



Canada's source for  
HIV and hepatitis C  
information

La source canadienne  
de renseignements sur  
le VIH et l'hépatite C

# **Room for improvement: Knowledge exchange needs of people living with hepatitis C**

**2015**

## Executive summary

---

In 2014-15, CATIE undertook a national needs assessment of patients engaged in hepatitis C care. The needs assessment was designed to provide information on the priority knowledge needs of people living with hepatitis C and how these needs can be met.

An online survey was developed and focus tested to assess the information needs of people engaged in hepatitis C care. Eight medical clinics serving people living with hepatitis C located in British Columbia, Alberta, Saskatchewan, Manitoba and Ontario were engaged to recruit participants to complete the survey.

In total, 326 people participated in the survey. Participant demographics included the following:

- 66% men
- 63% aged 46 and older
- 27% self-identified as Aboriginal
- 38% diagnosed within the past 10 years; 33% diagnosed 10 to 19 years ago; and 17% diagnosed 20 or more years ago

Participants were very engaged with care. Eighty-seven percent had discussed treatment options with their doctor, and 54% had some experience with treatment.

Participants wanted to be involved in decision making about their care. Eighty two percent were either very involved or somewhat involved in decision making around hepatitis C care. Forty one percent wanted more involvement in making decisions about their care.

Participants reported low levels of hepatitis C knowledge. Only 23% of participants reported knowing 'a lot' about hepatitis C generally and 20% reported knowing 'a lot' about hepatitis C treatment. Participants reported a large need for information; 85% reported needing at least 'a little' hepatitis C information.

Participants were asked to rank the importance of different topics (top three). Through these rankings, high and low priorities topics could be identified. For overall health information, high priority/importance and lower priority/importance topics were:

High priority/importance	Lower priority/importance
<ul style="list-style-type: none"> <li>• How hepatitis C affects the body</li> <li>• How to stay healthy</li> <li>• How to prevent transmitting hepatitis C to others</li> <li>• Treatments for hepatitis C</li> </ul>	<ul style="list-style-type: none"> <li>• The effects of alcohol and drugs on hepatitis C</li> <li>• Personal experience or stories of people living with hepatitis C</li> <li>• How to tell others they have hepatitis C</li> </ul>

For hepatitis C treatment information, high priority/importance and lower priority/importance topics were:

High priority/importance	Lower priority/importance
<ul style="list-style-type: none"> <li>• How to get ready to start treatment</li> <li>• How to deal with side effects</li> <li>• How to get and pay for treatment</li> </ul>	<ul style="list-style-type: none"> <li>• What happens after treatment</li> <li>• What they need to know if they also use other drugs, including street drugs</li> <li>• What they need to know if they have other infections like HIV</li> <li>• How to stay adherent to treatment</li> </ul>

Participants were also asked to rank the important of different formats for receiving information (top three). Through these rankings, high and low priorities formats could be identified. Priority formats for receiving information were:

High priority/importance	Lower priority/importance
<ul style="list-style-type: none"> <li>• Internet</li> <li>• Brochures, booklets or pamphlets</li> <li>• Workshops</li> </ul>	<ul style="list-style-type: none"> <li>• Phone/email</li> <li>• Apps</li> <li>• Text messages</li> </ul>

Participants primarily got their information from healthcare providers with ninety percent reporting doctors/nurses as the most common source of hepatitis C information. Substantially fewer reported using the internet (36%); support groups (29%); community organizations (28%); peers (27%); family/friends (23%); and media (16%) for hepatitis C information.

In summary, there is a high level of need for information on hepatitis C generally and on hepatitis C treatment among people living with hepatitis C who are engaged in hepatitis C care. There are clear priorities on topic areas and on preferred formats for receiving information. These can be used to develop resources and tools that support people living with hepatitis C to manage their health and to make informed decisions about their treatment.

# 1 Background

---

Hepatitis C is a liver disease caused by the hepatitis C virus. Some people are able to clear the virus from their body early on in infection; however, the infection becomes chronic in about three-quarters of people. Chronic infection can lead to severe liver damage (cirrhosis), liver cancer and liver failure (which requires a liver transplant). There are effective treatments for hepatitis C, but no vaccine exists to prevent infection.

Many people in Canada are affected by hepatitis C. An estimated 332,414 people in Canada were antibody positive for hepatitis C in 2011. This means they had evidence of a current or past infection with hepatitis C. An estimated 220,697 to 245,987 Canadians were infected with chronic hepatitis C in 2011.

It is important to understand the information needs of people living with hepatitis C to support them to manage their health and make informed decisions about treatment.

