

Social research needs analysis: Australian Intravenous League and Australian Hepatitis Council and member organisations

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Social Research Needs Analysis

Australian Intravenous League
and
Australian Hepatitis Council
and member organisations

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The Australian Intravenous League and
the Australian Hepatitis Council and their member organisations

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Monograph 2/2002

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Executive Summary

In terms of the published and grey literature from social research, the long history of research into the transmission of HIV and injecting drug use has produced more material in the areas of prevention and other transmission issues than in the areas of treatment, health maintenance, care, support and discrimination. Psycho-social research on treatment, care and support predominantly relies on the quality of life approach. Other social research approaches do not figure significantly. There are a number of existing literature reviews related to hepatitis C, and most of these also focus on the prevention of transmission area.

The Australian Intravenous League (AIVL) and its member organisations highlighted the following 5 priority areas for social research in hepatitis C, in order of importance: Peer education; discrimination and stigma; prisons; prevention; attitudes, beliefs and knowledge.

The Australian Hepatitis Council (AHC) and its member organisations highlighted the following 5 priority areas for social research in hepatitis C, in order of importance: Discrimination and stigma; the clinical encounter; impact of disclosure; prisons; rural and remote issues

In relation to the processes of social research, some user groups on the east coast of Australia, felt that they and their clients had been over-researched. Research, particularly recruitment, often affected the ability of staff and volunteers to carry out their core duties. In contrast, most hepatitis councils and user groups beyond the east coast, had only occasional contact with research and researchers.

User groups highlighted a number of ethical issues raised by research. These related to whether there were any practical benefits of research to the organisation and to people who use drugs illicitly; issues of privacy and confidentiality regarding how research instruments are administered; and lack of dissemination of research findings.

On the whole, hepatitis councils and user groups were committed to supporting social research providing equitable collaborations and partnerships were built at the beginning of the process.

Those consulted acknowledged the need for capacity building regarding the types, advantages and limitations of social research. There was a particular interest in developing ways of using social research to inform education and other activities. In addition many organisations expressed a desire to be “skilled-up” and supported in using applied research methods such as action research and rapid assessment procedure.

There was a widespread recognition of the need to develop mechanisms to facilitate on-going dialogue between community, researchers and government so that the research agenda was responsive to conditions “on the ground”. Such mechanisms could also be designed to enhance the dissemination of research findings and improve their applicability to education.

Introduction

Hepatitis C social research priorities to date

In August 2000 the Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) Hepatitis C Committee developed a set of research priorities¹, using the priority areas in the National Hepatitis C Strategy 1999-2000 to 2003-2004. Fifteen research priorities were developed by the Committee. Some of these priorities relate to virological, clinical, epidemiological research, while others are best addressed through social research or by having a social research arm built into the research. The full set of research priorities is outlined below. Those relevant to social research are 1, 2, 3, 4, 10, 11, 13, 14, 15:

“Reducing hepatitis C transmission in the community

1. Research programs demonstrating that reducing the sharing of injecting equipment will produce a significant decline in hepatitis C transmission.
2. Identifying sub-groups at increased risk of hepatitis C transmission, who act as core groups for the whole epidemic, especially including young people who inject, and monitoring transmission among these sentinel populations.
3. Qualitative and quantitative research into reasons for continuing to share injecting equipment among many populations of people who inject.
4. Ethnographic and other research on processes of initiation into injecting.

Treatment of hepatitis C infection

5. Retrospective and prospective cohort studies to better define the natural history of community acquired hepatitis C, so as to be able to target treatment and counsel people living with hepatitis C more effectively
6. Monitoring hepatocellular carcinoma incidence and causative associations
7. Identification and characterisation of major hepatitis C genotypes in Australia, and monitoring of trends in their distribution over time.
8. Further identification of virological and immunological factors involved in viral clearance (acute or later), and associated with disease progression and response to therapy clinic-based morbidity registers, and better links between clinical, social, epidemiological and virological investigations.
9. Development of diagnostic assays for acute hepatitis C infection.

¹ ANCAHRD Hepatitis C Committee “Hepatitis C Research Priority Areas” devised in August 2000.

Health maintenance, care and support for people affected by hepatitis C

10. Investigations of personal, social and economic costs of hepatitis C infection to the individual, the family, the health care system and the community.
11. Investigation of optimum methods for delivery of counselling, testing and treatment and other care for people living with hepatitis C, especially people who inject.
12. Health Program evaluation of models of specialist versus Care-Share community based care delivery.

