



Hepatitis C and Mental Health Issues Alberta Needs Assessment

**Hepatitis C Community-Based Prevention & Support
Fund, Public Health Agency of Canada**

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I. ACKNOWLEDGEMENTS

A special thank you is extended toward all those involved with the successful execution of the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment* research project. In particular, we extend appreciation to the mental health and medical care professionals who dedicate themselves in service toward Albertans affected by HCV. Their cooperation and completion of the online questionnaire has afforded valuable information. As importantly, we pay tribute with our utmost respect and gratitude toward participating HCV focus group clientele for coming forward and courageously providing intimate and heartfelt stories of successes, failures, needs, and concerns regarding living with Hepatitis C in the province of Alberta.

We would also like to acknowledge the NPNU mental health task group and the project Funders: Production of this report has been made possible through a financial contribution of the Public Health Agency of Canada. Other contributors include the Wild Rose Foundation and the Lethbridge HIV Connection Society.

This research is dedicated to the first HCV client interviewed in this study, who has since passed away, and to all like him who bravely and optimistically face their challenges in life and in death.

The opinions expressed in this publication are those of the respondents and do not necessarily reflect the official views of Health Canada, the Public Health Agency of Canada, the other Funders, the researcher or the Lethbridge HIV Connection. Information presented in this research is strictly limited to exact quotations and the research consultant's subjective summarization of transcriptions from interviewed focus group Hepatitis C clientele, questionnaire answers from mental health and medical health professionals, and dissemination lecture notes.

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II. INTRODUCTION

The Hepatitis C and Mental Health Issues – Alberta Needs Assessment is a compilation of information provided by persons living with Hepatitis C as well as professionals in the mental health and medical care fields throughout Alberta. The purpose of this community-based research is to increase knowledge and understanding of the need for professional and peer support for people living with Hepatitis C (HCV) in Alberta, and provide information for the enhancement of such supports. Data collected from focus group interviews, online questionnaires, and dissemination discussions afford a balanced representation of professional and layperson alike, in both rural and urban centers across the province. Findings include a rich and invaluable plethora of insightful dialogue spanning Hepatitis C targeted topics encompassing, but not limited to, available resources and services, education and awareness, medical/physical/emotional concerns, employment issues, housing, needle-exchange program utilization, financial burdens, and treatment and physician care. It is hoped that the depth and breadth of this research will assist in determining where funding and manpower would best be served to suit the needs of persons living with Hepatitis C throughout the province of Alberta.

III. PROJECT INCENTIVE

The purpose of this community-based research project is to increase knowledge and understanding of the need for professional and peer support for people living with Hepatitis C (HCV) in Alberta, and provide information for the enhancement of such supports.

The consultant conducted a needs assessment interviewing medical professionals (the majority of whom were nurses), and mental health care workers. All professionals interviewed represent health regions throughout Alberta. In the course of their duties, these professionals provide services to persons recently diagnosed with Hepatitis C, persons being treated for Hepatitis C, persons who consult a professional for mental health issues related to their Hepatitis C status, and in fine, all clients seeking professional services in one form or another who are at all affected by Hepatitis C.

In addition, focus groups were conducted with persons living with HCV as well as those attending such focus groups to become better educated and/or to support a loved one infected with HCV.

The project has been managed by the Lethbridge HIV Connection Society, on behalf of the NPNU mental health task group, and graciously acted as an advisory group to the researcher.

A. TIMELINE OVERVIEW

Start date for the project:	September 1, 2004
Research consultant selected:	October 28, 2004
End date for project:	March 31, 2005

B. PRIORITY POPULATION

The project is a provincial-based study and covered all health regions of Alberta. In each health region throughout Alberta, the following respondents were identified and petitioned to respond to the research:

- ❖ HCV workers:
 - Public Health Nurses collecting demographic data of new Hepatitis C cases
 - Nurses and/or physicians serving clients in treatment for Hepatitis C. There are 6 -8 nurses in Alberta who are members of the Canadian Association of Hepatology Nurses and who work with Specialists providing Hepatitis C treatment in Alberta
- ❖ Mental Health Workers
 - Representative from Regional Mental Health Programs
 - One or two community agencies providing support services (AIDS Service Organizations in each region recommended the agencies likely to provide Hepatitis C services in their communities)
 - Mental Health Counsellors working with HCV clientele
- ❖ Persons living with HCV:

The researcher conducted interviews within the following agencies, from six Health Regions, who graciously hosted support groups for people living with Hepatitis C. These agencies are listed in chronological order of focus group interviews:

- The HIV/AIDS Network of South Eastern Alberta HANSEAA (Palliser Health Region # 2). Contact: Elizabeth Anne Christie; Medicine Hat. Seven clients (one individual and six group participants) interviewed December 16, 2004.
- Bissel Centre in Edmonton (Capital Health Region # 6). Contact: Tracy Parnell; Edmonton. Nine clients interviewed December 18, 2004.
- Safeworks in Calgary (Calgary Health Region # 3). Contact: Linda J. Watson-Waddington; Calgary. Nine clients interviewed December 20, 2004.
- HIV North Society (Peace Country Health Region # 8). Contact: Bonnie Hessler; Grand Prairie. Twelve clients interviewed January 13, 2005.
- Safeworks in Calgary (Calgary Health Region # 3). Contact: Linda J. Watson-Waddington; Calgary. Eight clients interviewed January 20, 2005.
- The Lethbridge HIV Connection (Chinook Health Region # 1). Contact: Shirley Morgan; Lethbridge. Three clients interviewed January 26, 2005.
- The Life with Hepatitis Society, Red Deer (David Thompson Health Region # 4). Contact: Christine Thomas; Red Deer. Fourteen clients interviewed January 28, 2005.
- Individual interview in Lethbridge, at University of Lethbridge, February 1, 2005

C. STATEMENT OF NEED

According to the Alberta Health and Wellness¹ the prevalence rate of HCV infections in Canada is estimated to be 0.8 percent of the population. There were 2,191 new cases of HCV reported in Alberta in 2001. Much of the current burden of diseases for Hepatitis C in Alberta may come from chronic cases of HCV diagnosed prior to 1998. HCV rates were highest in the Edmonton area. Ethnicity data for HCV was incomplete, but HCV appears to affect First Nations in a disproportionate way.

Hepatitis C may be the biggest emotional challenge that infected clients will ever face. Learning about being infected with a chronic illness cannot be done without going through a grieving process. Grieving is nature's way of helping to adapt to new information about a chronic illness. Clients infected with Hepatitis C usually need help to cope at three phases of their illness:

- ❖ **Diagnosis:** clients and their family / friends may feel uncomfortable, have a sense of shock and loss, or go through denial. Special issues with Hepatitis C include feeling low, feeling contaminated, questions about how they got infected, looking good while being sick, a lack of information, and dealing with the fluctuating nature of Hepatitis C.
- ❖ **Impact:** persons infected with Hep C need to find out how to cope and live with the knowledge of the infection.
- ❖ **Reorganization:** clients have to come to term with a reduced energy level, make dietary changes, and decide on a treatment plan. Special issues at this phase include not knowing how the disease will progress and/or respond to treatment; recognizing sustained depression versus fatigue; understanding family and friends; creating and maintaining healthy boundaries.²

¹ Alberta Blood Borne Pathogens Surveillance Working Group. Alberta Blood-borne Pathogens Surveillance Report 2003. Edmonton, AB: Alberta Health and Wellness

² Everson, Gregory T., Living with Hepatitis C: a survivor's guide, Hatherleigh Press, 1999

All these emotional challenges can lead to stress. It is the opinion of many patients and a number of medical practitioners that the physical, mental and emotional symptoms of Hepatitis C are all accentuated either by high levels of stress or unhealthy methods of coping. Removing unnecessary sources of stress, developing healthy ways of responding to the inevitable levels of stress inherent in being alive and learning how to relax are therefore key issues for patients.³

Hepatitis C and mental health issues may become apparent to professionals at various stages:

- Mental Health Worker: A person seeking help for a mental health issue may also talk about being at risk or infected with Hepatitis C. In the course of seeking services from a mental health worker (in government, private or non-profit sector) the person may also need to be connected with professional or peer support services for their Hepatitis C condition.
- Public Health Nurse: When a person tests positive for Hepatitis C, a public health nurse will contact him/her for collecting demographic data and for contact tracing. This contact is also useful to provide additional information and referral services to the newly diagnosed person. Mental health issues may become apparent at this time. Alberta Health and Wellness is providing support and coordination to public health nurses in charge of Hepatitis C contact tracing.
- Nurses assisting with treatment for Hepatitis C. When a person needs treatment for Hepatitis C, the doctor and a nurse are usually the main contacts. They may seek additional professional and peer support during that time. Such nurses are members of the Canadian Association of Hepatology Nurses. They provide support to each other through meetings, updates and workshops. There are currently 6-8 Hepatitis C nurses in Alberta.

Although mental health issues are frequently mentioned in the literature, there are very few agencies currently funded in Alberta to offer peer and group support. The funding is almost always project funding and is therefore not sustainable.

In 2003-2004 the NPNU Mental Health Task group worked on a tool kit for helping agencies provide peer and group support to clients living with Hepatitis C. However, agencies interested in the kit do not necessarily have the human power or resources to facilitate the support work.

It is not known where persons living with Hepatitis C in Alberta find such support at the various stages of their illness. This needs assessment, in part, is designed to answer this and other questions thereby enlightening policy-makers and the general public as to the needs of HCV clientele and where funding would be best served.

D. AREA COVERED

Although the study area was the province of Alberta, there were health regions, or groups within health regions, that were not interviewed in this research project. The intent was not to purposely leave particular regions of Alberta without a voice in the subject matter. While additional health regions may have been able to host focus groups, thus greatly increasing the number of participants, the research committee became aware of focus groups interviewed by inquiry, investigation, and word of mouth. If the research consultant was unaware of a focus group, it became impossible to include the focus group in this particular research project. As well, time

³ Dolan, M., *The Hepatitis C Handbook*, North Atlantic Books, 1999

constraints and deadlines for this research project prevented further investigation into locating and petitioning additional focus groups for participation throughout other Alberta regions.

In spite of not being able to interview all Alberta health regions, this needs assessment is designed to benefit *all* health regions, as well as policy makers and planners, both provincially and nationally as we all work on Blood Borne and Hepatitis C strategies.

IV. WORK PLAN

A. GOAL/PURPOSE

The purpose of this community-based research project was to increase knowledge and understanding of the need for professional and peer support for people living with Hepatitis C in Alberta and provide information for the enhancement of such supports.

B. METHODOLOGICAL APPROACH

1. Qualitative data collection for this research project, based on naturalist and social constructionist research approaches, includes focus group research and grounded descriptive research.
 - *Focus Group Research*: A skilled facilitator mediates this audio-taped, interactive, homogenous group discussion within a permissive, non-threatening environment to better understand and evaluate the participants' views. Direct transcription of audiotapes provide a detailed account of focus group dialogues resulting in identification and assessment of common themes, summary descriptions, illustrative quotes, and researcher's conversational interpretations.
 - *Focus Group Research Strengths*: Discovery-oriented, usually a positive experience for clientele, is cost effective collecting meta-data in one sitting, is contextually sensitive, and capitalizes on the synergistic, snowballing effects of group discussion.
 - *Focus Group Research Confounding Variables*: Possibility of leading questions, respondents may answer according to what they perceive the facilitator wants to hear, audio-taped transcripts offer a limited portrayal of the interview (unable to capture emotional content and body language), inability to speak as candidly in front of others (or when being audio-taped) as when individually interviewed, results may not be generalized, reduces test-retest reliability, inability for clientele to attend the time/date of the scheduled focus group, Hepatitis C clientele may be hesitant to openly join a focus group fearing harassment &/or breach of confidentiality, not all persons with Hepatitis C know they carry the virus, limited non-random sampling, researcher bias, and limitations in quantitative empirically hypothesized testing.
 - *Grounded Descriptive Research*: Systematic data analysis, using both ordinal ranking of research results and interpretation of the research consultant, identify and assess common issues and themes within focus group transcriptions.
2. Quantitative data collection for this research project, based on mixed methodology research, includes intensive research, survey research, and Delphi research.
 - *Intensive Research*: Provides a rich description and analysis of the data collected.
 - *Survey Research*: Using a web-based method to collect questionnaire data has a number of advantages over its traditional paper and pencil counterparts. It was therefore the primary tool used to gather information from identified professionals. Web-based surveys are environmentally friendly in that they eliminate the need for paper, printing, envelopes, stamps, and the time and expense of physically preparing and mailing paper and pencil questionnaires. Web-based surveys automatically enter the data collected whereas with paper and pencil surveys the researcher enters the data manually. Response rates to paper and pencil questionnaires are considerably low compared to 50-90% U of L response rates from web-based instruments.