In 2014-5, CATIE undertook a national needs assessment partially funded by AbbVie (through an unrestricted educational grant). The needs assessment was conducted with patients engaged in hepatitis C care and was designed to provide information on the priority knowledge needs of people living with hepatitis C and how these needs can be met. The specific objectives were to:

- provide a description of people accessing hepatitis C care and treatment
- gain an understanding of hepatitis C treatment and people's preferred role in medical decision making
- gain an understanding of patients' current level of knowledge about hepatitis C and their current level of need for hepatitis C information
- identify the different types of hepatitis C information needed by patients
- identify differences in hepatitis C information needs among patients

The results of the needs assessment will inform the work of healthcare providers and other information providers working in hepatitis C, including CATIE.

## 2 Methodology

---

A survey was developed and focus tested to assess the information needs of people engaged in hepatitis C care. The survey was designed to be self-administered through an online survey. However, some clinics opted for a paper-based form which was subsequently entered into the online survey tool. In some instances a healthcare provider may have assisted in completion of the survey. The survey was available in both English and French and took approximately 10 minutes to complete. The survey asked some basic demographic questions and questions designed to better understand information needs among people living with hepatitis C and the best ways to fulfill those needs. All responses were confidential and anonymous.

Twenty medical clinics serving people living with hepatitis C were approached to help recruit people with hepatitis C in their care to complete an online survey. The survey was available through Fluid Survey on an iPad in each clinic (and in a few paper-based copies). Eight clinics in British Columbia, Alberta, Saskatchewan, Manitoba and Ontario recruited people living with hepatitis C to complete the online survey (Appendix B; Table 1). Every effort was made to recruit sites in other regions; however, this failed to produce recruitment sites.

A simple analysis (frequencies) was performed on all the questions in the survey. A more complex bivariate analysis (chi-square tests) was performed on selected questions in the survey to look for associations. All the results from the simple analysis are reported in the results section; however, only selected results from the more complex analysis will be highlighted in the results section. All results can be found in tables in Appendix B.

# 3 Results

---

## ***Section 1: Who completed the survey?***

Among those who completed the survey, 63% were 46 years of age and older and 37% were 45 years of age and under (Appendix B; Table 2).

Among those who completed the survey, 66% identified as men, 33% as women, and less than 1% identified as trans men or trans women (Appendix B; Table 3).

The most reported categories for origin/family background were:

- Aboriginal (27%)
- Western/Northern European (24%)
- Eastern European (14%)
- Southern European (6%)
- Middle Eastern (4%)
- South Asian (2%)
- Southeast Asian (2%)

The origin/family background of the remaining respondents can be found in Appendix B. (Appendix B; Table 4). People could identify with more than one origin/family background.

## ***Section 2: Health and care***

Just over one-third of respondents (38%) were diagnosed with hepatitis C less than 10 years ago, 33% were diagnosed 10 to 19 years ago, 17% twenty or more years ago, and 12% didn't know (Appendix B; Table 5).

Approximately 87% of respondents reported they have discussed hepatitis C treatment options with their doctor (Appendix B; Table 6).

Almost half of respondents reported they have never been on hepatitis C treatment (46%). Sixteen percent were currently on treatment. Twenty-two percent had taken treatment and cleared the virus, and 16% had taken treatment but not cleared the virus (Appendix B; Table 8).

In terms of their hepatitis C care, 64% reported being very involved in making decisions about their care. An additional 18% reported being somewhat involved in making these decisions, 7% reported other people make decisions for them, and 11% didn't know (Appendix B; Table 10). People who reported a higher level of hepatitis C knowledge were more likely to report being very involved in their hepatitis C care decisions (Appendix B; Table 11).

Around 52% of respondents thought their involvement level in decision making was about right, while 41% would prefer to be more involved. Only 1% wanted to be less involved and 6% reported they didn't know (Appendix B; Table 12). Younger respondents, Aboriginal respondents and respondents who reported a low level of knowledge of hepatitis C were more likely to want to be more involved in hepatitis C care decisions (Appendix B; Table 13).

### ***Section 3: General hepatitis C knowledge needs***

When asked to rate their hepatitis C knowledge, 23% reported knowing a lot, 40% reported knowing a fair amount, 31% reported knowing a little bit and 6% reported knowing nothing (Appendix B; Table 14). Younger respondents, men, and Aboriginal respondents were more likely to report low levels of knowledge about hepatitis C (Appendix B; Table 15).

### ***Section 4: Hepatitis C treatment knowledge needs***

In terms of hepatitis C treatment, only 20% reported knowing a lot, 33% reported knowing a fair amount, 38% reported knowing a little bit and 9% reported knowing nothing (Appendix B; Table 16). Younger respondents and Aboriginal respondents were more likely to report low levels of knowledge about hepatitis C treatment (Appendix B; Table 17).