Preventing discrimination and reducing stigma and isolation

13. Research to promote access of people who inject and their families to primary health care, and thereby access to hepatitis C treatment, vaccination (such as HAV/HBV) and other secondary services.
14. Systematic documentation of discrimination against people with hepatitis C, and investigation of underlying factors leading to discrimination.
15. Identification and investigation of barriers to appropriate treatment for people with hepatitis C."

The issue of research priorities was highlighted by a workshop organised by the ANCAHRD Clinical Trials and Research Committee (CTARC) and the ANCAHRD Hepatitis C Committee. The workshop, held at Coogee, Sydney, in November 2000, aimed:

- "To create a platform for hepatitis B and C research by bringing together researchers and other (sic) (to be) involved; and
- To discuss and develop a hepatitis B and C research agenda."²

A report on the workshop identified three priority themes.³ These were:

1. Markers of Risk and Disease Progression
2. Models of Care
3. Discrimination and Law Reform.

Under these themes a number of research priorities were identified. Although there were no social research priorities identified for theme 1, the monitoring of behaviour related to hepatitis C transmission is an important research priority. A number of research priorities are outlined below with regard to the other two themes:

² ANCAHRD Clinical Trials and Research Committee (CTARC) and the ANCAHRD Hepatitis C Committee (2000) "Adding Value: Hepatitis Research Workshop", ANCAHRD, page 2.

³ This report was in the form of correspondence from Professor Robert Batey, Chairman, ANCAHRD Hepatitis C Committee, dated March 6th, 2001.

“Models of Care

- Defining the treatment, care and support needs of people from diverse linguistic and culturally backgrounds.
- Research into the nature of symptoms and their impact on quality of life to determine optimal models of care for people with B and/or C.
- Studies into the reasons why some people with hepatitis B and/or C do not take up treatment or do not complete treatment.
- Studies to identify and define ongoing, non-medical and support issues of people affected by hepatitis C and/or B.

Discrimination and Law Reform

- Hepatitis B and C related discrimination needs to be defined more clearly and addressed actively.
- Studies are needed to assess the impact of discrimination and stigmatisation on the health, well-being and quality of life of people affected by hepatitis B and/or C.
- Partnership of affected communities with researchers is critical to any discussion of an evolving research protocol for research into discrimination and law reform.”

This project

This project was commissioned as a result of ongoing discussions that took place during 2000 between the Commonwealth Department of Health and Aged Care, HIV/AIDS and Hepatitis C Section, the Australian Hepatitis Council (AHC), the Australian Intravenous League (AIVL) and the National Centre in HIV Social Research (NCHSR). The project had two arms. The first involved a national consultation to be conducted with AIVL and AHC, and their member organisations in order to assess from the “ground up”, the social research needs of the sectors. The second arm involved gathering existing literature reviews and compiling a reference list of published social research articles, reports and policy documents related to hepatitis C in order to evaluate gaps in the literature. An advisory committee was established to oversee the process. Membership of this committee is given in Appendix 4.

This report begins by describing the methodology used in the project. Chapter 3 provides an overview of social research and other literature in the field. Bibliographies of this literature can be found in Appendixes 1, 2, 3. Chapters 4 and 5 outline the social research issues identified during the consultation.

Methodology

Aims

Arm 1 – Review of Literature

To locate literature relevant to the social research needs in order to a) identify gaps where existing research has not been synthesised into review format and, b) indicate where there is a lack of research in a particular area.

Arm 2 – Consultation

To undertake a consultation with AIVL, AHC and their member organisations in order to identify their social research needs.

Method

Arm 1 – Review of Literature

This arm involved locating literature on hepatitis C, specifically that which related to psychosocial aspects of the epidemic. This included:

- Searching for existing literature reviews on topics related to hepatitis C (e.g. reviews on the public health efficacy of needle and syringe programs).
- Compiling literature published in peer reviewed journals.
- Compiling “grey” material (e.g. research and technical reports, needs assessments, policy, briefing papers).
- Locating key government policy and other documents.
- Searching for literature published on areas related to, but not specifically about, hepatitis C (e.g. the experience of chronic illness).

