking research and policy in general: "it's actually quite a long way down the track before research and policy become interlinked" (AHS, non-Sydney).

## 10.2 Dissemination of research

Generally, participants were positive in their comments about the research dissemination section of the forum and felt that it "gave different points of view and gave you an opportunity to look at hep C in a different way and coming in at different angles." (AHS, Sydney).

The style of presentation was also positively received:

*"It engaged us, wasn't sort of like at conferences where they just deliver the research as results and this is what we've found. It was done in a way that invited comments as to give evidence and so engaged an open court discussion and it wasn't rushed so there was lots of opportunities for people to comment and tease out different aspects of it."* (AHS, non-Sydney)

The early dissemination of the research was also positively appraised:

*"What was known which was deemed as being important was being shared from the researchers early on, not waiting for it to become journal articles two years down the track."* (AHS, non-Sydney)

Others felt that the research offered no "revolutionary new information" for them (AHS, non-Sydney), but that it "reinforced" what was already known (AHS, Sydney).

Some participants found the exercise challenging particularly when dealing with the more abstract or conceptual hypotheses generated from the research findings and suggested a change in structure of the forum to support consideration of these findings:

*"Very challenging. Big challenge was when we got to debate it at the table to try and look at some of those more fringe ideas about blood and people's concept of blood and how you might turn that into a health promotion project. I thought it was quite challenging to actually debate on that table because you know, everybody was in a different space in terms of how accepting they were of that particular research, so that was quite difficult ... I would have liked to see the health promotion framework*

*up-front rather than on the second day ... when we were having our debate in the afternoon [after research presentation] there wasn't a lot of support on my table for the more sort of conceptual ideas that came out of the research and perhaps if we'd had that sort of refresher of health promotion framework prior to the presentation of the [research] perhaps the debate would have been ... we would have been able to apply those principles more effectively than we did."* (AHS, non-Sydney)

Another participant questioned one of the key aims of the research, that is, presenting the concept of blood awareness without fostering discrimination and stigma:

*"I don't know how [that] is going to happen."* (NGO, Sydney)

The use of qualitative research was described as "brave ... encouraging and refreshing" (AHS, non-Sydney) and others "liked the use of actual quotes from people" (AHS, Sydney). Another participant described presenting qualitative research as a "risk" and that with a different audience (ie. one with a more quantitative background) the research could have received "a lot of flack" (AHS, non-Sydney). However, other participants raised concerns about the generalisability of the research because of the small sample size (AHS, non-Sydney) and reiterated the limitations of the research:

*"Would have been good to see the difference in rural thinking and urban thinking."* (AHS, non-Sydney).

Participants also expressed a desire to know more about research done by NCHSR in general and additional results from this specific research project.

## 10.3 Impact of forum

Participants' opinions of the impact of the forum were varied. Some participants described making specific changes to their work practices, for example, in delivering education with at-risk clients, taking away the emphasis on injecting drug use when working with the general community and in developing teaching materials. Other examples of more general impacts included changes in perspective on future strategies due to witnessing and discussing other viewpoints and perspectives, raising the need to liaise and cooperate with other organisations and reinforcing "that we need to be looking at different ways of working with people, we can't just go on working with people and using the same language that we've been using year in and year out" (AHS, non-Sydney).

Others were not sure at that time how much an impact the forum will have on their work. Impact of the forum was less for those who do not work in the "frontline" [of health promotion delivery] (AHS, Sydney) and others felt that the impact "was positive, but its not going to create major changes" (NGO, Sydney).

## 10.4 Networking

Most people found the networking aspect of the forum useful, particularly for discussing different perspectives:

*"Sort of agencies that you deal with but you haven't actually dealt with those people exactly and so that you got to interact on a more in-depth level. Being able to get different points of view, especially from different agencies, so coming from a health agency networking with people from user groups and agencies such as that, just seeing the different ways we look at things"* (AHS, non-Sydney)

*"A good bunch, a good mix, with different philosophies and different ideas and that was good, also I made a couple of contacts"* (AHS, Sydney)

*"Our table had complete opposites, great opportunity to witness content of conversation"* (AHS, non-Sydney)

The forum was mentioned specifically by rural workers as a "one of our rare opportunities" to network and also by some Sydney-based participants who had opportunities to meet rural colleagues.

One other participant felt that networking is "over-rated". Some others felt that networking was not an important outcome of the forum as the small size of the hepatitis C field meant that they were well acquainted with individuals:

*"Hep C it's a small world and everybody knows everybody, we run into each other at every single conference. I mean it's really good to hook up but you do know everybody. It's better to incorporate other fields of service so that we can actually link, not link within hep C."* (NGO Sydney)

Some other participant felt that the diversity of participants could have been enhanced by a greater presence of hepatitis C coordinators from the area health services:

*"Did have a diversity of people there. I think there were people who were missing. Namely coordinators. They were on the list to attend, but and some attended for the first one or two sessions."* (AHS, non-Sydney)

## 10.5 NSW Hepatitis C Health Promotion Plan

This section of the forum was generally more negatively perceived than other sections. Typically, participants felt that they had little opportunity to contribute to the Plan in terms of time and receptiveness to comment ("it seems to me to be more presenting rather than interacting" AHS, Sydney), lack of advanced presentation of the document and that it was presented in "very broad strokes" without attention to the unique aspects of the hepatitis C epidemic (AHS, Sydney).