The University of Lethbridge Curriculum Re-Development Center converted the

traditional paper and pencil survey to an HTML (Hyper Text Mark-up Language) web-page interface. A link to this page was e-mailed to the professional respondents, who then completed the survey online. The results were stored in a confidential database until all of the responses had been collected. Access to a computer with an Internet connection and a web browser was the only requirement to receive and complete the survey. Once collected, the data was then exported directly to Microsoft Excel and Microsoft Word software packages which was then used by the research consultant for analysis. Funding originally allotted for mail-in questionnaires was used to employ the U of L for the web-page design.

- *Delphi Research*: Accessing expert/professional opinion from mental health and medical care professionals working with Hepatitis C clientele upon which a summarized consensus of qualitative information and empirically analyzed quantitative data was formulated by the research consultant.

3. Focus group protocol:

- The research consultant coordinated schedules with contacts from six Alberta health regions to secure a time and place for facilitating seven focus groups. The contacts from each focus group informed clients of the importance of participating in the research.
- Upon commencement of the focus group, the research consultant introduced herself and thanked all for attending. Each participant was given an “Authorization for Release of Information” and the researcher read, verbatim, the instructions and information while explaining and answering any questions⁴.
- Clients then completed the demographic information on the Authorization for Release of Information form, and signed and dated the consent forms while the group contact witnessed and signed the majority of the contracts.
- Once all consent forms were completed, the researcher began facilitating the focus group by beginning audio-recording and asking the previously designated questions.
- Each group interviewed generally took an hour and a half to finish.
- As a token of appreciation and extra incentive to draw Hepatitis C clientele to the focus group interviews, two strategies were utilized. Meals were provided for the focus group participants, as well as a \$10 remuneration for each respondent, which monies were issued upon completion of the focus group interviews. The focus group contact was also awarded a thank you card and \$15 gift certificate to Canada Safeway for her efforts in coordinating the group.

4. Professional online protocol:

- Seventy-three medical and mental health professionals throughout Alberta were e-mailed and an explanation of the research was given, along with a website requesting they take a few minutes to complete the online questionnaire. Each professional had to read and sign a confidentiality form permitting release of their information.
- While the response to the questionnaire was commendable, almost half of the professionals targeted (thirty-four respondents) simply filled out the initial demographic information and did not proceed to complete the questionnaire. The researcher believes the time commitment *perceived* by the professionals in order to complete the questionnaire may have been a deterrent.

⁴ See Appendix C: Authorization for Release of Information

- Nevertheless, the feedback offered by those who completed the questionnaire was invaluable. Twenty-eight professionals (a thirty-eight percent response rate) provided detailed information for this research project.

C. RESEARCH INSTRUMENTS

The following instruments were implemented by the project research consultant:

- Questionnaires: Web-based surveys, including open and closed-ended questions, were e-mailed to mental health and medical HCV workers⁵.
- Follow-up telephone interviews: It was proposed that follow-up telephone interviews be conducted with professionals who did not complete the web-based surveys. Due to time constraints and a respectable response rate, follow-up telephone interviews were not executed.
- Focus group discussions: Facilitated in at least six health regions representing large urban centres (Calgary and Edmonton), more rural areas (Medicine Hat), the North (Grande-Prairie), the South (Lethbridge and Calgary) and Central Alberta (Red Deer and Edmonton). Agencies consulted were informed that incentives would be provided to clients attending the focus groups in the form of a remuneration of \$10.00 per person participating in focus groups. As well, additional monetary compensation for food was supplied. The proposed budget included \$15.00 per person to cover such costs for 50 people. Budgetary discrepancies were considered and resolved in spite of the number of focus group participants exceeding the proposed estimations⁶.
- In-depth individual interviews: Administered in cases where focus groups can not happen because of confidentiality or other issues.
- Tele-health conferences with NPNU mental health advisory groups were held on a monthly basis.

D. EXPECTED OUTCOMES

It was expected the following information would be collected throughout the course of the project:

1. A list of Hepatitis C support services currently available, in Alberta, by Health Region.
2. Identification of discrepancies in available services between geographical areas in Alberta.
3. Increased knowledge about the kind of mental health issues faced by people living with Hepatitis C in Alberta.
4. Increased knowledge about types of referrals and agencies providing referral services to people living with Hepatitis C in Alberta.
5. Increased understanding of types of referral and support services currently missing for persons with Hepatitis C in Alberta.

E. SAMPLE POPULATIONS TARGETED

Mental Health Workers

- Alberta Health and Wellness gave the Lethbridge HIV Connection a list of contact names for the mental health program in each Health Region. Each Health Region's professionals were targeted, and asked to fill out one online questionnaire.

⁵ See Appendix A for mental health and medical care professionals questionnaire

⁶ See Appendix B for focus group/individual Hepatitis C client interview questions

- Other agencies included all AIDS Service Organizations and at least one other agency within each health region.

Medical HCV workers

- All Alberta nurses who are members of the Canadian Association of Hepatology nurses were contacted by e-mail and requested to complete an online questionnaire.
- Alberta Health and Wellness gave the Lethbridge HIV Connection a list of contact names of public health nurses for each Health Region. Nurses and medical doctors who work with HCV patients were e-mailed and asked to complete an online questionnaire.

Persons Living With HCV

- Facilitators from agencies listed in Section III, identified as hosting HCV support groups, contacted persons living with HCV who were willing to participate in the study. The researcher noted that all focus groups interviewed acknowledged a good turn-out by persons living with Hepatitis C compared to their usual support group meetings.

F. EVALUATION PLAN

Research evaluation representatives from the priority population are members of the NPNU Consortium and Mental Health Task Group. The Mental Health Task Group have been involved in planning for this needs assessment and has provided guidance throughout the process. Several program consultants of Alberta Health and Wellness have been petitioned and their expertise utilized in the planning stages and execution of this proposal.

The Advisory group provided guidance for the selected research consultant, met on a regular basis to review progress of research project, and reviewed and discussed findings and recommendations as presented by said research consultant.

The research consultant periodically reported project updates to Helene Wirzba: Project Manager.

G. PARTNERSHIPS

The principal partner for this needs assessment is the NPNU Mental Health Task Group.

The NPNU Mental Health task Group performed the following tasks:

- Reviewed and edited research proposal
- Assisted in selection of consultant
- Reviewed and approved of the research protocol
- Monitored progress of research (through NPNU mental health task group meetings and tele-health conferencing)
- Reviewed and discussed preliminary findings and recommendations
- Facilitated dissemination plan

The following organizations are currently represented in the mental health task group and graciously offered their support of this needs assessment project throughout the course of its execution (see letters of support):

- Regional Mental Health Program
- Alberta Mental Health Board
- Bissel Centre, Edmonton
- Life with Hepatitis C Society, Red Deer

- NPNU Program Consultant
- Lethbridge HIV Connection Society

Contacts were also made with representatives from the three target groups of respondents:

- Alberta Health and Wellness, Population Health Strategies and their Mental Health officer
- The Alberta Blood-borne Pathogen Surveillance Disease Control and Prevention Team Leader
- The Canadian Association of Hepatology Nurses.

All three groups have been aware of and supportive of the proposal. We received feed-back and suggestions from two of the three groups, and all of them agreed to provide contact names for each health region to the Lethbridge HIV Connection and the researcher.

The Lethbridge HIV Connection is currently receiving funding from the Wild Rose Foundation for its Hepatitis C programs in South-Western Alberta. This funding was used to cover the cost of office space and equipment rental used by the project manager.

In addition to the three agencies currently represented at the NPNU Mental Health Task Group, Safeworks, HANSEEA and HIV North Society agreed to host focus group discussions for persons living with Hepatitis C.

H. PROJECT FUNDING

Hepatitis C and Mental Health Issues – Alberta Needs Assessment submitted and approved by Health Canada, is funded by the Hepatitis C Community-based Prevention and Support Fund, Public Health Agency of Canada.

I. SHARING KNOWLEDGE

Respecting confidentiality of all respondents, the final report of the needs assessment is being shared with the NPNU consortium, all NPNU task groups, the respondents, AIDS Service Organizations and policy makers at Alberta Health and Wellness and Health Canada.

Findings and recommendations discussed by the Mental Health Task group will guide the work plan and priority settings of the task group.

The research findings were disseminated provincially at the Sixth Annual Alberta Harm Reduction Conference in Grand Prairie, Alberta, on March 23rd, 2005. Feedback from more than fifty people who attended the research dissemination has been documented and included in section V. I. of this research project.

J. SUSTAINABILITY

This was a one-time project which will hopefully feed into the development and implementation of Alberta Blood Borne Pathogen Strategy. Findings will also be useful to Regional Health Authorities and agencies providing support services to those living with or at risk of being infected with Hepatitis C.

V. PROJECT SCHEDULE AND DELIVERABLES

The project was designed to be executed in four phases, as displayed in Table 1.

Table 1. Project phases, schedule dates, research activities, and deliverables.

Schedule Dates	Research Activities	Deliverables
Phase I: November, 2004	<ul style="list-style-type: none"> Finalization of research proposal 	<ul style="list-style-type: none"> Research Proposal
Phase II: November, 2004 – January, 2005	<ul style="list-style-type: none"> Web page design and creation E-mail letter to respondents Arrange and facilitate focus group interviews Complete data collection Peer review 	<ul style="list-style-type: none"> Web page survey Survey responses Focus group and individual interview results Data analysis draft
Phase III: January, 2005 – February, 2005	<ul style="list-style-type: none"> Data analysis Draft report preparation Draft report peer review 	<ul style="list-style-type: none"> Draft report
Phase IV: March, 2005	<ul style="list-style-type: none"> Report finalization Dissemination 	<ul style="list-style-type: none"> 50 copy final report Peer presentation

Focus group interviews, professional survey responses, and data analysis as indicated in Phase II, were completed during Phase III. Deliverables from Phase III were completed during Phase IV. The research consultant was hired two months after the recommended start date, thus increasing the intensity of the proposed seven month workload by condensing it into a five month period.

Besides the initial two month cut from the research execution, winter weather conditions, frequency and availability of focus groups held throughout the province, and coordination of schedules between focus group facilitators and the research consultant throughout Christmas and New Years, were a few more challenges affecting the time frames wherewith the research was projected to be complete.

VI. RESEARCH RESULTS

Section V. delivers a summary of the project research results, addressing the expected outcome objectives as listed below in subsection A. Section B provides research based on the focus group interviews while section C identifies information provided by the professionals surveyed. Section D is a summary of comments made at a dissemination event of preliminary findings.

A. EXPECTED OUTCOME OBJECTIVE REVIEW

The project committee anticipated the following information would be collected throughout the course of the research:

1. A list of Hepatitis C support services currently available, in Alberta, by Health Region.
2. Identification of discrepancies in available services between geographical areas in Alberta.
3. Increased knowledge about the kind of mental health issues faced by people living with Hepatitis C in Alberta.
4. Increased knowledge about types of referrals and agencies providing referral services to people living with Hepatitis C in Alberta.
5. Increased understanding of types of referral and support services currently missing for persons with Hepatitis C in Alberta.

B. FOCUS GROUP RESEARCH RESULTS

Estimations and funding allocated, as outlined in the proposed research budget, projected fifty participants were expected to attend focus groups facilitated throughout Alberta. The final tally of HCV respondents interviewed, who participated in individual or focus group discussions throughout Alberta, was sixty-three.

Focus groups took place in six health regions only. The researcher was not aware of any organized Hepatitis C peer-support system in any of the other regions.

A 26% higher HCV clientele response rate than anticipated may be a message that persons living with Hepatitis C want to be heard, their needs articulated and met, and that there may be more people living with HCV than recognized.

The researcher commends those clients who stepped forward and participated in the focus groups despite fears of being stigmatized, persecuted, and their HCV illness revealed.

While facilitating focus groups of Hepatitis C related respondents throughout Alberta, the researcher found that particular sub-groups of persons living with HCV were not always represented in the sample interviewed. For example, the majority of focus groups consisted mainly of low income, unemployed clients.