Literature was located via the following strategies:

- Searching databases including: Current Contents, Medline, Psycinfo, Social Science Citation Index, Social Science Index, Social Science Plus and Sociological Abstracts. Key words used for searching were hepatitis C, blood borne virus, injecting drug use, injection drug use, intravenous drug use, prevention, treatment, antiviral therapy, discrimination, stigma, chronic illness, quality of life, illness and medicine.
- Searching university library catalogues from in the University of New South Wales, the University of Sydney, The University of Western Sydney, Macquarie University, and the University of Technology.
- Following up relevant studies from the National HCV Research Register for publication of reports.

- Obtaining conference papers from abstract books produced from relevant conferences.
- Contacting specialist libraries/resource centres for publications including Alcohol & Other Drugs Council of Australia; Australian Publishing Services; Centre for Education and Information on Drugs and Alcohol, NSW Department of Health; NSW Users and AIDS Association Resource Centre.
- Contacting research centres including Australian Institute of Criminology, Australian National University; MacFarlane Burnet Centre for Medical Research, University of Melbourne; National Centre for Education and Training on Addiction, Flinders University; National Drug and Alcohol Research Centre, University of NSW; National Centre in HIV Social Research, University of New South Wales; National Drug Research Institute, Curtin University; Turning Point: Alcohol and Drug Centre Inc., Victoria; and the Australian Centre in Health, Sex and Society, LaTrobe University.
- Contacting individual researchers in the field including Dr Nick Crofts, MacFarlane Burnet Centre, University of Melbourne; Dr Kate Dolan, National Drug and Alcohol Research Centre, UNSW; Professor Sandy Gifford, Deakin University; Associate Professor Wendy Loxley, National Drug Research Institute, Curtin University.

Arm 2 – Consultation

User groups and Hepatitis Councils were contacted to take part in a group discussion of social research needs. A document designed to prompt thinking about social research and its links with education was developed and circulated to the organisations prior to the discussion (see Appendix 5).

Consultations were conducted either face-to-face or by teleconference. The consultations were fairly free-flowing, however the consultant did facilitate discussion around the areas of research content/focus; research process; and research products. During the consultation, the consultant copied down, in 'dot point' form, the main issues discussed. This was then emailed to the organisations for them to check, correct and send back. The amended copy was then sent back to the consultant for final analysis. In a few cases the organisations opted to forward a list of social research foci to the consultant rather than have a face-to-face or teleconference consultation. The organisations consulted are listed below:

Peak Bodies

Australian Hepatitis Council (AHC)
Australian Intravenous League (AIVL)

Hepatitis C Councils

Hepatitis C Council of Western Australia
Hepatitis C Council of South Australia
Hepatitis C Council of New South Wales
ACT Hepatitis C Council
Tasmanian Council on AIDS and Related Diseases (TASCARD)
Hepatitis C Council of Victoria
Hepatitis C Council of Queensland

User Groups

Western Australian Substance Users Association (WASUA)
Canberra Injecting Network (CIN)
TopEnd Users Forum (TUF)
New South Wales Users and AIDS Association (NUAA)
Queensland Intravenous AIDS Association (QulVAA)
Drug Users Network Education and Support (DUNES)
Sunshine Coast Intravenous AIDS Association (SCIVAA)
South Australian Voice for Intravenous Education (SAVIVE)
Tasmanian User Health and Support League (TUHSL)
User Association of South Australia
Victorian Drug User Group (VIVAIDS)

Time frame

May 2001- July 2001

Analysis

Arm 1

Peer reviewed articles and grey material, (including existing literature reviews), were collected and examined in relation to the research priorities identified during the consultation process in order to identify gaps in the literature and areas of overlap.

Arm 2

Consultation information was thematised using the principles of grounded theory developed by Glaser and Strauss.⁴ Information was sorted according to key themes, areas and issues for research. The priority research areas identified by the organisations were taken into account when analysing areas for research.

⁴ Glaser, B.G. & Strauss, A.L. (1967) The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine

Social Research Literature on Hepatitis C

This arm of the project aimed to locate literature relevant to social research needs in order to identify gaps where existing research has not been synthesised into review format and indicate where there is a lack of research in a particular area.

Three bibliographies were produced using the method outlined in Chapter 2. These are:

Bibliography 1 — Organises hepatitis C literature under the headings outlined in the National Hepatitis C Strategy 1999-2000 to 2003-2004. (See Appendix 1).

Bibliography 2 — Organises hepatitis C literature under the headings: Literature reviews, Policy documents; Government reports; Other reports. (See Appendix 2).