*"One criticism I would have was with the initial framework of the hep C health promotion document. I would like to have seen some of it, debate that ensued on those two days actually appear in that document because it was, to me, it was a very flimsy document, with not much direction in the way it presented on the day, I thought there could have been a lot more work done in terms of applying that sort of policy, research and practice and putting it into a framework of health promotion."* (AHS, non-Sydney).

*"It felt to me as if they'd basically come through with the HIV health promotion plan to hep C and*

*they didn't really put much thought into ... the general community is affected far broader with hep C than with HIV and I don't think the health promotion plan actually took that much notice of that."* (AHS, non-Sydney)

*"It was just sort of given out, where it was up to. It didn't sort of engage people giving feedback to it. We could have had a more comprehensive document around it. It would have been useful to have a draft before the forum."* (AHS, non-Sydney)

*"If you really want people to comment on something then they need a bit more time than actually half commenting at a forum where a lot of people don't necessarily feel comfortable commenting in that capacity. I'd actually personally have rather seen something in writing, someone actually needs to read something of it before I really can comment properly."* (AHS, non-Sydney)

Some participants felt that the consultation process was effectively closed as they perceived the Plan to be already advanced in terms of approval processes:

*"Actual consultation process was disillusioned, because they are going to MACH [Minister's Advisory Committee on Hepatitis] in a few weeks. Consultation is difficult to actually do when it's already been planned out."* (NGO, Sydney)

One participant was happy with this section of the forum and felt that she "always has her say" (AHS, non-Sydney).

## 10.6 Overall Organisation of the Forum

A number of individual comments were expressed by the participants and are summarised below. One participant felt the forum could have been more effective if the discussion had also focused on issues of implementation of health promotion messages:

*"Focus was on messages, rather than strategies, how we are doing it, implementation issues."* (AHS, non-Sydney)

One participant felt that the small group discussions were not useful for him, as his perspective was very different to others:

*"Workshops were not always useful because other participants were quite at odds with my own perspective."* (NGO Sydney)

One participant felt that the health promotion theory presentation was not needed as most participants would be familiar with the topics covered:

*"Didn't need health promotion presentation. Most people quite aware of what health promotion is, those not familiar with this could have just been given notes instead of this discussion on the Ottawa Charter."* (NGO, Sydney)

Some other participants felt the health promotion presentation was a very useful aspect of the forum:

*"Health promotion presentation (ie. skin penetration) very useful."* (AHS, Sydney; AHS, non-Sydney)

Some participants felt that their experience could have been enhanced by mixing the small groups on the second day.

Finally, one participant was very positive about the forum:

*"I've never got so much out of a forum in three years as what I have from that one."* (AHS, non-Sydney)



## 11 Blood Forum Evaluation – Interview Schedule

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### Introduction:

- confirm that participant has 20 minutes to talk
  - explain purpose
  - ask participant to describe their job role.
1. One aim of the forum was to bring together people who work in research, practice and policy. Can you rank your experience – with 1 as being a rating of most experience and 3 least experience. Rank: Research, Practice, Policy
  2. What is your interest in each of these, on a scale of 1–10, with 1 being absolutely no interest, and 10 being very, very interested. Rating: Research, Practice, Policy (and then prompt for discussion around rating).
  3. Can you describe a scenario in which you have seen (or see the potential) good links between research, practice and policy.
  4. Can you tell me what you think are the benefits, in general, of linking research, practice and policy? Prompt – any specific benefits for hepatitis C?
  5. Can you tell me about tensions or difficulties in linking research, practice or policy? Prompt – any specific tensions for hepatitis C?

### Now about this forum:

6. How well do you think the forum was able to link research, practice and policy? Could you rate on a scale of 1–10 with 1 being no links whatsoever to 10 being obvious, strong links. Rating (and then prompt for discussion around rating).
7. Another aim of the forum was to disseminate the results of the “blood awareness” research conducted by UNSW. How useful did you find the presentation and discussion of these findings? Rate, 1–10.
8. What impact do you think the forum has had or will continue to have on your work? Rating from 1 = absolutely no impact, to 10 = major impact (and then prompt for discussion around rating, especially in regard to prevention messages). Rate 1–10.
9. Also, the forum aimed to bring together people in various sectors for networking. How useful did you find the forum for connecting with other people? Rate 1–10.
10. The NSW Health Hepatitis C Health Promotion Plan was a focus of the second day of the forum. How satisfied do you feel with your opportunity to contribute to this plan? Rate 1–10.
11. What was the “lowlight” of the forum for you?
12. What was the highlight of the forum for you?
13. Any other comments to make?