1. Professional/Educational Resources

Professional Support/Educational Resources in Each Region: Focus Group Perspective

Region #1	Chinook Health Region, Lethbridge
Support Group	Hepatitis C support group through Lethbridge HIV Connection
Support Within Region	Hepatologist at Lethbridge Regional Hospital, Sexual Health Center in Lethbridge, National Hepatitis C Society of Canada, library (client found the library useless/void of information but appreciated accessing the internet at the library where client learned about HCV), AADAC
Support Outside Region	Boyle Street McCauley Health Center in Edmonton (before client moved to Lethbridge), Transplant Community in Edmonton, mental health counsellor in Calgary, Hepatitis C clinic in Calgary, Hepatitis C Clinic in Toronto
Other Resources Accessed	Pamphlets, internet websites, books, persons living with HCV

Region #2	Palliser Health Region, Medicine Hat
Support Group	Hep C Support Group through HIV/AIDS Network of South Eastern Alberta
Support Within Region	family doctor (minimally helpful), AADAC, Canadian Mental Health (minimally helpful)
Support Outside Region	Hepatology Clinic in Calgary for the majority of medical treatment, Lethbridge
Other Resources Accessed	Psychiatrist (no longer in practice), persons living with HCV, internet websites, pamphlets

Region #3	Calgary Health Region, Calgary
Support Group	Safeworks support group
Support Within Region	Awareness Trade Fairs in Calgary, Hepatologist/HCV specialist, CUPS, counsellors at CUPS, detox, doctors
Support Outside Region	Needle exchange program in Vancouver, Edmonton University Hospital
Other Resources Accessed	Books, pamphlets

Region #4	David Thompson Health Region, Red Deer
Support Group	Life with Hepatitis Society of Central Alberta Support Group
Support Within Region	AADAC counsellors, outreach workers at Canadian Mental Health, free meals at Loaves and Fishes, a listening ear at Potters Hands kitchen and housing, psychiatrist/David Thompson health region, psychologist, doctors, when I registered with the health nurse, self motivated research
Support Outside Region	Liver specialist in Calgary
Other Resources Accessed	Persons living with HCV, books, pamphlets, limited research/resources pertaining to children with Hepatitis C, book and video supplied by the Pegatron drug company, newspaper articles

Region #6	Capitol Health Region, Edmonton
Support Group	Bissell Center Hepatitis C Peer Support Group
Support Within Region	Street Works needle exchange program (insufficient assistance to meet the client demands since cutbacks), Canadian Liver Foundation
Support Outside Region	
Other Resources Accessed	Persons living with HCV, internet websites, books, videos (one of which clients in this group produced themselves, which they report is receiving international attention)

Region #8	Peace Country Health Region, Grande Prairie
Support Group	HIV North Society support group
Support Within Region	Psychiatrist
Support Outside Region	Specialist in Edmonton, a friend who is a nurse in California
Other Resources Accessed	Magazines on Hepatitis C, internet, "The Survivor's Guide", books, persons living with HCV, drug companies supplying Hep C medication provide videos and books on their particular medication as well as education about HCV, "Living with Hepatitis C", by Gregory T. Everson, book "Everything You Need to Know", by Jenny Heathcoat

Professional and educational resources/support services listed above have been investigated and/or utilized by focus group participants. This list does not necessarily mean, however, that the clients were satisfied with the services, nor is it an inclusive list of all resources available. There may have been services which the focus group clients either forgot to mention, do not need, or resources available that the clients are not aware of and thus are not identified in this research.

2. Peer Support Resources

Peer Support in Each Region: Focus Group Perspective

Region	Peer-support available
Chinook Health Region #1, Lethbridge	Persons living with HCV, Hepatitis C support group, family, friends, children, significant other
Palliser Health Region #2, Medicine Hat	Hep C Support Group through HIV/AIDS Network of South Eastern Alberta, persons living with HCV, friends, some clients said they have no one to support them
Calgary Health Region #3, Calgary	Wife, doctor, persons living with HCV, Safeworks support group in Calgary, friend
David Thompson Health Region #4, Red Deer	Friends, Life with Hepatitis Society of Central Alberta Support Group is my family, persons living with HCV, family, none/no support other than this group, roommates
Capitol Health Region #6, Edmonton	Persons living with HCV, Bissell Center Hepatitis C Peer Support Group, partner/significant other (if the client has one), Street Works needle exchange program

Region	Peer-support available
Peace Country Health Region #8, Grande Prairie	HIV North Society support group, persons living with HCV, church, recovery programs, significant other, friends, a friend who is a nurse in California

Most focus group participants who were interviewed declared they had little or no support except from the actual support group members. For most interviewed, the support groups provide an unparalleled place of security, confidentiality, education, strength, and camaraderie. While having the support group is a necessary ingredient for meeting the emotional and educational needs of the majority of client's, it is a large burden and responsibility on the support group leader to be the sole source of professional support for so many people. Plus, the support group facilitator is only as effective as the amount of information and knowledge she/he possesses, and only as effective as the available time she/he has to not only run the group but offer a listening ear and/or counselling to all who are in need.

3. Discrepancies Between Health Regions

Participants in focus groups identified the following discrepancies in peer and professional support between regions:

- Persons living in smaller communities, cities, rural areas, and Aboriginal reservations are forced to travel to bigger cities to meet their professional and medical treatment needs
- Less resources/support in Edmonton than Calgary
- Calgary has a Hepatologist whereas most other regions do not

Perceived Areas Currently Underserved or Void of Support Services include

- Northern communities
- Smaller, rural, or remote communities
- Aboriginal reservations
- All of Alberta except perhaps Calgary. Even Calgary has difficulty bridging the gap between the services and citizens' access to the services. Also, creating an awareness of the services available is difficult
- Some clients attending the Grande Prairie support group travel at least 100 kilometres from rural areas and some travel as much as 200 km to get to the focus group. When the focus group is at night, and a client has to drive 200 km home, and they are feeling lousy due to the Hepatitis C, it is difficult to be on the road safely. Since the focus group is only once a month, clients are desperate to attend at almost all cost

4. Responses to questions addressed to focus group participants

The following information was reported by clients and has not been verified for accuracy by researcher.

Answers to each question are broken down into geographical areas, where appropriate, to specify differences between Alberta health regions. As well, answers to some questions have been grouped into sub-categories for your convenience.

1. What are your greatest **medical concerns** about Hepatitis C?

Doctors:

- No doctors that treat Hepatitis C in Medicine Hat

- Once you've been diagnosed, your doctor basically has no time for you
- Doctors are not sympathetic
- Doctors stereotype people/doctors are biased against you or stigmatize you
- Doctors are pretty ignorant about Hepatitis C and how to treat it
- Doctors prescribe medications and send you out the door without information about the treatment, effects, and how to care for yourself as you take the meds
- Doctors handing you antidepressants as an answer for the symptoms of depression
- The doctor told me there were risks of suicide while on treatment and I should take an antidepressant
- Doctor pronounces you may as well get your affairs in order because you will die from Hepatitis C
- Doctor's not informing patients about the tests to be done

Treatment:

- I am forced/coerced by my doctor to take a medical or to go on treatment
- The drugs/treatment are really hard on you
- I've suffered through the treatment two times and I haven't gotten rid of Hep C
- Your body can be in torture for days at a time during treatment
- Couldn't finish the treatment because of contracting another disease, or getting too sick, or becoming suicidal
- Realizing after months of treatment that it is not working and having to stop without successful results
- Not aware of treatments that will work

Education:

- Can Hepatitis C be cured?
- If the doctors aren't educated about Hep C, how can they inform me?
- Education about HCV should come from the doctor who diagnoses you instead of sending you on your way in shock, not knowing what to think

Socioeconomic/financial aspects:

- Not aware of financial support available to be able to afford a liver transplant

Lack of resources/professionals:

- We don't have a Hepatologist in Medicine Hat
- You have to go to a Liver Clinic for the preliminary assessment to evaluate your candidacy for treatment. No clinic in Medicine Hat.

Other issues:

- How long you've got to live
- One of the first questions you are asked when assessed is 'Are you a druggie?' or 'Are you an intervenes drug user?'
- When treatment fails, just waiting to die
- I might have to get a liver transplant
- Will there be a liver donor for me?
- It's difficult having a dual diagnosis. I have diabetes and it's hard to eat the proper diet for your liver and diabetes and confusing keeping medications straight when trying to take injections for treatment and diabetes

2. What are your greatest **physical concerns** about Hepatitis C?

Physical symptoms:

- Weird, goofy spells
- Dizziness from the treatment
- Equilibrium/sense of balance
- Fainting
- Nausea
- Liver is tender and sore to touch/tender in the area where the liver is
- Skin rashes/breaking out from rashes
- Intense itching/no remedies to alleviate and cope with the itching
- Dry patches
- Arthritis
- Trigger finger
- Bleeding
- Bruising
- Aches in the knees, wrists, chest bone,
- Seizures
- Patterns of symptoms following treatment
- Memory loss
- Fatigue/loss of energy
- Sleeping disorders
- Difficulty staying awake
- Infections
- Hair loss
- Sores in mouth
- Lose your sense of smell
- Weight loss/loss of appetite
- Digestive system dysfunction
- Diarrhoea
- You sweat a lot
- You are freezing for eight to twelve hours after the treatment injection

Treatment:

- Treatment not being successful
- Long-term negative effects from the treatment
- Not completing treatment because of being too sick from it

Education:

- Not having access to answers about treatment and/or physical concerns

Other issues:

- Major complications due to Dual-Diagnosis from multiple mental health issues and/or physical issues such as Fibromyalgia
- Will the new liver take?
- Liver cancer

3. What are your greatest **mental health concerns** about Hepatitis C?

Abnormal affect:

- Depression/more depressed
- Sense of hopelessness
- Helpless
- Fear
- Frustration
- Cry easily
- Overly sensitive
- Inappropriate affect
- Worry
- Loneliness and isolation
- Embarrassment
- Shame
- Heartache
- Anxiety
- Guilt

Specific concerns:

- People look at you and judge you because you look fine so they think you are lying about being sick or you should be working
- You pretend you are fine and hide how sick and hopeless you feel
- You are too sick to work but you want to
- Fear that someone will find out you have HCV
- You resign yourself to chronic sickness
- Can't commit to anyone or anything because you don't know if you will be well enough to follow through
- Worry about infecting others – especially your kids
- Fear of even going on the treatment and how it will affect you emotionally even more negatively
- Not having the love and companionship that comes from intimate and/or sexual relationships
- Fear of rejection, so I don't even bother looking for love – I've been alone for over 15 years
- Heartache that comes from being shunned and treated like I have leprosy by people when they find out I have HCV
- You don't want others to judge you
- Don't want to have to tell people I have Hepatitis C
- It sometimes takes people years to tell others about their HCV
- You can tolerate the disease and treatment/medication, but when you've been a productive part of society, it is difficult to become a number and being treated like the plague
- Worry and anxiety wondering if the rejection drugs will work when you've had a liver transplant
- Guilt, for example, from lying about having HCV because you don't want to be judged or anyone to find out and then treat you badly
- Loneliness because you don't have a social life and you especially don't date because you don't want to chance the rejection when you tell your partner you have Hep C
- Suicide ideation, serious threats, attempts
- You drink to self medicate to escape your emotional pain

4. Where can you go to get **educational** information about Hepatitis C?

Professionals:

- Doctors
- Doctors didn't offer any information about HCV, pamphlets with information, or information about Hepatitis C support groups
- Hepatologist out of Lethbridge Regional Hospital
- Hepatitis C specialist in Calgary

Peers:

- From other people with Hepatitis C
- The support groups are a really great source of education

Organizations:

- AADAC
- Government of Ontario Hepatitis C Society
- Boyle Street McCouley Health Center in Edmonton
- Sexual health center
- National Hepatitis C society of Canada
- Hepatitis C society in Toronto
- Street Works/needle exchange programs
- Red Cross
- Safeworks
- Canadian Liver Foundation

Books/pamphlets/videos:

- Pamphlets/brochures
- Books (i.e. *The Gift of Death*, by Henri Picard; *The Survivors Guide*; *Living with Hepatitis C* by Gregory T. Everson; *Everything You Need to Know* by Jenny Heathcoat)
- Videos (one focus group made a video that is becoming internationally known)

Other:

- Internet websites (Webdoctor)
- Word of mouth
- Library for internet access
- HCV clients diagnosed years ago found there was no literature or information available
- Professionals rely on Hepatitis C clients to educate them. For example, one client was asked to analyze a film about HCV to assess accuracy
- Hepatitis C conferences in Toronto and Edmonton
- Vancouver, British Columbia has good resources
- University Hospital in Edmonton
- Conferences/Medical Trade Fairs
- Jail

5. How often do you utilize these educational resources?
 - Medicine Hat clients utilize the support group/agency twice a month, a couple times a week
 - Daily

6. Are there any barriers preventing you from easily accessing these educational resources?
 - Information on some websites may be available to the general public, but the dialogue is difficult to understand because it is for highly educated people like doctors, making the information meaningless to the layperson
 - Not knowing where to find the information
 - There is even less educational material for children with HCV than for adults
 - Ignorance of doctors
 - Computer illiterate
 - Cutbacks at Street Works make accessing professionals more difficult
 - Being treated and categorized with those persons having HIV
 - I won't go back to the doctor because I know more than he does and I don't trust him or his suggestions
 - People who don't have Hep C aren't interested in becoming educated. They aren't going to pick up a brochure and read about it because it doesn't effect them
 - How do you educate the layperson about Hep C if they aren't affected by it and have no desire to go out of their way to learn about it?