Bibliography 3 — References select articles and books related to, but not specifically on, hepatitis C under the headings: Living with chronic illness; Living with cirrhosis; Mental health/depression and physical illness; The clinical encounter; Alternative treatments. (See Appendix 3).

It should be noted that not all literature referenced in the bibliography stems from social research or is psycho-social in its focus. The bibliographies are fairly inclusive of different types of publications from a variety of areas including epidemiology, policy and some clinical research, where appropriate. The bibliographies were produced as resources to be drawn on, not as lists of social research papers.

With regard to the first aim, a number of existing literature reviews (a review synthesises international and local research findings) were located (see Appendix 2). For example there is a review from a sociological perspective that examines research and material on issues relating to living with hepatitis C, including discrimination; the experience of diagnosis, disclosure and the psycho-social impact of treatment and medicalisation (Hopwood and Southgate, 2001). This review draws on peer reviewed journal articles, books, government policy and reports, needs assessments and popular texts such as survivors guides. As the authors note there is a relatively little peer-reviewed literature on issues related to living with hepatitis C.

Most reviews focus on injecting drug use, where there is a longer history of behavioural research into the transmission of blood borne viruses such as HIV, and more recently, hepatitis C. For example, there are reviews of the evidence base for public health efficacy of needle and syringe programs (Dolan et al., 2000); indigenous injecting drug use (Holly, 2001; Meyeroff, 2000); and initiation and transition to injecting amongst young people (Zinkiewicz, 2001). There is also a review of the literature of educational interventions aimed at preventing the transmission of blood borne virus including hepatitis C (Dowsett et al., 1999). Sykes (1996) provides a review of social research related to hepatitis C and injecting drug use.

With regard to the second aim, identifying where there has been a lack of research, Bibliography 1 (Appendix 1) reveals that most research has focused on prevention and

transmission-related issues because of the longer history of research into the transmission of blood borne viruses, in the first instance HIV and injecting drug use. Less research has been conducted around the psycho-social aspects of treatment. Research that does exist in this area often uses the construct of health-related quality of life and the quantitative instruments devised to measure this construct (for example the Short Form 36 survey [SF36] or the Sickness Impact Profile [SIP]). The quality of life approach also figures significantly in the area of health maintenance, care and support. In the area of discrimination and stigma, there are a couple of key documents including work by Burrows and Bassett (1996) and Crofts et al. (1997). Recent research by Gifford et al. (2001) promises to explore the issue further.

In summary, there is more social research on prevention and transmission-related issues than on the other areas outlined in the *National Hepatitis C Strategy 1999-2000 to 2003-2004*. Most existing literature reviews concentrate on injecting and transmission of blood borne viruses. The quality of life approach is frequently employed in the areas of treatment and health maintenance, care and support. Other social research approaches such as those informed by narrative theories do not figure in these areas. Some key documents have been produced in the area of discrimination and stigma. Information on this topic will be greatly enhanced by the release of findings from current research studies in the area (for example in studies undertaken by a collaborative team made up of participants from Deakin University, ARCSHS, NCEPH, AIVL and AHC, and by the National Centre in HIV Social Research).

Research Needs

During the consultation process, organisations were asked to identify key areas or issues for hepatitis C social research. These areas were formulated into 18 domains by the researcher. The peak bodies, AIVL and AHC, in consultation with their members, then prioritised the domains.

The 18 domains are:

1. Prevention
2. Peer education
3. Advocacy
4. Discrimination and stigma
5. Attitudes, beliefs and knowledge
6. Experience of testing and diagnosis
7. Impact of disclosure
8. Antiviral treatment
9. The clinical encounter
10. Complementary and alternative therapies
11. Chronic illness
12. Mental health
13. Prisons
14. Rural and remote issues
15. Issues for people who are differently-abled
16. Issues for people from indigenous backgrounds
17. Issues for people from culturally and linguistically diverse backgrounds
18. Issues for young people

The consultation process produced a list of possible research questions under each domain:

1. Prevention

- What factors affect negotiating safer injecting drug use (e.g. gender, age)?
- What rituals of group injecting contribute to hepatitis C transmission? What injecting practices between serodiscordant couples (one who is infected and one who is not) are risky?
- What is people's knowledge of re-infection? What is their understanding of infectivity?
- What place does hepatitis C hold in users' hierarchy of immediate needs? How does this impact on safer use?
- What cultures of injecting and their associated risk practices involve the injection of drugs other than heroin and amphetamines e.g. pharmaceutical pills, methadone, morphine?