### ***Section 5: Reported need for hepatitis C information***

When asked about their need for hepatitis C information, 32% reported needing a lot of information, 31% reported needing some, 17% reported needing a little, 15% reported needing none and 5% were unsure (Appendix B; Table 18). Aboriginal respondents were more likely to report needing more hepatitis C information (Appendix B; Table 19)

### ***Section 6: Importance of specific hepatitis C information topics***

Participants were asked to rate various hepatitis C topics by their importance (Appendix B; Tables 20 to 33):

- 93% rated information about staying healthy as important or very important
- 92% rated information about hepatitis C treatments as important or very important
- 91% rated information about preventing transmission as important or very important
- 90% rated information about hepatitis C's effect on the body as important or very important
- 82% rated information about the effects of alcohol and drug use on hepatitis C as important or very important
- 74% rated information about disclosure as important or very important
- 70% rated personal experiences/stories of people with hepatitis C as important or very important

### ***Section 7: The most important hepatitis C topics***

Participants were asked to choose their three most important hepatitis C information needs. Through these rankings, high and low priorities were identified (Appendix B; Table 35).

High priority/importance

- How hepatitis C affects the body (reference group= 1.0)
- How to stay healthy (ratio = 0.91)
- How to prevent transmitting hepatitis C to others (ratio = 0.91)
- Treatments for hepatitis C (ratio = 0.74)

Lower priority/importance

- The effects of alcohol and drugs on hepatitis C (ratio = 0.20)
- Personal experience or stories of people living with hepatitis C (ratio = 0.17)
- How to tell others they have hepatitis C (ratio = 0.16)

### ***Section 8: Importance of specific hepatitis C treatment information topics***

Participants were asked to rate various categories of hepatitis C treatment information by their importance (Appendix B; Tables 36-49):

- 91% rated information about dealing with side effects as important or very important



- 87% rated information about what happens after treatment as important or very important
- 85% rated information about getting ready to start treatment as important or very important
- 79% rated information about help with taking medications on time (adherence) as important or very important
- 78% rated information about how to get and pay for treatment as important or very important
- 76% rated information about co-infections (like HIV) as important or very important
- 72% rated information about the use of other drugs (including street drugs) as important or very important

### ***Section 9: The most important hepatitis C treatment topics***

Participants were asked to choose their three most important hepatitis C treatment information needs. Through these rankings, high and low priorities were identified (Appendix B; Table 51).

#### High priority/importance

- How to get ready to start treatment (reference group= 1.0)
- How to deal with side effects (ratio = 0.99)
- How to get and pay for treatment (ratio = 0.91)

#### Lower priority/importance

- What happens after treatment (ratio = 0.50)
- What to know about co-infections like HIV (ratio = 0.23)
- What to know when using other drugs (ratio = 0.23)
- What will help with taking medicines on time (adherence) to (ratio = 0.22)

### ***Section 10: Format preferences***

Participants were asked to rate the importance of various formats for receiving information about hepatitis C (Appendix B; Tables 52-63):

- 70% rated brochures, booklets, or pamphlets as important or very important
- 64% rated the internet as important or very important
- 63% rated workshops as important or very important
- 53% rated phone/email as important or very important
- 37% rated text messages as important or very important

- 37% rated apps for mobile devices as important or very important

Younger respondents and women were more likely to report the internet as an important source of information (Appendix B; Table 53). Aboriginal respondents were more likely to report print-based resources and in-person workshops as an important source of information (Appendix B; Table 55 and 63). Younger respondents were more likely to report apps as an important source of information (Appendix B; Table 57).

### ***Section 11: The most preferred formats***

Participants were asked to choose their three most preferred formats for receiving information about hepatitis C. Through these rankings, high and low priorities were identified (Appendix B; Table 65).

#### High priority/importance

- Internet (reference group = 1.0)
- Brochures, booklets or pamphlets (ratio = 0.90)
- Workshops (ratio = 0.60)

#### Lower priority/importance

- Phone/email (ratio = 0.43)
- Text messages (ratio = 0.13)
- Apps for mobile devices (ratio = 0.13)

### ***Section 12: Sources of information***

The respondents reported receiving their hepatitis C information from diverse sources (Appendix B; table 66). Almost all (90%) receive information from their doctor/nurse; 36% from the internet; 29% from support groups; 28% from community organizations; 27% from their peers; 23% from family/friends; 16% from the media; and 4% from other sources.

### ***Section 13: Qualitative results***

Participants were asked what their greatest concern about living with hepatitis C is. The most common responses were:

- The effects of hepatitis C on the body/progression of hepatitis C/quality of life
- Cure

- Death
- Transmission/disclosure
- Treatment and side effects
- Staying healthy

Qualitative responses can be found in Appendix C.