7. How did you find out about the places you can frequent for educational information about Hepatitis C?
 - Word of mouth
 - Self taught and self motivated to seek out information
 - Doctor
 - Churches
 - Already a client for depression and then my Hep C flared up

8. Where do you go for **professional support**, like counselling, for Hepatitis C?

Positive/useful:

- AADAC
- This agency/support group
- HIV office
- Transplant community in Edmonton
- Counsellor
- Lethbridge Family Services
- CUPS in Calgary – they have counsellors and doctors who specialize in HCV

Negative/not useful:

- Canadian Mental Health
- Our doctors have *not* been helpful
- We end up educating the doctors about support systems
- Even psychiatrists don't understand

9. How often do you utilize these professional support resources?

Focus group participants answered just about everything from several times a day to once every couple of months.

10. Are there any barriers preventing you from easily accessing professional resources?

List the barriers – not examples.

- Lack of professional understanding
- Misdiagnosis creates mistrust
- Depression is diagnosed and anti-depressants are suggested
- Not knowing what is available for me to access
- Not telling anyone you have it because you don't want to face the negative reactions
- Gossip
- Professionals refusing to work on you, like dentists, once they find out you have HCV

11. How did you find out about the places you can go to acquire professional support, like counselling, for Hepatitis C?

- People with HCV
- Doctor
- Pamphlets
- Internet websites

12. Where do you go for **peer support** for Hepatitis C?

- There are not enough support groups
- Here at the agency/at this support group where I can feel safe and not judged
- Street Works
- Family
- Best friend/friends
- Neighbour
- Churches/spiritual people
- Spouse
- Employer
- Transplant Association
- Twelve Step Program
- People with Hepatitis C
- Hepatologist
- Safeworks

13. How often do you utilize these various peer support resources?

- Every day. It's what keeps me going
- Every other day

14. Are there any barriers preventing you from easily accessing peer support resources?

- I have nobody to turn to except this group
- Isolation
- Not knowing you have HCV because you aren't sick yet
- Friends, family, and associates who were once an intimate part of my life have now abandoned and alienated me
- When you feel depressed and physically ill from HCV, it is difficult to get out of bed let alone attend support groups

- Ignorance and fear not knowing how they can catch it can cause family and friends to turn their backs on you
- Too far to travel/too much effort to access the support
- Fear of discrimination so I don't disclose I have Hep C
- I'm the only native that even comes forward admitting I have Hep C where I live
- It's difficult to spend time with others or share experiences when they are uneducated and believe you can give them Hepatitis C by breathing on them, or touching them, or sharing a joint with them

15. How did you find out about the places you can go to seeking peer support for Hepatitis C?

- People with HCV
- Doctor
- Pamphlets
- Internet websites

16. Where do you go for **medical support** for Hepatitis C?

- Medicine Hat clients go to Calgary and Lethbridge
- I have doctors at my fingertips ever since I have permanently resided in the hospital
- Doctor/Private clinic

17. How often do you utilize these various resources?

Answers to this question ranged from many times a month to once a month.

18. Are there any barriers preventing you from easily accessing medical resources?

Doctors:

- Most doctors in my town prescribe anti-depressants for our problems. Since I don't want to be on anti-depressants because I don't think that is the solution, I don't go to the doctor to get the medical assistance I need
- The doctor prescribes medication that says not to take it if you have liver disease
- The pharmacist knows more about medications you should or should not take than the doctor who prescribes the meds
- I did not get along with my doctor so I changed doctors
- The lack of Hep C knowledgeable doctors
- Only one doctor in Lethbridge and his bedside manner and attitude is unacceptable. His nurse's compassion and knowledge is the doctor's only saving grace
- Lack of doctor compassion
- My doctor didn't tell me there was a cure or treatment. I never found out until recently, from this support group, so how are you supposed to take advantage of the treatment if you don't even know its available?
- Don't trust the doctors because they are not educated about Hep C

Treatment:

- If you drink you can't be on treatment
- Not being able to meet the criterion for treatment even though I want the treatment
- Seeing how hard the treatment is on people in this support group helped me decide not to get the treatment
- Don't want to put myself through the traumatic negative affects of treatment

Lack of services:

- There are so few specialists that they don't have time to see you because there are so many clients

Socioeconomic/Financial:

- Even if you want a second set of testing to verify the accuracy of the first, they won't do it because of the cost
- Without the financial support of the group, using their HIV fund raising monies, I couldn't travel for my appointments
- No insurance
- Costs too much money

Transportation/travel:

- Small towns don't want to deal with you so they send you to a big city
- If you live in Medicine Hat and go to Lethbridge for an hour long appointment, you have to leave at 5:30am and you don't get back until 8:30pm. What do you do between the time?
- It takes a whole day to travel to Calgary from Medicine Hat to go for an appointment
- Driving so far to attend an appointment takes a lot out of you when you feel so fatigued as it is
- Being fatigued, it is easier to fall asleep driving when you are forced to take long road trips
- Transportation stops me from accessing treatment
- Traveling is mentally, physically, and financially draining
- People don't realize that if you are not well, you can have your traveling subsidized

Other:

- Medical staff breaching confidentiality by allowing unauthorized access to records
- What's the sense going through the treatment when you can't afford to eat properly to take care of yourself during treatment as well as afterwards
- When you arrive in a bigger city with money in your pocket for a hotel room and expenses, chances are you will spend that money on drugs or gamble it away instead of using it for the purpose it was intended – that being treatment.
- No caregiver to assist me during treatment
- Dishonest clients who do not want to admit they used drugs in the past
- To receive treatment, I have to go to a counsellor and I don't want to

19. How did you find out about the places you can go to seek medical support for Hepatitis C?
- Currently I have a wonderful family doctor who refers me to the clinic but prior to that I had a horrible doctor
 - People with HCV
 - Doctor
 - Pamphlets
 - Internet websites
20. Do you have access to a **needle-exchange** program?
- The needle-exchange program in Medicine Hat is effective and serves the clients well
 - Street Works
 - Six places in Edmonton plus a van that delivers right to your door
21. How often do you utilize this needle-exchange program?
- Answers to this question ranged from every day to a few times a month.

22. What are some of the barriers to utilizing the needle-exchange program?
- Don't want to be identified as a drug user
 - Don't want to worry about the police following me
 - Too busy using to stop and make my way to exchange needles
 - No way to get there/transportation issues
 - They are not open on weekends
 - I don't want to go in to the needle exchange program because I am trying to quit using. Then I end up using and not having the new needles or clean equipment
 - People go for me so I don't have to
 - It's a depressing place and I don't like to go there
 - I don't want to be around other users
 - I don't want to feel the stigma
23. How did you find out about the needle-exchange programs?
- Word of mouth
 - Hep C support group
 - Pamphlets
 - HCV specialist
24. Do you encounter barriers for **employment** because you have Hepatitis C? If so, what are the employment barriers?

Unpredictable health/physical limitations:

- You try to work and you get more sick
- Even if it's part-time work, you never know the days you will feel good enough to work so you can't guarantee an employer when you can work
- You can't get a job because you can't commit to specific hours not knowing when you will be healthy enough or have enough energy to work
- It's difficult when you have worked for years, really liked your job, was good at your job, and you have to give it up because you are sick and/or in treatment
- Knowing you can't perform like you used to
- An employer is not sympathetic to my having to take more breaks due to fatigue, or missing work because I can't get out of bed
- Memory loss can affect certain job performances
- I want to work but I am so tired and fatigued that I can not perform the required tasks at work
- Social workers want to send me to work because they don't believe I'm too tired

Emotional concerns:

- Going from job to job gets old - being fired or having to quit because of illness - you come to the point where you don't want the embarrassment or hassle anymore so you just don't work
- Bad attitude
- Lack of employer empathy/understanding

Lack of education:

- Employer ignorance about HCV prevents them from hiring you
- Co-workers do not know how to deal with a situation where you get cut on the job
- It took years before my co-workers became educated enough to be cool with my HCV

Discrimination/stigma:

- If you are honest and tell your employer you have Hepatitis C, you probably won't get the job
- Fired because you have HCV
- Co-workers may not want to be touched or not want to work side-by-side

Other:

- Difficult to go from disability back into the workforce
- Facing a moral and ethical dilemma not knowing whether to tell the employer you have HCV
- Some jobs aren't good for someone with Hepatitis C to have because of the increased risk of being cut – like being a chef, for example
- I can't work if I'm on disability

25. Is your **support system** affected because you have Hepatitis C? If yes, how so?

- You pull back from people/relationships
- Your support system becomes the Hep C support group because most everyone else turns their back on you
- You are isolated, alienated, and abandoned by friends and family at a time when you need friendship and support even more so

26. Are any of you **co-infected** with Hepatitis C and HIV?

Only two males reported being co-infected.

27. What are your main concerns about being co-infected?

The two co-infected clients declined to answer.

28. Do you think your concerns about being co-infected are different or greater than if you only had Hepatitis C? If yes, how so?

29. Do you have any **needs** related to Hepatitis C and mental health that are **not being met** at this point? (i.e. needs related to ethnicity, risk factors, etc.)

Financial issues:

- Financial benefit workers do not divulge information about the available funding resources for housing, diet, etc.
- I'd like to know what resources and funding are available to me
- I'd like to know what paper work I have to fill out, and how to fill in the paper work necessary for financial assistance

Diet:

- Diet/special nutritional needs not being met because you can't afford to eat properly
- No dietician to educate them about harmful foods or risky substances
- Repeated requests asking for a dietician have been futile

Treatment:

- If you're homeless you aren't eligible for treatment
- Medication needs to be refrigerated so if I have housing, but I live in a house sharing the kitchen, my meds will get stolen so I can't go on treatment
- I'd like to see the government do more research to find a cure for those people who have taken the available treatment and it hasn't worked

- I want someone available to administer the medication to me because preparing the syringe and giving it to myself is a trigger making me want to use again

Other:

- We would like a house like the one the HIV persons have where we can have free meals, keep our medications in the fridge, have access to counselling and professionals to talk to, and have someone to administer my medication to me
- They took away our bus passes so we have little or no transportation now

30. How would you suggest the needs identified in question # 29 be met?

Throughout the interviews clients would present solutions about various problems, but for the most part, focus group participants were eager to share their needs and concerns and time did not permit the dialogue to go into detail about what they deemed to be solutions to the problems.

31. Do you believe there are **differences in availability of support** services between geographical areas (North, South, Edmonton, Calgary), urban and rural as defined by Alberta Health and Wellness Health Surveillance?

- Each province has their own resources and regulations about funding
- Calgary has a Hepatology Clinic and Medicine Hat does not
- One Medicine Hat client had to wait three and a half months after initial diagnosis, until an appointment was scheduled in Calgary. In the meantime, the client knew nothing about HCV, what was going to happen to the client, what HCV does to other people, and proceeded to isolate from others until the client became educated about HCV from the Calgary specialist. If it wasn't for the client searching the Internet and finding out about the support group in town, they would have remained in the dark until their appointment in Calgary. The support group was a lifesaver and not only began the process of education, but alleviated a lot of concerns
- Lethbridge and surrounding area has to travel to Calgary or Edmonton to see a specialist
- No peer support focus groups in rural areas
- Spread of HCV in smaller communities because they don't have needle exchange programs
- Smaller communities will ostracize you if they find out you have HCV
- Rural areas and aboriginal reservations do not have specialists and have to travel great distances to be treated
- Less education about the spread of HCV in remote areas
- Less available resources and services in Edmonton than Calgary
- Vancouver, British Columbia has an exemplary system for servicing HCV clients

32. What are the differences in availability of support between the geographical areas described in question #32?

See question #31 for answers

33. Do you think persons living with Hepatitis C have difficulties securing adequate housing/living accommodations? If so, what are the difficulties?