*Thank you for your time.*

## Appendix: Forum Attendees

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<b>Jose Ascencio</b> Central Sydney Area Health Service	<b>Detlev Jackson</b> ACON	<b>Richard Sulovsky</b> NSW Users and AIDS Association
<b>Clive Aspin</b> REPIDU (CSAHS)	<b>Karen James</b> Fairfield Council	<b>Phillipa Thornton</b> South Western Sydney Area Health Service
<b>Tim Baxter</b> Kirketon Road Centre	<b>Sarah Jones</b> Australian Hepatitis Council	<b>Carla Treloar</b> NCHSR, UNSW
<b>Pat Bindley</b> Illawarra Area Health Service	<b>Sue Kippax</b> NCHSR, UNSW	<b>Andrew Trist</b> NSW Users and AIDS Association
<b>Marilyn Bliss</b> Hunter Area Health Service	<b>Jenni Lampard</b> Southern Area Health Service	<b>Bev Tyson</b> Macquarie Area Health Service
<b>Norman Booker</b> NSW Health WDP	<b>Anne Lawrence</b> Drug Programs Bureau, NSW Health	<b>James Urban</b> Sex Workers Outreach Project
<b>Megan Buddle</b> NCHECR, UNSW	<b>Chantay Link</b> REPIDU (CSAHS)	<b>Kylie Valentine</b> NCHSR, UNSW
<b>Trish Bullen</b> Macquarie Area Health Service	<b>Michael Lodge</b> NSW Users and AIDS Association	<b>Sharon Valks</b> ACON
<b>John Caesar</b> New England Area Health Service	<b>Andrew Lowth</b> South Eastern Sydney Area Health Service	<b>Peter Wallace</b> South Eastern Sydney Area Health Service
<b>Sallie Cairnduff</b> Hepatitis C Council of NSW	<b>Rose Mason</b> South West Sydney Area Health Service	<b>David Webber</b> Illawarra Area Health Service
<b>Leigh Cantero</b> Australian Society for HIV Medicine	<b>Nicole McDonald</b> Central Coast Area Health Service	<b>Owen Westcott</b> AIDB, NSW Health
<b>Jenny Curnow</b> Northern Rivers Area Health Service	<b>Susan McGuckin</b> NSW Users and AIDS Association	<b>John Wiggers</b> Hunter Area Health Service
<b>Shaun Davies</b> AIDB, NSW Health	<b>Tadhg McMahon</b> Multicultural HIV/AIDS & Hep C Service	<b>Chris Wilson</b> Hepatitis C Council of NSW
<b>Mark Denoe</b> Kirketon Road Centre	<b>Kevin Menzies</b> Mid Western Area Health Service	<b>Rob Wilkins</b> Workforce Development Project
<b>Rosemaree Dowling</b> New England Area Health Service	<b>Gabrielle Murphy</b> Hunter Area Health Service	<b>Stephen Wye</b> NSW Users and AIDS Association
<b>Lorraine Dubois</b> Southern Area Health Service	<b>Lesley Painter</b> South Eastern Sydney Area Health Service	<b>Julian Zhou</b> NCHECR, UNSW
<b>Barry Edwards</b> South Eastern Sydney Area Health Service	<b>Kerry Paterson</b> Australian Hepatitis Council	
<b>Catriona Elek</b> Hepatitis C Council of NSW	<b>Fiona Poeder</b> Western Sydney Area Health Service	
<b>Abigail Elliot</b> NSW Assoc for Adolescent Health	<b>Sue Polis</b> Central Sydney Area Health Service	
<b>Wendi Evans</b> Northern Rivers Area Health Service	<b>Patricia Preston</b> Wentworth Area Health Service	
<b>Adrian Foon</b> YAA Health Outreach Team	<b>Janice Pritchard-Jones</b> Central Sydney Area Health Service	
<b>Denilson Fukunishi</b> Multicultural HIV/AIDS & Hep C Service	<b>Nandine Ray</b> NSP Workforce Development Project	
<b>Gary Gahan</b> Northern Sydney Area Health Service	<b>Linden Rhodes</b> Central Coast Area Health Service	
<b>Ronald Govers</b> AIDB, NSW Health	<b>Maria Romaniw</b> TRAIDS	
<b>Dash Gray</b> Central Sydney Area Health Service	<b>Scott Russel</b> Northern Rivers Area Health Service	
<b>Paul Harvey</b> Hepatitis C Council of NSW	<b>Bedelia Skinner</b> Macquarie Area Health Service	
<b>Sonja Hill</b> Australian Society for HIV Medicine	<b>Annette Slater</b> New England Area Health Service	
<b>Kate Hipsley</b> Ambulance Service of NSW	<b>Doug Smyth</b> Drug Programs Bureau, NSW Health	
<b>Max Hopwood</b> NCHSR, UNSW	<b>Aldo Spina</b> Consultant	