## 4 Conclusion

---

### **What did we learn about the knowledge exchange needs of people living with hepatitis C?**

There is significant room for improvement in the hepatitis C knowledge levels among people living with hepatitis C engaged in care. Only 25% of respondents reported they know a lot about hepatitis C generally or about hepatitis C treatment specifically. In addition, 85% reported they need at least a little hepatitis C information.

Knowledge exchange priority needs included general hepatitis C topics:

- How hepatitis C affects the body
- How to stay healthy
- How to prevent transmitting hepatitis C to others
- Treatments for hepatitis C

Knowledge exchange priority needs included treatment-related topics:

- How to get ready to start treatment
- How to deal with side effects
- How to get and pay for treatment

People prefer specific formats for knowledge exchange materials:

- Internet-based resources
- Print-based resources (brochures, booklets or pamphlets)
- In-person workshops

Points of dissemination could include:

- Physicians' offices
- The internet

- Support groups
- Community organizations

In summary, there is a high level of need for information on hepatitis C generally and on hepatitis C treatment among people living with hepatitis C engaged in care, especially for Aboriginal peoples and younger people. There are clear priorities on topic areas and clear priorities on preferred formats for receiving information. These can be used to develop resources and tools that support people living with hepatitis C to manage their health and make informed decisions about their treatment.

## Appendix A – Survey

Are you living with hepatitis C?  
Maybe we can help.

### Who are we?

CATIE is Canada’s source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life.

For more than 24 years, CATIE has been there to provide information that enables people to make informed choices about their health and enhances the ability of healthcare providers and other frontline organizations to respond to their clients’ needs.

### What are we asking you to do?

We are asking you to complete a short survey, so we can better tailor our services to your needs. The information you provide is confidential and anonymous.

How old are you? (Please select only one response)

- Less than 25 years old
- 26 to 35 years old
- 36 to 45 years old
- 46 to 55 years old
- 56 to 65 years old
- 66 years or older

What is your gender? (Please select only one response)

- Man
- Woman
- Trans man
- Trans woman
- Other (please specify) \_\_\_\_\_

What place of origin or family background do you identify with? (Please select as many options as apply to you)

- Aboriginal (e.g. First Nations, Inuit, Métis)
- Eastern European (e.g. Czech Republic, Poland, Bulgaria)
- Southern European (e.g. Portugal, Greece, Italy)
- Western/Northern European (e.g. United Kingdom, Austria, France)
- Caribbean (e.g. Cuba, Jamaica, Bahamas)

Central, and South American (e.g. Costa Rica, Brazil, Argentina)  
East Asian (e.g. Japan, Korea, China)  
Southeast Asian (e.g. Philippines, Thailand, Vietnam)  
South Asian (e.g. Pakistan, India, Nepal, Sri Lanka)  
Middle Eastern (e.g. Iran, Syria, Israel)  
North African (e.g. Algeria, Morocco)  
Sub-Saharan African (e.g. Kenya, South Africa, Zambia, Ghana)  
There is no option that applies to me, I identify as \_\_\_\_\_  
Don't know

Please tell us the name of the clinic where you heard about this survey.

\_\_\_\_\_

### **Health and care**

In what year were you diagnosed with hepatitis C? \_\_\_\_\_

Have you discussed hepatitis C treatment options with your doctor? (Please select only one response)

Yes

No

Don't know

Please describe your (latest) experience with hepatitis C treatment? (Please select only one response)

I have never been on hepatitis C treatment.

I am currently on hepatitis C treatment.

I have taken hepatitis C treatment and I cleared the virus.

I have taken hepatitis C treatment, but it did not clear the virus.

Don't know.

How involved are you in making decisions around your hepatitis C care? (Please select only one response)

I am very involved in making decisions.

I am somewhat involved in making decisions.

Other people make the decisions for me.

Don't know.

I would like to be... (Please select only one response)

More involved in making decisions about my health.

Less involved in making decisions about my health.

I think my level of involvement is about right for me.

Don't know.

**Knowledge needs**

Please rate how much you know about hepatitis C. (Please select only one response)

- I know nothing about hepatitis C.
- I know a little bit about hepatitis C.
- I know a fair amount about hepatitis C.
- I know a lot about hepatitis C.
- Don't know.

Please rate your level of knowledge about hepatitis C treatment. (Please select only one response)

- I know nothing about hepatitis C treatment.
- I know a little bit about hepatitis C treatment.
- I know a fair amount about hepatitis C treatment.
- I know a lot about hepatitis C treatment.
- Don't know.

How much information about hepatitis C do you need? (Please select only one response)

- I don't need any information.
- I need a little information.
- I need some information.
- I need a lot of information.
- Don't know.