- Living in a low income house with other users makes it difficult to stay clean (abstinent) or get clean
- Difficult to find affordable housing
- Living conditions in low income housing are substandard
- You can't be on treatment when you live in a house where you share the kitchen because your medication will be stolen out of the refrigerator

- Most housing is not wheelchair accessible
- Can't afford to make my home wheelchair accessible
- Anyone on AISH or not working can't afford the housing that's available
- More subsidized housing would be beneficial
- Housing rules about no drugs and drinking need to be enforced because even when you sign a contract saying you won't use, there is a house full of other people using drugs and the landlords turn their heads and let it happen
- When you have no money and you have to choose between eating and a roof over your head, you choose to eat
- By putting all the hard-to-house people in the same residence, like the Langdon House (Calgary), its like keeping all the sick people together. Its not a very good place to live if you are trying to get off of drugs

34. Do you have any issues and/or concerns we have not yet discussed?

Education:

- People/the public have to get the message and become educated about HCV
- There needs to be more awareness about Hepatitis C
- As much as you try to educate people, it seems futile
- People need to be educated about the benefits of the needle exchange programs because so many people believe that Safeworks and the van promote drug use
- You can't get a straight answer on medications you can or can't take, such as the effects of Advil on the liver
- Police, ambulance workers, lawyers, judges, doctors, and all others who deal directly with persons living with HCV need to be educated about Hepatitis C
- Doctors (and all professionals) should be required to take training workshops and become educated about Hepatitis C
- Doctors get a lot of their education from the pharmaceutical companies so their knowledge is biased based on the company who has the greatest influence on them
- Emotional damage can occur if doctors are not properly educated. For example, one doctor cautioned a mother not to breast feed her baby because she could spread Hepatitis C through breast milk. This caused both mother and baby significant distress financially, emotionally, and it negatively affected the baby's health and well-being.

Insurance:

- I can't get life insurance nor can I get mortgage insurance on my house. I sold my house and when I went to purchase mortgage insurance on my new house, I was denied. I never would have sold my old house and bought a new one had I known
- Insurance plans at work may not cover you because they claim you had a pre-existing condition
- You can't get life insurance if you have HCV. I went to the doctor to get the routine check-up for a life insurance policy and that's when I found out I have Hepatitis C. Then I was denied life insurance. It was a double emotional hit at the same time
- Applying for and securing life insurance is impossible once you've been diagnosed with Hepatitis C

Services/resources:

- If there was a Hep C house to go to, like the HIV Heart house, a Hep C client's money could be sent to the workers at the house so the finances would be accounted for and not misused by the patient. The house would also act as a source of education, support, a

- roof over your head so you don't live on the street when in town for treatment, and a safe place for refuge
- People getting out of jail need some financial assistance to give them a clean start. Low income often causes crime in order to survive. There needs to be a transition place to stay where you have the support and structure you need to adjust to reality
- Lack of transportation is an issue
- As a single mother, I find it hard to care for my children, especially during treatment, when I can barely take care of myself
- Lack of housekeeping assistance
- You can't afford the proper diet and/or you don't know what the proper diet entails because you don't have access to a dietician familiar with Hep C issues
- Cutbacks in agencies are reducing the number of professionals we can talk to
- There are a lot of people with Hep C who are unaware of available resources

Spread of HCV:

- There are a lot of people with Hep C who do not know they have it
- People who have Hepatitis C need to be educated about spreading various strains of Hep C to each other. For example, drug users sharing needles are complacent thinking it doesn't matter since they all have Hep C anyway because they don't know the dangers of spreading various strains with each other
- Anyone knowingly having Hep C and purposely trying to infect others, or neglectfully infecting others, should be punished by law

Advocacy/liaison:

- We would like an advocate, someone who understands the available funding, the paperwork, the treatments available, and who can walk you through the steps
- There needs to be more awareness and fairness, like someone to regulate available resources, because two people with exactly the same circumstances are getting hundreds of dollars a month difference from the government

Testing:

- We want access to our genotypes viral loads and we want to have liver biopsies without getting hassled about it. I am forced to go on to treatment in order to have certain types of testing done. I don't want the treatment but I do want the testing
- People have been misdiagnosed because the testing is inaccurate. Some have been told they have HCV when they don't and some have been told they do not have HCV when they do
- Second testing should be mandatory to verify initial testing because the testing is often inaccurate
- There should be mandatory testing for Hep C at pregnancy, or certain jobs, or anyone exposed to drug use or fighting so that the virus can not be spread because the carrier doesn't know they have it

Funding:

- We want funding for alternative methods of treatment, like holistic treatments, but we are forced into having the medication because that is what the government will pay for
- You can't get assistance from AISH unless you have had the treatment. You have no choice and are forced into having the treatment if you want to receive AISH
- Someone with HCV who goes to a financial worker should automatically receive the maximum amount of benefits available without having to find out about the different

- services and funding, and filling out all the paperwork for it, and then having to wait forever to get it if you are approved in the first place
- People with HIV get more funding and resources than HCV clients
 - In the later stages of Hepatitis C, should clients require a wheelchair, most places of residence are not wheelchair friendly/accessible. Government funding to offset the costs of renovation and reconstructing a home to become wheelchair accessible would be helpful
 - Social workers/financial workers aren't willing to divulge information about available funding (for example, dietary needs, housing, etc)

Communication/informing client of diagnosis:

- You should be referred to a support liaison/counsellor to offer you comfort and educate you when you get the callous phone call saying you have HCV
- The one doctor in Lethbridge that HCV clients are referred to has unacceptable bedside manner and if it weren't for his nurse, most would not go back to see the doctor
- There needs to be a medical alert bracelet everyone with HCV has to wear
- Everybody knows your business in a small town. I got a phone call from a contact nurse telling me I was HCV positive. Even after I re-tested and was found to be HCV negative, the contact nurse was not informed which means there are who knows how many people out there still thinking I have HCV

Other:

- Alberta has the worst social system in Canada
- Even though I don't have Hep C, since my son does then people don't want to have anything to do with me either
- Families of people with HCV need counselling too, but we can't afford it
- Massages help me feel better and I am now not taking any medication at all and am trying to eat better and exercise, etc, to approach HCV in a holistic and natural manner
- Low or no income increases crime rates and theft just to survive

C. PROFESSIONAL ONLINE RESEARCH RESULTS

Fields of expertise and educational backgrounds of those professionals who participated in completing the questionnaire included sociology, administration, communications, psychology, social work, human services, medicine (including one physician), and finally, the overwhelming majority of responses came from professionals in the field of nursing.

Various responsibilities and capacities of service offered by these professionals, toward HCV clientele in their respective communities throughout Alberta, involve:

- Providing resources to staff directly involved with initial interviewing and counselling of HCV clients within the realm of communicable disease control
- Support for individuals infected with, or closely affected by Hepatitis C, including those at risk of infection
- Education throughout community and surrounding rural organizations for professionals and HCV clients
- Administration
- Facilitation of skill building workshops
- Medical assessment and treatment
- Community education and awareness of liver disease in children/youth
- In-service and workshop presentations

- Partnership development with community groups/agencies, school boards and regional health authorities
- Developing harm reduction programs including health promotion and prevention strategies for populations at risk
- Provide emotional support
- Provide community resource referrals, to community agencies, better meeting the needs of HCV clients
- Provide education to professionals working with HCV clients
- Provide and promote HCV awareness to general public
- Provide post diagnosis support for HCV persons
- Contact tracing with STI/HIV follow-up of HCV+ patients
- Encourage physicians to do testing of HCV patients
- Outreach support including advocacy, support groups, and needle exchange programs utilizing Harm Reduction approaches
- Provide outreach support to reduce the impact of addiction and poverty issues
- Assessment of new HCV patients
- Physical and lab work administration
- Treatment Preparation to see Infectious Disease physician
- Going throughout the inner city as well as the shelters to assess and meet the needs of HCV clients
- Clinical supervision of mental health therapists
- Physician at a federal jail
- Policy development
- Sexual health education at the junior and senior high levels, STI and testing (HIV/Hep B and C), pregnancy and testing, birth control counselling,

Summary of Questionnaire Responses

Where applicable, the research consultant summarized the professionals’ answers into sub-categories, namely:

- Risky Behaviour
- Emotional Concerns
- Medical/Physical Well-Being
- Socioeconomic/Financial Aspects
- Sociocultural/Relational Considerations
- Education
- Funding/Services/Resources.

Duplicate answers offered by various professionals are highlighted in bold font and presented in order of popular ranking.

Perceived Most Significant Hepatitis C Issues

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Questions number 1, 2, and 3 asked professionals to identify, **according to their perception**, what the five most significant **Hepatitis C issues** are (including mental health issues) **of greatest concern to mental health HCV workers, medical care workers, and persons living with Hepatitis C**. The following charts delineate the answers:

Professional Perception of Risky Behaviours

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • addiction (5 responses) • substance abuse (2 responses) • alcohol abuse (2 responses) • precautions 	<ul style="list-style-type: none"> • addiction (4 responses) • substance abuse • alcohol abuse • how do we deal with clients who put others at risk • spread of disease through drug use 	<ul style="list-style-type: none"> • addiction (3 responses)

Professional Perception of HCV Knowledge and Education

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • awareness (2 responses) • education (2 responses) • comprehension of HCV • harm reduction • prevention • wellness promotion • lack of information that is clear and current • who can be consulted and maintain confidentiality • basis knowledge of the disease • understanding about addictions • understanding psychological side effects of treatment • understanding physical side effects of treatment 	<ul style="list-style-type: none"> • comprehension of HCV – pathophysiology • up to date treatment information • comprehension of universal precautions and harm reduction • lack of knowledge around Hep C and mental health issues • education and awareness • keeping updated on the status of research on this disease • correct information • updated information in a timely manner • understanding effect of treatment on immune system • understanding psychological side effects of treatment 	<ul style="list-style-type: none"> • educating themselves about HCV (3 responses) • Where do I get up to date and credible information? (3 responses) • How confidential is my result? (2 responses) • lack of knowledge about healthy lifestyles • understanding • awareness • What will happen to me? • knowing how to prevent the spread of HCV • how to change some high risk behaviours • chances of cure • how to live a healthy life

Professional Perception of Emotional Concerns

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • depression (4 responses) • mental health issues (2 responses) • achieving empathy for the client - nonjudgmental care • affect that liver disease can have on brain function • establishing trusting relationships with HCV persons • untreated mental illness • exacerbation of depression during treatment • fear that they might contract the disease • pre-existing and emerging mental health issues/factors 	<ul style="list-style-type: none"> • depression (2 responses) • dealing with sequelae of Hepatitis C • achieving empathy for the client -nonjudgmental care • not able to connect with clients (clients untrusting of medical profession) • how to counsel clients who face unknown outcome • untreated mental health problems • mental health issues 	<ul style="list-style-type: none"> • stigma (4 responses) • depression (3 responses) • discrimination (2 responses) • feelings of isolation (2 responses) • fear of disclosure (2 responses) • fear of progressive liver disease • fear of liver cancer • fear of HCV transmission • self acceptance - grief - anger - blame – shame • lack of empathy by health professional • worry re status being revealed - stigma still re being HCV+ • worry re feeding self and family • remaining anonymous • fear of the unknown • mental health issues (feelings of despair, hopelessness) • temptations • fear that there is no cure, that this may be terminal • dealing with a chronic potentially life threatening diagnosis • anxiety • psychological side effects of treatment

Professional Perception of Medical/Physical Well-Being

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • HIV co-infection • dealing with impact of chronic disease • treatment barriers • getting patients to see a physician • poor nutritional status • access to medicines, supplies • treatments • illness 	<ul style="list-style-type: none"> • liver damage (2 responses) • liver failure • liver cancer • liver cirrhosis • dealing with potential BBF exposures • infectious disease • treatment barriers • waiting time to treatment • poor nutritional status • inability to follow through with treatment plans • co-morbidity (i.e. HIV infection) • understanding physical side effects of treatment 	<ul style="list-style-type: none"> • side effects of HCV treatment (2 responses) • lack of HCV sensitive medical professionals in our community • living with chronic condition • limited options for management (i.e. treatment) • knowing where to go for health care and understanding treatment options and alternatives • infecting others • waiting time to see specialist • waiting time to treatment • issue of being contagious • food/diet • perceived stigma from health care professionals • poor treatment from health care professionals • liver damage • co-morbid infection • cancer • Tylenol use

Professional Perception of Socioeconomic/Financial Aspects

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • inadequate or no housing options (3 responses) • stable housing while on treatment • lack of time and resources • lack of desire to work • long waiting times for referral to dry-out settings • finances • cost of treatment • economic concerns • understanding patient's socioeconomic background 	<ul style="list-style-type: none"> • inadequate housing/housing options • finances • cost of treatment • cost to health care • all avenues of financial coverage for treatment 	<ul style="list-style-type: none"> • lack of affordable/adequate housing (5 responses) • poverty (2 responses) • unable to work due to health • employment / unemployment issues / loss of income • finances • cost of treatment • economics

Professional Perception of Sociocultural/Relational Considerations

Mental Health Worker	Medical Care Worker	Hepatitis C Client
<ul style="list-style-type: none"> • support systems (professional and peer) (2 responses) • lifestyle adjustments • stress on family members • stable environment • implications of Hepatitis C on life and family • lifestyle acceptance • meeting people where they are at, not only mentally but physical locations - out in community • lack of support for what they are trying to accomplish • peer support 	<ul style="list-style-type: none"> • stable environment • family/significant other support • quality of life 	<ul style="list-style-type: none"> • family support • dealing with family and friends • acceptance by family and friends • living / quality of life • lack of support from family and friends • How will this impact my relationships? • stability