- Who are the hidden groups of injectors (e.g. white collar) and what are their risk practices?
- What risk practices are associated with amphetamine use?
- Are there workplaces where transmission risks are high e.g. hairdressers, pathology labs?
- Are there issues of trauma, such as sexual assault and domestic violence, that impact on the ability of women to practice safer use?
- Are needle and syringe vending machines effective in reducing transmission?
- What do users know about cleaning fits? How do they clean fits?

2. *Peer education*

- How effective is peer education in prevention? What models are available?
- What ethical issues arise when conducting peer education and research?
- What do consumers expect from the advocacy process?

3. *Advocacy*

- How effective is advocacy? What models are available?
- What ethical issues arise when advocating for people with hepatitis C and/or those who inject illicitly?
- What do consumers expect from the advocacy process?

4. *Discrimination and stigma*

- What is at the root of hepatitis C discrimination?
- How does systemic discrimination operate in particular settings (e.g. hospitals)?

5. *Attitudes, beliefs and knowledge*

- Community attitudes- What are the broader community attitudes, beliefs and knowledge about hepatitis C prevention and harm reduction and illicit drug use?
- Service provider attitudes- What are the attitudes, beliefs and knowledge about hepatitis C among those in direct contact with people affected by the virus e.g. prison guards, judiciary, nurses, pharmacists, dentists, community health workers, doctors?

6. *Experience of testing and diagnosis*

- What are people's experiences of pre/post test counselling? How does the experience of pre/post test counselling affect a person's sense of empowerment or powerlessness?
- What messages are conveyed at the point of diagnosis, particularly around "innocence" versus "guilt" regarding the mode of infection.
- What impact does testing have in detoxification situations?

7. *Impact of disclosure*

- What is the impact of disclosing one's hepatitis C status to children, family and friends?
- What impact does the mode of infection (medically acquired versus injecting) have on the disclosure process?

8. *Antiviral treatment*

- What are the barriers and facilitators to treatment uptake?
- How well informed are people before they go into treatment? Are there “myths” surrounding treatment?
- What are the psycho-social impacts of undergoing treatment?
- What effect does injecting as a part of treatment have on former injecting drug users?
- What are the psycho-social impacts of treatment failure? Do people feel like “bad patients” if their treatment fails or if they are asked to leave treatment?
- What are the attitudes of treatment staff to people affected by hepatitis C?
- What are the attitudes of treatment staff to former and current injecting drug users?

9. *The clinical encounter*

- What is the dynamic of the clinical relationship between the person affected by hepatitis C and their general practitioner (GP) or specialist? What understandings of infectivity, prognosis and disease are produced during the clinical encounter?
- How does information flow from the specialist to the GP in regard to antiviral treatment and health maintenance? Is this flow affected if the GP is rural?
- Does the relationship between the affected person and the GP/specialist change when the GP/specialist finds out that the patient is a current or former injecting drug user?
- How do people use their clinical markers (ALT levels, biopsy results) to understand their health? Do these understandings/interpretations of clinical markers impact on quality of life?

10. *Complementary and alternative therapies*

- Who seeks complementary/alternative therapies? At what stage of their lives or prognosis do people affected with hepatitis C seek complementary/alternative therapies?

11. *Chronic illness*

- How do people manage symptoms in their everyday lives?
- What impact does living with hepatitis C have on one’s working life?
- What role do GPs have in health monitoring and maintenance?
- What are people’s experience of a cirrhosis diagnosis? Are they followed-up, supported and referred?
- Is there a burden of illness? How do people cope with isolation, discrimination, lack of access to health care and social support?
- Is the experience of chronic hepatitis C different according to time since diagnosis (e.g. those diagnosed in 1990 versus those recently diagnosed)?
- What are the barriers and facilitators to adopting a healthy lifestyle (e.g. in diet, alcohol consumption, stress management)?

12. Mental health

- What is the relationship between a hepatitis C diagnosis and depression?
- How do people cope with depression during treatment?

13. Prisons

- What are the practices and contexts of hepatitis C transmission in prisons? Are there gender, ethnicity and age differences that affect these?
- How does social stratification in prison affect risk taking?
- How is the safer using knowledge of prisoners circumvented by the constraints of the prison environment?
- What affects prisoners' decisions to test for hepatitis C and what are their expectations of care and support? Are there "continuity of care" issues?
- What is the experience of pre/post test counselling in prisons?
- What information and support is offered to HCV positive prisoners?