Please rate how important hepatitis C information in the following areas is for you. (Not at all Important, Somewhat Important, Important, Very important)

- How can I prevent transmitting hepatitis C to others?
- How does hepatitis C affect my body?
- What are the treatments for hepatitis C?
- What things can I do to stay healthy?
- How can I tell other people I have hepatitis C?
- What are the effects of alcohol and drug use on hepatitis C?
- Personal experiences/stories of people with hepatitis C.
- Other (please specify) \_\_\_\_\_

The next three questions ask about your three most important information needs.

My most important information need is: (Please choose only one option)

- How can I prevent transmitting hepatitis C to others?
- How does hepatitis C affect my body?
- What are the treatments for hepatitis C?
- What things can I do to stay healthy?
- How can I tell other people I have hepatitis C?
- What are the effects of alcohol and drug use on hepatitis C?

Personal experiences/stories of people with hepatitis C.  
Other

My second most important information need is: (Please choose only one option)

How can I prevent transmitting hepatitis C to others?  
How does hepatitis C affect my body?  
What are the treatments for hepatitis C?  
What things can I do to stay healthy?  
How can I tell other people I have hepatitis C?  
What are the effects of alcohol and drug use on hepatitis C?  
Personal experiences/stories of people with hepatitis C.  
Other

My third most important information need is: (Please choose only one option)

How can I prevent transmitting hepatitis C to others?  
How does hepatitis C affect my body?  
What are the treatments for hepatitis C?  
What things can I do to stay healthy?  
How can I tell other people I have hepatitis C?  
What are the effects of alcohol and drug use on hepatitis C?  
Personal experiences/stories of people with hepatitis C.  
Other

Please rate how important information about hepatitis C treatment in the following areas is for you. (Not at all Important, Somewhat Important, Important, Very important)

How to get and pay for treatment  
How to get ready to start treatment  
How can I deal with side effects  
What will help me take my medicines when I'm supposed to?  
What do I need to know if I have other infections, like HIV?  
What do I need to know if I also use other drugs, including street drugs?  
What happens after treatment?  
Other (please specify) \_\_\_\_\_

The next three questions ask about your three most important hepatitis C treatment needs.

My most important treatment topic is: (Please choose only one option)

How to get and pay for treatment  
How to get ready to start treatment  
How can I deal with side effects  
What will help me take my medicines when I'm supposed to?  
What do I need to know if I have other infections, like HIV?



What do I need to know if I also use other drugs, including street drugs?  
What happens after treatment?  
Other

My second most important treatment topic is: (Please choose only one option)

How to get and pay for treatment  
How to get ready to start treatment  
How can I deal with side effects  
What will help me take my medicines when I'm supposed to?  
What do I need to know if I have other infections, like HIV?  
What do I need to know if I also use other drugs, including street drugs?  
What happens after treatment?  
Other

My third most important treatment topic is: (Please choose only one option)

How to get and pay for treatment  
How to get ready to start treatment  
How can I deal with side effects  
What will help me take my medicines when I'm supposed to?  
What do I need to know if I have other infections, like HIV?  
What do I need to know if I also use other drugs, including street drugs?  
What happens after treatment?  
Other

What are your preferred formats for receiving information about hepatitis C?

Internet  
Brochures, booklets or pamphlets  
Apps for mobile devices  
Phone/email  
Text messages  
Workshops  
Other (please specify) \_\_\_\_\_

The next three questions ask about your three most preferred formats in which to receive hepatitis C information.

My preferred format is: (Please choose only one option)

Internet  
Brochures, booklets or pamphlets  
Apps for mobile devices  
Phone/email  
Text messages

Workshops  
Other

My second most preferred format is: (Please choose only one option)

Internet  
Brochures, booklets or pamphlets  
Apps for mobile devices  
Phone/email  
Text messages  
Workshops  
Other

My third most preferred format is: (Please choose only one option)

Internet  
Brochures, booklets or pamphlets  
Apps for mobile devices  
Phone/email  
Text messages  
Workshops  
Other

How do you get your hepatitis C information? (Please select all that apply to you)

Doctor/nurse  
Community organizations  
Internet  
Family/friends  
Support groups that meet in person  
Media (ex. television, radio, newspapers)  
Peers (talking to other people who have hepatitis C)  
Other (please specify) \_\_\_\_\_

What is your greatest concern about living with hepatitis C?

---

---

---

Please name any specific resources you have found helpful in managing your hepatitis C.

---

---

---

Is there anything else you would like to tell us about your needs?

---

---

---

---

Thank you for taking the time to complete this survey! It will help CATIE tailor information to the needs of people living with hepatitis C in Canada.