Question # 4

Where are persons with Hepatitis C referred to for information about Hepatitis C, professional support, and peer support? Please identify names of agencies, existing support groups, and so on:

Coverage	Types of Services	
Specific to Regions	Region # 1, Chinook Health Region	<ul style="list-style-type: none"> ➤ Peer Support Group ➤ Lethbridge HIV Connections Society
	Region # 2, Palliser Health Region	Peer Support Group, HANSEEA
	Region # 3, Calgary Health Region	<ul style="list-style-type: none"> ➤ SAFEWORKS HIV/HCV - support group ➤ CUPS (Calgary Urban Projects Society). They offer a Hepatitis C clinic aimed at the marginal population that includes treatment options and support ➤ 8th & 8th Health Centre (Calgary) ➤ AIDS Calgary Awareness Association ➤ Alexandra Health Centre
	Region # 4, David Thompson Health Region	<ul style="list-style-type: none"> ➤ Peer Support Group ➤ Life with Hepatitis C Society of Alberta
	Region # 6, Capital Health Region	<ul style="list-style-type: none"> ➤ Bissell Centre (2 responses) Peer Support Group ➤ U of A Hepatitis C clinic ➤ University Hospital Hepatitis C peer support group ➤ HIV Edmonton ➤ Streetworks
	Region # 8, Peace Country Health Region	Peer Support Group
Available to all	Organizations	<ul style="list-style-type: none"> • Canadian Liver Foundation (6 responses) • Hepatitis C Society of Canada (3 responses) • Health Canada • HCV Global foundation • Hepatitis information Network • Mental health clinics in the region • Alberta Mental Health • Social services in the region • Canadian Mental Health Association • ADDAC services (useful if alcohol or drug abuse are current issues)

Coverage	Types of Services	
	Medical services	<ul style="list-style-type: none"> • Family physician (4 responses) • Jail nurses • Hepatitis C outpatient clinic • Community Outreach Nurses • CDC Contacts
	Websites	HCV/Canadian Liver foundation; Canadian websites (if they can access a computer)

One respondent stated that s/he does NOT recommend peer support: “it is destructive”.

Question # 5:

What do you perceive are the five most significant **issues** (including mental health issues), **concerning persons co-infected with Hepatitis C and HIV?**

Risky Behaviour:

- **addiction** (4 responses)
- active substance abuse

Emotional Concerns:

- **depression** (4 responses)
- **stigma** (3 responses)
- **feelings of isolation** (2 responses)
- **loss** (2 responses)
- fear of disclosure
- discrimination
- rage
- fear of the future - becomes consuming
- re-building of self and life - changed hopes, dreams, directions
- social outcast
- lack of emotional support
- worry about confidentiality in small centers
- grief
- fear of death
- fear of losing family and friends
- mental health concerns
- Will I die? Fear

Medical/Physical Well-Being:

- treatment/treatment options
- treatment barriers
- lack of sensitive medical professionals in our community
- progression of liver disease
- poor response of HCV treatment in co-infection
- polypharmacy
- dealing with 2 chronic diseases with major health issues
- health - treatment options and costs
- staying alive
- preventing spread of disease

- we have had very few co-infections in our region – interesting
- inability to access care - waiting periods
- which infection to treat first medically
- food
- possibility of a terminal illness.....impending death
- cost of medications
- advancement of HIV
- treatment issues
- diagnosis issues
- compounding illness
- How do I make the most of my health?

Socioeconomic/Financial Aspects:

- **adequate housing/housing options/lack of affordable housing** (3 responses)
- **financial** (2 responses)
- poverty
- dealing with 2 chronic diseases with major lifestyle issues
- money
- usually can't work/permanent unemployment
- economics

Sociocultural/Relational Considerations:

- **support** (2 responses)
- how this affects my family and relationships
- loss of purpose in society
- lack of peer support
- living well
- family support/ dealing with family and friends
- stability of life
- life style adjustments

Education:

- lack of education regarding infection and potential treatment
- lack of understanding of infections by rural Albertans
- education
- best practices for care giving
- how to plan for future

Funding/Services/Resources:

- drug coverage
- financial support during therapy
- dealing with all of the professionals that become part of their lives now
- need for on-going stable and knowledgeable support
- lack of knowledge around community resources
- lack of resources in immediate area
- income supports
- funding for proper dietary needs
- travel expenses for medical appointments
- clean needles
- advocacy for government assistance
- no hospice

- lack of access to follow up and treatment programs
- lack of community supports
- supports to help deal with quality of life issues such as relationships, employment etc

Question # 6:

What would you identify as the five most significant **needs** of clientele with HCV (if any), related to Hepatitis C and mental health, that are **not being met at this point?** (i.e. needs related to ethnicity, risk factors, place of residence, etc.)⁷

Risky Behaviour:

- wishing to continue risky life-style
- addiction

Emotional Concerns:

- **stigma** (2 responses)
- professional assistance for suicide risk
- need for more acceptance by others
- high cost of living causing stress and anxiety
- fear of "being found out"
- discrimination
- not trusting the system
- denial
- non-judgmental care/support
- stress related to disease
- stress related to financial concerns
- depression

Medical/Physical Well-Being:

- need liver biopsy
- availability of mental health assessment (lack of psychiatrists)
- treatment barriers
- long waits for treatment
- side effects of treatment
- lack of educated professionals in our community

Socioeconomic/Financial Aspects:

- **housing** (3 responses)
- **poverty** (2 responses)
- permanent residence, especially in rural areas
- lack of available housing for the affected street and low income HCV clients
- housing the actively using
- finances
- lower/sufficient income
- inability to afford treatment

Sociocultural/Relational Considerations:

⁷ Some answers given by professionals in question #6 are in the form of identifying problems, not needs. One way, however, of articulating a need is by offering examples. The researcher has thus left the answers as they were presented by the professionals to further preserve the integrity of the research.

- support for family members
- support in home - if in rural community, may be reluctance to seek local support
- family support

Education:

- more information about recent treatment methods
- education for spread of infection
- ignorance of disease
- grasping at information they wish to hear
- lack of comprehension regarding infections
- lack of knowledge about symptoms and how to effectively deal with them
- increased awareness

Funding/Services/Resources:

- \$\$ for treatments
- lack of funding for mental health initiatives
- money for food, housing, etc
- support groups, especially in rural areas
- increase in community supports
- transportation to medical appointments.
- in-house care during treatment
- money for transportation, treatment and food
- community support
- 24-hour support group or drop-in
- making treatment accessible to people with transient lifestyles
- help with access to treatment
- not accepted as a diagnostic code by Regional Mental health and therefore are not eligible for mental health counseling
- need a needle exchange program
- treatment services out of town
- professional and peer support initiatives
- lack of easy accessibility
- lack of local support group & local ease of accessing drugs
- Street population - mental health issues that are often not met
- Inability to maintain a treatment plan due to lack of on-going support
- Funding ends and support ends, no consistency to care and support
- easy access to care (most centered in Edmonton and Calgary)
- drug coverage/ financial support during therapy
- we need more drug addiction treatment programs
- services for children with HCV

Question # 7:

How would you suggest the needs identified in question #6 be met?

Funding:

- Funding directed towards long-term projects, not short term, this would provide consistency of care and support, enabling relationship building that could be maintained.
- Funding for treatment.
- Providing more resources to establish support workers specifically regarding HCV
- Increased, significant funding to NGO's and non-profit programs for persons with HCV and HIV/HCV co-infection.
- Cost of treatment and testing should be covered by health care, as should the cost of travel for treatment.
- Allowance of government assistance should be on par with the cost of living in Ft. McMurray.
- Funding (federal, provincial, private?)
- We need specialists in this area and the resources to employ them.

Resources/services:

- A coordinated network of services; coalition to provide a united voice.
- Increase the number of programs or size of existing programs. It takes far too long to access methadone in Alberta.
- Province wide program developed to meet people's needs where they are at, rather than where the professionals are located.
- More long term options - most professional involvement is time limited.
- Treatment support programs initiated with direction towards street or low income/low level education clients.
- Support groups for different clientele who are affected by HCV. Not all groups want to get together and we are then missing people.
- Community agencies working together and combining their talents and resources to provide excellence in care and support for all categories of clients.
- Treatment centers that are not so overbooked the client can receive more staff time.
- Support from home care if required to deal with side effects of treatments.
- Addictions treatment that is not necessarily abstinence based.
- Mental health services accepting HCV clients for support. Rural communities do not have broad access to psychological services and mental health may be the only players in town.
- More treatment programs with more control over distribution of medication, weekly visits etc.
- Provide a place for Hepatitis C positive individuals on treatment to stay, especially if they are sick or suffering from side effects of treatment.
- Provide a 24-hour drop in centre with staff that are knowledgeable about Hepatitis C, treatment, and side effects and can provide nutritional food.
- Provide a van for transportation to medical appointments and to the drop-in.
- Increase in low cost and transitional housing.
- Promote mental health services specifically to that population of clients.
- We need to attract more physicians to go into psychiatry - period.

Education:

- Awareness education for health care professionals and public.
- Try to educate the health professionals.
- Get information out to the public.

- Public education.
- More education on TV and through health magazines about Hepatitis C and the treatment available.
- Education campaigns
- Increase awareness of HCV infection with general public and to decrease the stigma related to the disease.
- Nation wide media campaigning

Other:

- Governmental changes for increased social programs that consider the rights and needs of individuals and don't discriminate based on addiction history, prison history, mental health issues.

Question # 9:

Do you perceive any **differences** in availability of support services **between geographical areas**? If yes, please identify the geographical areas with which you are referring, and what you perceive to be the differences in availability of support between said geographical areas.

Generally, more support services are available in urban centers as opposed to rural areas who lack support groups, services, resources, and opportunities for monitoring treatment on a regular basis. As well, some people are more able to get the treatment for themselves as opposed to those in lower socioeconomic regions that have difficulty coming to large centers and seeing a specialist let alone dealing with all the steps to get to treatment.

In smaller communities, there is a great concern about client confidentiality. While the amount of testing is probably higher in the larger communities/cities because there is greater access to a larger number of testing sites, clients in smaller communities may be less likely to come forward to be tested simply because at the local lab the chance of knowing the workers are high.

As well, there seems to be a need for resources for aboriginals living both on the reserves and off the reserves.

Urban dwellers have better access to transportation and do not have to worry about staying overnight to see a specialist.

Also, the urban workers probably deal with more HCV+ people so perhaps they would be more knowledgeable and of more assistance to persons living with Hepatitis C.

Hepatitis care is centered in Edmonton or Calgary clinics. There are no support lines/programs in southern Alberta. The CLF is currently developing a program for Northern Alberta but does not have funding for Southern Alberta. Rural areas are particularly out of the loop.

Health care professionals in rural areas are not willing to take on clients with significant health issues such as HCV, HBV and HIV as they are often time consuming clients and are often poor participants in their treatment plans especially when mental health issues are combined with physical health concerns.

Question # 11:

Pertaining to HCV, do you perceive any differences between what mental health workers, medical care HCV workers, and persons living with HCV would view as needs and issues? If yes, please identify what you perceive to be the differences in the issues and needs of mental health workers, medical care HCV workers, and persons with HCV.

Diagnosis/treatment:

- Too many patients with HCV expect MDs to complete disability forms so they don't have to work, but in fact very few patients with HCV have sufficiently severe disease that would justify medical disability.
- Persons with HCV want a treatment/cure. The medical workers feel like their hands are tied, as only so many are suitable for treatment. There is no hope for someone denied treatment or who has had treatment withdrawn.
- Physicians are too busy to spend a lot of time with these folks.
- Some folks think that because they are HCV+ and well, that they cannot work - some have so many other social problems that they become a real challenge to untangle.

Care coordination across professions:

- Mental health workers and medical care workers need to combine their talents to develop a protocol that will address as many of their clients' needs as possible. It would be nice to see groups working together and utilizing each other's specialties. Mental health and medical workers address the immediate and obvious needs and have been used to providing these services in a facility.
- Mental health workers deal with the stress of an incurable disease that also affects mental functioning as it progresses. But who are these people? Where are they? WE have only had the opportunity to work with *medical* workers thus far.
- I think that all of these individuals share common concerns; however, the focus is different. Mental Health is concerned with the MH issues as medical is concerned with the medical. The person infected would have both concerns.

Services/resources:

- The need is to go to the community and serve the client where they are at.