14. Rural and remote issues

- Does living in a rural area affect a person's disclosure of hepatitis C status to their GP?
- What are the barriers and facilitators to treatment uptake for people living in rural and remote areas?

15. Issues for the differently-abled

- How are differently-abled people affected by hepatitis C?

16. Issues for people from indigenous backgrounds

- What are the prevention issues for indigenous people?
- What is the experience of diagnosis for indigenous people?
- Is there access to culturally/linguistically appropriate information and services?
- What types of social support are needed for this group?
- What are the barriers and facilitators to treatment uptake for indigenous people?
- Are there culturally different understandings of hepatitis C infection, biopsy, treatment and blood?
- What types of discrimination do indigenous people affected by hepatitis C face?

17. Issues for people from culturally and linguistically diverse (CALD) backgrounds

- What are the prevention issues for those from CALD backgrounds?
- What is the experience of diagnosis for those from CALD backgrounds?
- Is there access to culturally/linguistically appropriate information and services?
- What types of social support do people from CALD backgrounds need?
- What are the barriers and facilitators to treatment uptake for those from CALD backgrounds?
- Are there culturally different understandings of hepatitis C infection, biopsy, treatment and blood?

- What are the needs of refugee groups in relation to diagnosis, support and treatment?
- What types of discrimination do people from CALD backgrounds affected by hepatitis C face?

18. Issues for young people (under 26 years)

- What is the impact of a diagnosis on young people? Does it lead to behaviour change or increased risk taking?
- How do young people view hepatitis C (e.g. as a “badge” of a real user; as inevitable)?
- Where do young people access new injecting equipment? Do young people access needle and syringe programs?
- What are the circumstances surrounding young people’s initiation to injecting?

In general, the 18 research domains fit within the four areas outlined in the *National Hepatitis C Strategy 1999-2000 to 2003-2000*: Reducing hepatitis C transmission in the community; Treatment of hepatitis C infection; Health maintenance care and support for people affected by hepatitis C; and Prevention of discrimination and reducing stigma and isolation. Some domains span the four areas of the Strategy, indicating a need for social research to ask questions across the areas. For example, the domain of “Chronic illness”, takes in issues of care and support, mental health, the clinical encounter between people with hepatitis C and their doctors, isolation and access to services and the impact of discrimination and stigma on the above. Finally, the domains identified by the community sector enhance and in some cases add to those priority research areas established by the Hepatitis Committee of ANCAHRD. For example, while there are no social research questions addressing the experience of antiviral treatment in the Committee’s document, the community sector singled treatment out as an important domain for social research.

Social research priorities

AIVL and AHC, in consultation with their member organisations, undertook to prioritise the 18 research domains. The following represents the top five research priorities of the two groups:

AIVL with user groups

Peer education
Discrimination and stigma
Prisons
Prevention
Attitudes, beliefs and knowledge

AHC with hepatitis councils

Discrimination and stigma
The clinical encounter
Impact of disclosure
Prisons
Rural and remote issues

The Research Process

The consultation process aimed to elicit insights into the processes of social research as much as the content. A number of issues regarding research were raised. These included the difficulties that social research sometimes generated; issues of partnerships in research between community organisations and researchers; capacity building; dissemination; and the usefulness of research products. The consultation also sparked ideas for building mechanisms for ongoing dialogue about social research priorities between the community sector, researchers and government.

Difficulties

Most organisations indicated a willingness to actively engage with social research and social researchers. All hepatitis councils and some user organisations not located in the eastern states expressed an enthusiasm for collaborating on research. However, some user organisations, had experienced a range of difficulties as a result of taking part in research. These included:

Research fatigue

The issue of research fatigue was restricted to a few user groups (mainly in the eastern states). Some user organisations described themselves and their clients as being over-researched. The problem of research fatigue resulted in clients not responding to the organisation's own data collection process, an outcome that proved detrimental to the organisations ability to justify or increase their funding through the use of their own statistics. Because of this situation some organisations had adopted a policy of screening research proposals by asking the question - "What benefits does the proposed research have for our organisation and the consumer?".

Impact on staff and volunteers

Staff and volunteer participation in recruitment for research was sometimes viewed as time-consuming and an unwelcome distraction from core duties. In addition, some staff members felt that in needle and syringe program (NSP) contexts their relationship with the client sometimes changed for the worse if they had to administer a research instrument, usually a questionnaire. They felt that many NSP clients preferred their anonymity and did not like to disclose personal information to a staff member or volunteer.