## Appendix B – Tables of results (combined)

Table 1. Sites

	Frequency	Percent
Viral Hepatitis Clinic, Health Sciences Centre	21	6.4
Bloom Clinic, Wellfort Community Health Centre	11	3.4
Pender Community Health Centre	36	11.0
Prince Albert Community Hepatitis C Program	35	10.7
Calgary Urban Project Society (CUPS)	33	10.1
Hepatitis Support Program, Kaye Edmonton Clinic	12	3.7
Vancouver Infectious Diseases Centre	112	34.4
Toronto Liver Centre	66	20.2
Total	326	100.0

Table 2. Age

	Frequency	Percent
Less than 25 years old	9	2.8
26 to 35 years old	39	12.0
36 to 45 years old	72	22.2
46 to 55 years old	114	35.1
56 to 65 years old	76	23.4
66 years or older	15	4.6
Total	325	100.0

Table 3. Gender

	Frequency	Percent
Man	213	66.1
Woman	107	33.2
Trans man	1	0.3
Trans woman	1	0.3
Total	326	100.00

Table 4. Origin/family background

	Frequency	Percent
Aboriginal (e.g. First Nations, Inuit, Metis)	86	26.9
Eastern European (e.g. Czech Republic, Poland, Bulgaria)	45	14.1
Southern European (e.g. Portugal, Greece, Italy)	18	5.6
Western/Northern European (e.g. United Kingdom, Austria, France)	78	24.4
Caribbean (e.g. Cuba, Jamaica, Bahamas)	3	0.9
Central and South American (e.g. Costa Rica, Brazil, Argentina)	2	0.6
East Asian (e.g. Japan, Korea, China)	3	0.9
Southeast Asian (e.g. Philippines, Thailand, Vietnam)	5	1.6
South Asian (e.g. Pakistan, India, Nepal, Sri Lanka)	7	2.2
Middle Eastern (e.g. Iran, Syria, Israel)	12	3.8
North African (e.g. Algeria, Morocco)	1	0.3
Sub-Saharan African (e.g. Kenya, South Africa, Zambia, Ghana)	2	0.6
Don't know	19	5.9
There is no option that applies to me, I identify as: (see below)	66	20.6

'Other' responses: Adopted, African American, French Canadian and Italian, American, Ashkenazi Jew, Born in Canada, Born in Vancouver, Canada, Canadian, Canadian, Canadian Ukraine Irish, Canadian white, Caucasian, Central Asian, Central Asia Uzbekistan, Dutch Irish, East coaster, English, French, French Canadian, French Canadian, French-Italian, From Quebec, German, I am adopted by my biological father was Mexican and my biological mother I don't know, I was born in Canada, Jewish, Mulatto, New Brunswick, Ontario, Persian, Russia, Spanish and Native, Ukraine, Vancouver, Vancouver BC, Vietnam, White, White Canadian, White guy.

Table 5. Years since diagnosis

	Frequency	Percent
Less than 10 years	123	37.7
10 to 19 years	108	33.1
20 or more years	56	17.2
Don't know	39	12.0
Total	326	100.00

Table 6. Discussion of hepatitis C treatment options with doctor

	Frequency	Percent
Yes	263	87.1
No	39	12.9
Total	302	100.0

Table 7. Factors associated with reporting having hepatitis C treatment options discussion with doctor

	%	P-value
<i>Age</i>		<0.01
45 and under	77.7	
46 and older	92.6	
<i>Gender</i>		0.149
Man	84.9	
Woman	90.9	
<i>Aboriginal</i>		0.066
No	89.4	
Yes	81.5	
<i>Involvement in hepatitis C care decisions</i>		0.035
Very involved	93.3	
Somewhat involved/others make decisions for me	85.1	
<i>Treatment experience</i>		<0.001
Never been on treatment/taken treatment and did not clear virus	74.8	
Currently on treatment/taken treatment and did clear the virus	96.4	
<i>Knowledge of hepatitis C</i>		<0.001
Nothing/little	74.0	
Fair amount/a lot	93.9	

Table 8. Latest experience with hepatitis C treatment

	Frequency	Percent
I have never been on hepatitis C treatment.	140	46.2
I am currently on hepatitis C treatment.	47	15.5
I have taken hepatitis C treatment and I cleared the virus.	67	22.1
I have taken hepatitis C treatment, but it did not clear the virus.	49	16.2
Total	303	100.0

Table 9. Factors associated with reporting hepatitis C treatment experience (currently on treatment or taken treatment and cleared virus)

	%	P-value
<i>Age</i>		0.005
45 and under	34.6	
46 and older	52.4	
<i>Gender</i>		0.005
Man	51.2	
Woman	32.6	
<i>Aboriginal</i>		<0.001
No	54.5	
Yes	22.7	
<i>Involvement in hepatitis C care decisions</i>		0.312
Very involved	51.9	
Somewhat involved/others make decisions for me	44.3	
<i>Knowledge of hepatitis C</i>		<0.001
Nothing/little	30.9	
Fair amount/a lot	54.6	