Compassionate liaison/expert:

- Clients with HCV often feel stigmatized and isolated when reaching out to mental health and medical workers. What I have noted is a statement of need in the community for a non-judgmental one-stop place to visit. People, specifically people who don't want anyone to know they are infected want to maintain their anonymity, they don't want to go to the HIV place, or the HCV place, or even the mental health office.
- People prefer one-on-one and that their needs be met in a non-judgmental manner and that their confidentiality and respect be maintained.
- Care without stigmatization.
- Lack of empathy from medical persons in regards to clients.
- Work together as agencies to facilitate excellence of care and support to our joint clients - increase communication between agencies.

Education:

- Mental health workers are limited in what they can provide for these folks.
- Major difference in understanding and acceptance of risky behaviors and putting others at risk.
- Mental health workers might require more education in dealing with this specific client group. Other workers might need more education on the mental health consequences of the medical condition.
- There is a need for wellness programming - education to improve the general health of those living with Hepatitis C.

Question # 12:

Please identify any **issues** and/or concerns **not previously addressed** in this questionnaire.

The only comment made in this section that had not already been previously addressed was that the whole issue around hepatitis C should not be developed in isolation. Many of the concerns are also of concern for other disease conditions, and the same approaches can be developed to meet these, thus utilizing already proven strategies. This approach would likely result in more services being available throughout the province as there would then be a critical mass to support professional positions.

D. DISSEMINATION FEEDBACK

Preliminary findings were presented at the Sixth Annual Alberta Harm Reduction Conference in Grand Prairie, Alberta, on March 23rd, 2005. The fifty participants of this workshop were asked to provide feed-back on the findings and recommendations on how the report could be disseminated and used to benefit persons living with Hepatitis C. They made the following suggestions.

1. Need to create a single point of entry for Hep C information and treatment
2. Send a summary of the findings to doctors and other professionals (one page faxed summary may be a good way to go for practicing physicians)
3. Need to inform the public about the findings
4. Travelling clinics (doctors going to where clients are, instead of clients going to the big cities)
5. Continue advocacy efforts regarding poverty-related and housing issues
6. Treatment to be covered by government
7. Need to educate politicians
8. Create ways for active users to access treatment
9. Networking to address social determinants of health
10. Need to create a training module HCV 101 for students who will be in contact with persons at risk for HCV or infected.
11. Spread information about existing resources
12. Empower the clients
13. Explore the role of health regions in prevention and support of HCV
14. Create some benefits for physicians who take the time for clients
15. Offer letters of support to clients / advocate for them

VII. CONCLUSION

One client was quoted as saying that there is more attention out there given to the flu than to Hepatitis C. Maybe if people understood the dynamics of the Hepatitis C virus, there would be just as much, if not more, attention paid to Hep C.

Focus group interviews, as well as questionnaire responses by professionals, provided much needed insight into the concerns of Albertans living with Hepatitis C. The following summarization of information is taken from both Hepatitis C clients and professionals alike.

A. SUPPORT GROUPS

The overwhelming majority of clients interviewed stated emphatically that they would be lost without their support group. The support group is, for most, the *only* emotionally non-threatening safe place where they can go to for support, a listening ear, compassion, understanding, not having to fear being judged, where they can learn from peers who have been there, receive direction, and become better educated about HCV

B. EMOTIONAL CONCERNS

Shame, fear, guilt, rejection, isolation, abandonment, loneliness, frustration, confusion, hopelessness, helplessness, suicidal ideation, depression, anxiety, worry, devastation, and heartache were a few of the common emotionally negative companions of persons living with Hepatitis C.

Many clients interviewed had been on treatment, some more than once, and the treatment failed. Many clients had been on treatment and stopped after a few months for various reasons such as they became too sick from the treatment, treatment was proving ineffective, suicide risks increased on the treatment, or they couldn't afford to maintain the treatment. The researcher observed mixed emotions as clients shared their successes and failures with treatment. Clients whose treatment had failed wanted to rejoice with those who were pronounced clean of the Hepatitis C virus and at the same time they mourned for their own losses. Those whose treatment had worked either vanished from the support groups wanting to forget about that aspect of their past, or rallied around those whose treatment failed and consoled them in their grief. A type of guilt was common among those who were cured as they experienced the deterioration of those who did not respond well to treatment.

C. EDUCATION

Clients have been long oppressed because of the ignorance of the general public pertaining to Hepatitis C. Often the researcher heard clients say they were the ones who were educating the doctors about Hepatitis C. Persons living with HCV find themselves mistreated, shunned, stereotyped, persecuted, feared, and abused by the uninformed. Isolation and minimal to no relationships are often the result leaving persons living with Hepatitis C void of support when its needed the most. Clients are continually fighting to inform and educate, but the battle often seems futile. There is a distinct unified front on the part of HCV clients and those few compassionate professionals working closely with them, but overall Hepatitis C clients seem to be standing alone in their efforts to be heard and understood. Public awareness and adequate funding are essential in combating the spread of Hepatitis C and the humane treatment of people living with it. Examples of ignorance enhancing fear are that some people wonder if the virus is

transmittable through touch or if the virus is airborne and can be spread by breathing the same air as someone carrying Hepatitis C. Another factor in public education is that people can go for twenty or thirty years without knowing they are carrying HCV. Often a person finds out he/she has Hepatitis C because physical health problems arise warranting testing. Identifying and diagnosing HCV in its early stages, before physical health problems and liver damage, may prevent spreading of the virus.

A cry for knowing what financial assistance is available and how to tap into the resources was heard across the board. HCV clients would appreciate an expert walking them through the processes of filling out paperwork and directing them toward avenues of financial assistance, including what is and is not a tax write-off.

D. PHYSICIANS

During the focus group interviews, clients words continually rang throughout Alberta as they expressed the lack of competent, educated, and compassionate professionals.

The majority of clients shared their fear, confusion, and disgust with what they termed as doctors' ignorance, poor bedside manner, stereotyping clients as drug users, negative attitudes toward clients, lack of time or empathy for patients, and doctors misinforming patients. Clients shared stories where doctors blatantly told them there is no cure for Hepatitis C, advised them that the best timing for treatment is when they manifest severe symptoms of being ill, prescribed medications not appropriate for persons with liver dysfunctions, left client with a diagnosis but no explanation of HCV or the treatment modalities, and simply offered incorrect information.

According to clients, other professionals in need of Hepatitis C education included law enforcement officers, judges, attorneys, EMTs, social workers, and in fine, the majority of those who come in contact or work with Hepatitis C clientele.

E. HOUSING

Another consistent theme throughout the focus groups has been the lack of affordable, liveable housing for the majority of Hepatitis C clientele who find themselves in with low to no income. Far too many clients were living on the streets and even more resided in housing where community kitchens and bathrooms were shared. Problems arising from this type of residential setting include the inability to be on medication which has to be refrigerated. Theft is likely the result of keeping medication in a community refrigerator and filth is the norm when exposed to a community bathroom. Such housing accommodates a wide variety of drug users and mentally dysfunctional occupants. Hepatitis C clients expressed their concerns and the difficulty with striving toward or maintaining abstinence in an environment conducive for substance abuse.

F. TREATMENT

Fear, confusion, mistrust of information, lack of information, and the tormenting effects of treatment were common themes throughout the research. Clients either were not aware of available treatment, thus had not looked into treatment possibilities, or they were very aware of the negative effects of treatment and not sure they wanted to suffer through it with no guarantee of success when all was said and done. The physical, emotional, and financial costs of treatment often outweighed a client's desire to engage in the available cures. Some clients who desperately wanted treatment were denied such by being unable to meet the criteria designed as a pre-treatment assessment check-list.

According to the HCV clients, there seems to be no rhyme or reason why some people respond positively to treatment and others do not.

Clients said their Hep C got worse over the 20 or 30 years they didn't know they had it, until it got so bad it finally manifest itself with symptoms. They would have gotten it treated years earlier when it was in its infancy if they had know they even had it. The clients whose treatment was unsuccessful wondered if they could have been cured had they been diagnosed years earlier and the HCV not had as many years to develop.

G. SPREAD OF HCV

Although HCV clients are becoming increasingly aware of ways in which Hepatitis C can be spread, the general public are not.

As well, apathy on the part of some clients with HCV enhances the risk of knowingly continuing to infect others. Various strains of Hepatitis C are being transmitted from one carrier to another compounding and complicating the virus. This could, in fact, be one of the reasons some clients respond positively to treatment and some do not. Nevertheless, persons carrying Hepatitis C need to understand that just because they have the virus, it is still dangerous to spread your particular strain of HCV to others.

H. NEEDLE-EXCHANGE PROGRAMS

Not many Hepatitis C clientele attending the focus groups were utilizing the services of needle-exchange programs. One client reported not using needles herself but she goes to pick up hundreds of syringes for people that she knows are in need. The stigma, being seen and identified as a drug user, transportation issues, and the depressing atmosphere are some of the issues that prevent most people from utilizing the needle-exchange program.

I. TRANSPORTATION

Lack of adequate funding to offset transportation costs was an issue for the majority of HCV clientele. Those who had to travel out of town for treatment or even to see a Hepatologist specialist were the most affected by transportation. Vast amounts of out-of-pocket expenses are incurred as clients make their way to far distant destinations for appointments, interviews, assessments, and treatment. If a client has to spend the night or stay for any length of time because of the length of treatment, for example, hardships are compounded as families are split apart and cost of living expenses for their temporary residence and their permanent residence become overwhelming. The lack of local available resources forces the client to travel if they want to utilize the services of experts, thus placing burdens in all aspects of life upon the person living with Hepatitis C, who is desperate enough to travel great distances seeking out any means they can simply to survive. Even those desiring to participate in support groups have to travel from rural areas to attend. Some people traveled one hundred and two hundred kilometres just to attend the support group. When ill health is eminent, and traveling such great distances required, the health and well-being of the client is further jeopardized. Groups are often in the evening and traveling long distances late at night adds to a clients emotional and physical trauma.

J. DIETARY REQUIREMENTS

A common complaint throughout Alberta was the lack of adequate funding and/or income necessary to purchase and therefore consume the diet recommended for Hepatitis C clientele. Most HCV clients are low to no income and likely do not have enough finances to meet their basic needs, let alone have any extra money to put toward special food that costs more than they can afford. Some clients went so far as to question the practicality of following through with treatment when they are not in a position to care for their bodies by eating properly during and after treatment. One barrier to proper nutrition was not knowing what the diet should consist of. A common request was that a dietician who specializes in Hepatitis C be an available resource.

K. EMPLOYMENT ISSUES

When Hepatitis C symptoms become full blown, more often than not you become sick and weak and depressed, and most of the time you lose your job while exhausting your finances with treatment and simply trying to survive. Most people with Hep C find themselves with low or no income and barely able to exist let alone embrace any semblance of an acceptable quality of life. How can they eat properly or receive the necessary treatment to recover from HCV when they can't even meet their basic needs? Ethical dilemmas surface when clients debate divulging to their employer that they have Hepatitis C. Clients have had to quit their jobs and/or be fired from their jobs due mainly to fatigue, low energy, and other physical symptoms of HCV preventing them from executing their required responsibilities. When a person with Hep C is able to work, stigma or persecution from co-workers is not uncommon, making the working environment unpleasant to say the least. Some HCV clients are forced to quit their jobs to go on treatment and after treatment are still not able to return to the workforce.

L. FUNDING NECESSITIES

Plas across the province for financial assistance were requested in a variety of areas. Circumstances where clients once had bus passes but have since had them revoked because of budget cutbacks prevent clients from getting from place to place as readily. Walking or searching for someone to drive them to support groups or appointments is usually futile. Immobility is becoming one of the greatest barriers to properly accessing resources and services. With low to no income, a bus pass is not in the Hepatitis C clients' budget. Even if a client has a vehicle, travel expenses to other cities for treatment, and to see specialists, becomes financially burdensome. If the province will not supply the necessary resources, and a person has to travel to access them, clients propose the government finance the trip.

A roof over your head is a basic necessity that most Hepatitis C clients struggle to afford. More subsidized housing would greatly assist persons living with HCV to be able to have enough money to survive, and possibly in some cases free up enough money to eat properly and travel to receive treatment. If a person with Hepatitis C already has housing, they may find themselves in a wheelchair with no funding available to convert their home into a wheelchair friendly condition.

A grave concern for a great number of HCV clientele is not being able to afford the cost of treatment because they don't have insurance or they can't afford the initial expense to travel to receive treatment.

A united front of Hep C clients declared the government allotment for monthly living expenses was unacceptable. Most agreed a person needs approximately \$1200 monthly to meet the basic

needs of a person with Hepatitis C. The reality is that people are receiving income in the \$400 to \$700 range which is reportedly impossible to survive on.

As well, if a Hep C client is living in a home sharing a kitchen and bathroom, any medication needing refrigerated is more often than not going to be stolen.