Ethical issues

Some user organisations raised the question of confidentiality and privacy in relation to the practice of administering questionnaires and interview schedules in public spaces such as NSP reception areas. Service providers were also concerned that research often raises sensitive issues for people and that there was often no referral or debriefing process available when these issues arose. Others from user organisations suggested that many questions asked of users were "offensive" and "stereotyping". Some user organisation staff also expressed concern over where the findings of research were disseminated and how these findings were used.

Building partnerships and collaborations

There was unanimous agreement that the research process worked well when an equitable partnership between researchers, community organisations and the groups being researched was formed. This meant involving community organisations and affected groups from the very beginning of the research process. Devising clear strategies to involve community organisations and those being researched was fundamental. This meant establishing, at the beginning of the process, clear expectations about levels of involvement, time frames and modes of ongoing feedback and final dissemination of findings. Many of those consulted stated that it was important to invite representatives from community organisations and affected communities onto steering and advisory committees. Finally, any partnership needed to take into account the research needs of the organisation as well as the researcher. For example, while many organisations saw value in quantitative research they also recognized the way in which qualitative research could directly inform the production of education materials and strategies.

Understanding social research: The need for capacity building

There was widespread acknowledgement among both user groups and hepatitis councils that they have a limited understanding of social research, its uses, advantages and limitations, and its relationship to education. Many stressed the need for capacity-building around these issues and offered the following suggestions:

- Existing “get-togethers”, for example the Hepatitis C Educators Workshop and the Australasian Conference on Hepatitis C, could be used as an opportunity to bring researchers and educators together to build capacity and workshop research findings.
- A clearinghouse for hepatitis C research could be established so that research can be disseminated in a timely fashion.
- The Social Research Register should be updated so that people in community organisations can make contact with researchers who are doing work in their field.
- A list-server established so that dialogue could take place online.
- An education-research liaison staff position should be established to build capacity and workshop findings with community organisations.
- A model needs to be developed so that community organisations can be “skilled up” and supported to do action research and other applied research methods such as rapid assessment procedure and needs assessment.
- Where possible, researchers should return to organisations to workshop findings and discuss the applicability of findings to education. It would be useful to discuss reports or papers when they are in draft form as waiting for final publication means that education programs are not informed by research. Timeliness of dissemination is important.

The products of research

Those consulted found executive summaries in reports and one page sheets summarizing findings to be most useful. Many commented that research findings should be concise and written in accessible language. Easy-to-read graphs were considered an appropriate mode of delivering information. Due to low literacy levels among some groups, it was suggested that in some cases research findings could be disseminated in audio or video tape form.

Mechanisms for producing research priorities

There was a widespread recognition of the need to develop mechanisms to facilitate on-going dialogue between researchers, community organisations, affected groups and government. An ongoing dialogue would allow the research agenda to become responsive to changes “on-the-ground” which would in turn, lead to research that better informed the development of relevant education programs. Those working in hepatitis C education acknowledged the relatively dispersed nature of the sector, both for educators and researchers. This dispersal meant that it was important to develop a mechanism or mechanisms for feeding back research findings and setting research priorities. Suggestions for ongoing mechanism/s to set the research agenda included:

- An annual consultation round, similar to the one conducted for this project or one conducted by the peak bodies on behalf of the constituents.
- A broader annual consultation that took in the Haemophilia Foundation and key stakeholders working outside user organisations and hepatitis councils.
- The use of existing meetings such as the Hepatitis C Educators Workshop to consult with stakeholders.
- An online consultation process that could be linked to the development of a list-server and/or online bulletin board or chat room.
- An annual meeting specifically designed to discuss the research agenda involving community, researchers, government and other stakeholders.
- An education liaison person could feedback community research priorities in an ongoing fashion.

In summary, the majority of organisations acknowledged the need for strategic social research and supported the idea of collaborating on social research studies providing the partnership was equitable and ethical. All recognized the need for capacity building in regard to the types, uses and limitations of social research and the relationship between social research and the development and delivery of effective education. Most were interested in building the capacity of community organisations to conduct applied research, where appropriate. There was widespread support for creating mechanisms to facilitate on on-going dialogue with social researchers in order to make the research agenda responsive to changes in the field and to provide a means for timely feedback of research findings.