Table 10. Current involvement in hepatitis C care decision making

	Frequency	Percent
I am very involved in making decisions.	200	63.9
I am somewhat involved in making decisions.	57	18.2
Other people make the decisions for me.	22	7.0
Don't know.	34	10.9
Total	313	100.0

Table 11. Factors associated with reporting being very involved in hepatitis C care decision making

	%	P-value
<i>Age</i>		0.269
45 and under	76.0	
46 and older	69.8	
<i>Gender</i>		0.044
Man	67.8	
Woman	79.3	
<i>Aboriginal</i>		0.321
No	73.4	
Yes	67.2	
<i>Treatment experience</i>		0.312
Never been on treatment/taken treatment and did not clear virus	69.4	
Currently on treatment/taken treatment and did clear the virus	75.5	
<i>Knowledge of hepatitis C</i>		<0.001
Nothing/little	55.8	
Fair amount/a lot	80.0	

Table 12. Preferred level of involvement in hepatitis C care decision making

I would like to be...	Frequency	Percent
More involved in making decisions about my health.	127	41.0
Less involved in making decisions about my health.	3	1.0
I think my level of involvement is about right for me.	161	51.9
Don't know.	19	6.1
Total	310	100.0



Table 13. Factors associated with reporting wanting to be more involved in hepatitis C care decision making

	%	P-value
<i>Age</i>		0.002
45 and under	55.7	
46 and older	37.0	
<i>Gender</i>		0.259
Man	46.6	
Woman	39.6	
<i>Aboriginal</i>		0.009
No	39.2	
Yes	56.4	
<i>Involvement in hepatitis C care decisions</i>		0.306
Very involved	60.9	
Somewhat involved/others make decisions for me	54.1	
<i>Treatment experience</i>		<0.001
Never been on treatment/taken treatment and did not clear virus	57.5	
Currently on treatment/taken treatment and did clear the virus	30.6	
<i>Knowledge of hepatitis C</i>		<0.001
Nothing/little	58.3	
Fair amount/a lot	36.0	

Table 14. Knowledge of hepatitis C

	Frequency	Percent
I know nothing about hepatitis C.	16	5.5
I know a little bit about hepatitis C.	92	31.4
I know a fair amount about hepatitis C.	118	40.3
I know a lot about hepatitis C.	67	22.9
Total	293	100.0

Table 15. Factors associated with reporting a fair amount or a lot of knowledge about hepatitis C

	%	P-value
<i>Age</i>		0.002
45 and under	51.9	
46 and older	69.7	
<i>Gender</i>		0.002
Man	57.1	
Woman	75.8	
<i>Aboriginal</i>		<0.001
No	69.8	
Yes	44.2	
<i>Involvement in hepatitis C care decisions</i>		<0.001
Very involved	74.5	
Somewhat involved/others make decisions for me	47.9	
<i>Treatment experience</i>		<0.001
Never been on treatment/taken treatment and did not clear virus	48.9	
Currently on treatment/taken treatment and did clear the virus	72.0	

Table 16. Knowledge of hepatitis C treatment

	Frequency	Percent
I know nothing about hepatitis C treatment.	26	8.8
I know a little bit about hepatitis C treatment.	113	38.2
I know a fair amount about hepatitis C treatment.	99	33.4
I know a lot about hepatitis C treatment.	58	19.6
Total	296	100.0

Table 17. Factors associated with reporting a fair amount or a lot of knowledge about hepatitis C treatment

	%	P-value
<i>Age</i>		0.003
45 and under	41.8	
46 and older	59.7	
<i>Gender</i>		0.137
Man	50.0	
Woman	59.2	
<i>Aboriginal</i>		<0.001
No	60.3	
Yes	32.1	
<i>Involvement in hepatitis C care decisions</i>		<0.001
Very involved	66.8	
Somewhat involved/others make decisions for me	30.6	
<i>Treatment experience</i>		<0.001
Never been on treatment/taken treatment and did not clear virus	31.5	
Currently on treatment/taken treatment and did clear the virus	67.9	
<i>Knowledge of hepatitis C</i>		<0.001
Nothing/little	9.3	
Fair amount/a lot	78.7	

Table 18. Amount of hepatitis C information needed

	Frequency	Percent
I don't need any information.	45	15.1
I need a little information.	52	17.4
I need some information.	92	30.9
I need a lot of information.	95	31.9
Don't know.	14	4.7
Total	298	100.0

Table 19. Factors associated with reporting needing some or a lot of hepatitis C information