Preparing foods and properly meeting Hep C dietary needs is more expensive than a regular diet. Most low to no income Hep C clients claim difficulty eating three meals a day, let alone buying and preparing a nutritional diet. Plus, clients expressed concerns because even if they were aware of the need for proper nutrition, most people had no idea what their diet was to consist of. Funding providing a Hep C dietician specialist in more areas of the province was suggested.

As it is, limited funding is only available for medication treatment and no funding is provided for alternative methods of treatment. For those people who do not wish to take medication, they are left with the choice of either medicating themselves or going without treatment. Some would appreciate the freedom of experimenting with alternative cures. Massage therapy is also a soothing, comforting, and healing balm, which luxury most can not afford.

More support groups are needed throughout the province and government funding would assist in meeting this need.

Funding is also needed for the purpose of educating professionals and the public alike. Awareness campaigns and conferences may assist in educating those who work with Hepatitis C clientele.

For those clients receiving treatment in their own home, financial assistance or providing in-home resource people would be appreciated. Most clients profess to barely be able to care for self during treatment. Their houses go unkempt and their children neglected. Home visits by child care workers and housekeepers would be beneficial.

A “safe house”, such as is provided in some areas to clients with HIV, with access to professional counselling, medical advice, persons qualified to administer medication, support groups, meals, a place to sleep, etc., is greatly needed. If funding is available for this type of facility for HIV clients, then people with Hepatitis C would like the same.

VIII. RECOMMENDATIONS

The purpose of this community-based research is to increase knowledge and understanding of the need for professional and peer support for people living with Hepatitis C (HCV) in Alberta, and provide information for the enhancement of such supports.

While the data collected answered all questions proposed by the project, an unexpected greater response and measurement of information was accrued. Time constraints dictated minimal analysis and organization of said collected data.

Furthermore dissemination has been limited to one workshop only at the sixth Alberta Harm Reduction Conference in Grande Prairie in March 2005 and sharing of the report with key stakeholders of the project.

Our recommendations therefore focus on three areas: improvement of Hepatitis C services in Alberta; future research focusing on data already collected, and dissemination of the findings:

A. Hepatitis C Prevention and Support Services In Alberta

Findings of this study should be reviewed in light of the upcoming Alberta Blood Borne Pathogens and STI Strategy. Professionals and clients suggested highlighted short-comings in Hepatitis C Prevention and Support Services in Alberta in the following areas:

- Stigma and Discrimination related to Hepatitis C
- Limited access to peer and professional support
- Shortage in competent, educated and compassionate professionals
- Access to safe housing, employment, adequate nutrition and other determinants of health as they relate to Hepatitis C
- Access to treatment
- Transportation issues (access to medical clinics and support services)
- Discrepancies of services between urban and rural areas, on and off-Reserves, North and South

B. Further Analysis of the Research Information

Although the Alberta Needs Assessment project was primarily completed according to the timelines proposed, future research recommendations include securing the research consultant at the beginning of the research project to ensure maximum benefits from utilizing the full suggested allotment of time. A list of suggested areas to be further analysed is presented in Appendix D.

C. Dissemination

At the completion date of this research project, March 31, 2005, findings of this report had been shared only once, at the Sixth Annual Harm Reduction Conference in Grande Prairie in March 2005. Professionals and clients who attended the workshop recommended that:

- Findings should be shared with the public, professionals and students
- Findings should be used to further advocate for clients, better care and support
- Findings should be used to reduce fear, discrimination and stigma attached to Hepatitis C.

IX. APPENDICES

Appendix A

Mental Health and Medical Care Professional's Web-Based Questionnaire:

1. What do you perceive are the five most significant Hepatitis C issues (including mental health issues), of greatest concern to mental health workers?
2. What do you perceive are the five most significant Hepatitis C issues (including mental health issues), of greatest concern to medical care HCV workers?
3. What do you perceive are the five most significant Hepatitis C issues (including mental health issues), of greatest concern to persons with Hepatitis C?
4. Where are persons with Hepatitis C referred to for information about Hepatitis C, professional support, and peer support? Please identify names of agencies, existing support groups, and so on:
5. What do you perceive are the five most significant issues (including mental health issues), concerning persons *co-infected* with Hepatitis C and HIV?

What would you identify as the five most significant needs (if any), related to Hepatitis C and mental health that are *not* being met at this point? (i.e. needs related to ethnicity, risk factors, place of residence, etc)
7. How would you suggest the needs identified in question # 6 be met?
8. Do you perceive any differences in availability of support services between geographical areas (North, South, Edmonton, Calgary), urban and rural as defined by Alberta Health and Wellness Health Surveillance? **Y / N** (If you answered Yes, proceed to question # 9. If answer is No, proceed to question # 10.)
9. Please identify what you perceive to be the differences in availability of support between the geographical areas described in question # 8.
10. Do you perceive any differences in the issues and needs of mental health workers, medical care HCV workers and persons living with HCV?
Y / N (If you answered Yes, proceed to question # 11. If answer is No, proceed to question # 12.)
11. Please identify what you perceive to be the differences in the issues and needs of mental health workers, medical care HCV workers, and persons with HCV.
12. Please identify any issues and/or concerns not previously addressed in this questionnaire.

Thank you for completing this questionnaire.

Appendix B

Focus Group/Individual Interview Questions for Hepatitis C Clientele:

1. What are your greatest medical concerns about Hepatitis C?
2. What are your greatest physical concerns about Hepatitis C?
3. What are your greatest mental health concerns about Hepatitis C?
4. Where can you go to get educational information about Hepatitis C?
5. How often do you utilize these educational resources?
6. Are there any barriers preventing you from easily accessing these resources?
7. How did you find out about the places you can frequent for educational information about Hepatitis C?
8. Where do you go for professional support, like counselling, for Hepatitis C?
9. How often do you utilize these professional support resources?
10. Are there any barriers preventing you from easily accessing these resources?
11. How did you find out about the places you can go to acquire professional support, like counselling, for Hepatitis C?
12. Where do you go for peer support for Hepatitis C?
13. How often do you utilize these various resources?
14. Are there any barriers preventing you from easily accessing these resources?
15. How did you find out about the places you can go to seeking peer support for Hepatitis C?
16. Where do you go for medical support for Hepatitis C?
17. How often do you utilize these various resources?
18. Are there any barriers preventing you from easily accessing these resources?
19. How did you find out about the places you can go to seek medical support for Hepatitis C?
20. Do you have access to a needle-exchange program?
21. How often do you utilize this needle-exchange program?
22. What are some of the barriers to utilizing the needle-exchange program?
23. How did you find out about the needle-exchange programs?
24. Do you encounter barriers for employment because you have Hepatitis C? If so, what are the employment barriers?
25. Is your support system affected because you have Hepatitis C? If yes, how so?
26. Are any of you co-infected with Hepatitis C and HIV?
27. What are your main concerns about being co-infected?
28. Do you think your concerns about being co-infected are different or greater than if you only had Hepatitis C? If yes, how so?
29. Do you have any needs related to Hepatitis C and mental health that are *not* being met at this point? (i.e. needs related to ethnicity, risk factors, etc.)
30. How would you suggest the needs identified in question # 30 be met?
31. Do you believe there are differences in availability of support services between geographical areas (North, South, Edmonton, Calgary), urban and rural as defined by Alberta Health and Wellness Health Surveillance?
32. What are the differences in availability of support between the geographical areas described in question #32?
33. Do you think persons living with Hepatitis C have difficulties securing adequate housing/living accommodations? If so, what are the difficulties?
34. Do you have any issues and/or concerns we have not yet discussed?

Appendix C
Authorization for Release of Information

Welcome and thank you for consenting to participate in the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment* research project, sponsored by the NPNU mental health task group and funded by the Public Health Agency of Canada, Hepatitis C Community Fund.

The purpose of this community-based research project is to increase knowledge and understanding of the need for professional and peer support for people living with Hepatitis C (HCV) in Alberta, and provide information for the enhancement of such supports.

This is a one-time project which will hopefully feed into the development and implementation of Alberta Blood Borne Pathogen Strategy. Findings will also be useful to Regional Health Authorities and agencies providing support services to those living with or at risk of being infected with Hepatitis C.

Please be advised that all information provided, whether written or verbal, will be strictly confidential. No names or identifying information will compromise your anonymity. The research consultant, Donna Weighill, will transcribe verbatim the audio-taped focus group discussions for the purpose of this study, but the final report will have omitted any information breaching confidentiality.

After the study is completed, originally transcribed documents and informed consents with any identifying features will be kept under lock and key at the Lethbridge HIV Connection agency for seven years, after which time the files will be destroyed.

You do NOT have to answer any questions that make you feel uncomfortable. You are not obligated to complete the survey and can opt out of finishing the focus group discussion with no penalization.

Please feel free to ask the research consultant any questions you may have about the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment* study. Should you have further inquiries after the focus group discussions are over, or if you have any additional information to offer the study, please feel free to contact Helene Wirzba (project coordinator) at Lethbridge HIV Connection at (403) 328-8186 or e-mail her at ED@lethbridgehiv.com

Hepatitis C and Mental Health Issues – Alberta Needs Assessment study will be complete March 31, 2005, at which time you are welcome to contact Helene Wirzba for a copy of the research results.

Thank you once again for your participation!

*Please keep page number one for your records and sign and give page number two, upon completion, to the research consultant facilitating the focus group.

Appendix C: Continued
Authorization for Release of Information

The focus group facilitator has explained the purpose of this research investigation, confidentiality, my right to end participation at any time, where and when I am able to obtain a copy of the research results, and who I contact should I have any questions.

I understand the aforementioned information and am signing this authorization, of my own volition, consenting to release any data collected for the purpose of the *Hepatitis C and Mental Health Issues – Alberta Needs Assessment* research study.

Signature of client:

Printed name of client:

Date signed:

Health region:

Age:

Gender: Female / Male

HCV/HIV Co-infected? Yes / No

of Years you have known you are HCV positive?

Age at time of HCV diagnosis:

How do you think you contracted HCV?

Witness signature:

Printed name of witness:

Date signed:

Appendix D:
Suggested Future Research Questions

1. A comparison between the professionals' answers and the focus group answers thus providing further insight as to the strengths and weaknesses of the professionals understanding about Hepatitis C.
2. Discrepancies between what professionals identify as available resources and what clients are aware of/accessing.
3. Conduct additional interviews with persons from sub-groups not represented.
4. Further investigate and identify geographical areas where services are missing or are not well coordinated.
5. Levels of coordination between health services and social support networks.
6. Increased assessment and awareness about services required.
7. Partnerships to be created and/or maintained.
8. Compiling the stories and situations related to the researcher by the HCV clients to provide real life evidence to corroborate their needs.
9. Identify needs, other than those proposed by the research, as explained by the HCV clients.
10. Identify needs, other than those proposed by the research, as explained by the professionals.
11. Assess the ages, educational backgrounds, years of experience working with HCV clients, and genders of the professionals working with HCV clients.
12. Compare and contrast the needs as seen by the clients and the professionals' point of view.
13. Identify the differences in needs between the clients and the workers.
14. Identify needs of the professionals.
15. Identify the needs of the clients.
16. Identify ways in which the professionals propose that needs be met.
17. Identify ways in which HCV clientele propose their needs be met.
18. Identify negative situations, attitudes, treatment, and all other negativity as reported by clients and professionals alike.
19. Identify how long clients had Hep C before they were diagnosed.
20. Identify the ratio of males to females with Hep C.
21. Assess age range of clients with Hep C.
22. Assess the ratio of clients who contracted Hep C through blood transfusions as opposed to tattoos, drug needle exchange, or body piercing.
23. Assess barriers for accessing resources like finances, not meeting listed treatment criterion, lack of transportation, depression/emotional concerns, poor health, unavailable housing, etc.
24. Assess not just what resources the clients utilize for support but how, why, and the frequency with which they utilize the resources (for example, clients go to the Hepatologist but for various helpful reasons like learning to administer treatment especially if they are not drug users and are unaware of how to inject themselves).
25. Identify the most utilized and effective resources to know where funding should be channelled.
26. Assess the number of people who are now Hep C negative but still go to Hep C support groups.
27. Ratio of HIV/HCV co-infected.
28. Sort question 4, for example, by region for specific agencies, and resources which are common to all.
29. Combining the responses from professionals and clients
30. Identify if some services were named by clients or professionals only.

Appendix E:
List of Acronyms

AADAC	Alberta Alcohol and Drug Abuse Commission
AIDS	Acquired Immuno Deficiency Syndrome
AISH	Assisted Income for Severely Handicapped
CUPS	Calgary Urban Projects Society
HANSEAA	HIV-AIDS Network of South-Eastern Alberta Association
HCV	Hepatitis C Virus
Hep C	Hepatitis C
HIV	Human Immuno-deficiency Virus
NPNU	Non-Prescription Needle Use Consortium
U of L	University of Lethbridge
STI	Sexually Transmitted Infection