Appendix 1

Bibliography 1:

Literature related to areas outlined in the National Hepatitis C Strategy 1999-2000 to 2003-2004

Published and unpublished articles, chapters in books and books organised under the headings of the National Hepatitis C Strategy 1999-2000 to 2003-2004 – Reducing hepatitis C transmission; Treatment; Health maintenance, care and support; and reducing discrimination and stigma.

1. Reducing hepatitis C transmission

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Appendix 2

Bibliography 2:

Literature reviews, policy and reports

This bibliography lists existing literature reviews, policy documents and government and non-government reports (including research and consultation papers).

Literature Reviews

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Appendix 3

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Appendix 4

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Appendix 5

What are your social research needs?

This project is assessing the social research needs of those working in hepatitis C and the injecting drug use field. We are talking to a variety of individuals and organisations, including AIVL, Australian Hepatitis Council, and state/territory based drug user groups and Hepatitis C Councils. The consultation will lead to an outline of research priorities for those working in the field. To assist us in this process we have produced this sheet for broad distribution as a way of getting staff, volunteers and peers thinking about their research needs.

We look forward to receiving your input.

Regards,

Erica Southgate, National Centre in HIV Social Research.



What is social research?

Social research investigates social and cultural phenomena. Social research aims to find out *what* is happening as well as improve our understanding of *why* it is happening.

For example there may be a particular group of people who inject drugs who appear to have different patterns of drug use from other groups. We might want to confirm our hunches about this group. The starting point might be to gather evidence to establish *what* they are doing. Once we have done this however we may require further understanding of the practice if the research is to be useful for our work. We may then want to know *why* they have the patterns of use they do. This type of research would then focus on the meanings and values the target population might attach to such practices, as well as what social processes might produce them.

Another example would be an investigation into why people with hepatitis C access antiviral treatment. Given that antiviral treatment has many side effects and needs to be undertaken for a long period of time, understanding people's decision making processes related to treatment uptake is important. Of equal importance would be examining psycho-social barriers to antiviral treatment uptake. Findings from a research project that explored antiviral treatment uptake could assist services in targeting education and support interventions.

Types of social research

Often people only think of research as surveys or data that focuses on collecting numbers. While this type of research is often important, it remains one of many approaches that can be used.

Social research includes case studies, focus groups, action research, a series of one-on-one interviews, cohorts where the same group of people are studied over a long period, and many other possibilities.

Whatever research method is adopted, it remains important to first clarify what the research question might be, and then once this has occurred, the best method of investigation is chosen.

All research approaches have their strengths and weaknesses. Often to overcome these research might adopt more than one approach, hoping to build a more detailed picture of what is occurring and why it is.

How can social research assist your work?

Good research should be able to assist you in your work. It could help you decide what programs might be needed for a particular target group, it might help you understand your target population, it might help you review current programs to determine if they are still appropriate, it might produce evidence that indicates your current programs are effective or ineffective. *What research will enable you to do this in your work?*

At other times research might be useful to produce evidence of events you already know are occurring. This type of data is often useful when negotiating funding and policy with government organisations.

It is also important that we not only identify research questions but that we think about why the answers to certain questions is important or useful. *How will we use the knowledge that emerges from research projects?*

Rarely does social research answer all your questions. Some of the questions we ask often have very complex answers that don't point to a simple program solution.

How you can assist social research?

Staff, volunteers and peers who work directly with people with hepatitis C and/or people who inject drugs play an important role in assisting the development and implementation of social research. Often 'frontline' staff, volunteers and peers have many hunches about consumer issues. Sharing these with the researcher helps in formulating research questions. So too is advising social researchers in accessing particular groups or the best research method to use with a group. This avoids valuable resources being wasted on research that is either not valuable or unlikely to successfully reach the target population.

Being clear on the priority research questions is an important starting point.

Some questions to ask yourself....

Over the coming weeks consultation meetings with individuals and organisations will be scheduled. To ensure these meetings are effective, below are some questions that may assist you and your colleagues in identifying research needs.

- What are some current issues you face in you work? What research might assist you in addressing those issues?
- What are some current issues affecting consumers? What research might assist you in addressing those issues?
- Is there more information (behaviour, practice, attitudes, values) about consumers that you would like, in order to inform your education programs?
- What research might help you plan and evaluate future activities?
- What research have you found useful in informing your education programs? Why?
- What research have you found less useful in informing your education programs? Why?