	%	P-value
<i>Age</i>		0.892
45 and under	66.3	
46 and older	65.6	
<i>Gender</i>		0.534
Man	64.7	
Woman	68.5	
<i>Aboriginal</i>		0.002
No	60.8	
Yes	80.5	
<i>Involvement in hepatitis C care decisions</i>		0.364
Very involved	63.9	
Somewhat involved/others make decisions for me	70.0	
<i>Treatment experience</i>		0.101
Never been on treatment/taken treatment and did not clear virus	71.2	
Currently on treatment/taken treatment and did clear the virus	61.0	
<i>Knowledge of hepatitis C</i>		0.164
Nothing/little	70.6	
Fair amount/a lot	62.4	

Table 20. Importance of information regarding: transmission prevention

	Frequency	Percent
Not at all important	15	5.0
Somewhat important	12	4.0
Important	73	24.4
Very important	199	66.6
Total	299	100.0

Table 21. Factors associated with reporting information on how to prevent transmitting hepatitis C to others as important/very important

	%	P-value
<i>Age</i>		0.655
45 and under	90.0	
46 and older	91.5	
<i>Gender</i>		0.669
Man	91.4	
Woman	89.9	
<i>Aboriginal</i>		0.981
No	91.2	
Yes	91.2	
<i>Involvement in hepatitis C care decisions</i>		0.595
Very involved	90.0	
Somewhat involved/others make decisions for me	92.1	
<i>Treatment experience</i>		0.068
Never been on treatment/taken treatment and did not clear virus	88.9	
Currently on treatment/taken treatment and did clear the virus	95.4	
<i>Knowledge of hepatitis C</i>		0.456
Nothing/little	89.8	
Fair amount/a lot	92.3	

Table 22. Importance of information regarding: effect of hepatitis C on the body

	Frequency	Percent
Not at all important	8	2.7
Somewhat important	22	7.4
Important	81	27.2
Very important	187	62.8
Total	298	100.0

Table 23. Factors associated with reporting information on how hepatitis C affects their body as important/very important

	%	P-value
<i>Age</i>		0.442
45 and under	88.2	
46 and older	91.0	
<i>Gender</i>		0.429
Man	88.9	
Woman	91.8	
<i>Aboriginal</i>		0.399
No	90.7	
Yes	87.3	
<i>Involvement in hepatitis C care decisions</i>		0.452
Very involved	91.1	
Somewhat involved/others make decisions for me	88.0	
<i>Treatment experience</i>		0.337
Never been on treatment/taken treatment and did not clear virus	88.0	
Currently on treatment/taken treatment and did clear the virus	91.7	
<i>Knowledge of hepatitis C</i>		0.987
Nothing/little	90.7	
Fair amount/a lot	90.7	

Table 24. Importance of information regarding: hepatitis C treatments

	Frequency	Percent
Not at all important	5	1.7
Somewhat important	19	6.4
Important	77	26.1
Very important	194	65.8
Total	295	100.0

Table 25. Factors associated with reporting information on hepatitis C treatments as important/very important

	%	P-value
<i>Age</i>		0.179
45 and under	89.1	
46 and older	93.5	
<i>Gender</i>		0.951
Man	91.9	
Woman	91.7	
<i>Aboriginal</i>		0.229
No	93.0	
Yes	88.6	
<i>Involvement in hepatitis C care decisions</i>		0.094
Very involved	94.1	
Somewhat involved/others make decisions for me	88.0	
<i>Treatment experience</i>		0.087
Never been on treatment/taken treatment and did not clear virus	88.0	
Currently on treatment/taken treatment and did clear the virus	94.4	
<i>Knowledge of hepatitis C</i>		0.178
Nothing/little	88.8	
Fair amount/a lot	93.3	

Table 26. Importance of information regarding: staying healthy

	Frequency	Percent
Not at all important	3	1.0
Somewhat important	19	6.4
Important	66	22.4
Very important	207	70.2
Total	295	100.0

Table 27. Factors associated with reporting information on things they can do to stay healthy as important/very important

	%	P-value
<i>Age</i>		0.328
45 and under	94.5	
46 and older	91.4	
<i>Gender</i>		0.523
Man	91.8	
Woman	93.9	
<i>Aboriginal</i>		0.850
No	93.0	
Yes	93.6	
<i>Involvement in hepatitis C care decisions</i>		0.981
Very involved	92.0	
Somewhat involved/others make decisions for me	91.9	
<i>Treatment experience</i>		0.404
Never been on treatment/taken treatment and did not clear virus	91.7	
Currently on treatment/taken treatment and did clear the virus	94.4	
<i>Knowledge of hepatitis C</i>		0.629
Nothing/little	92.5	
Fair amount/a lot	93.9	

Table 28. Importance of information regarding: hepatitis C status disclosure

	Frequency	Percent
Not at all important	34	11.4
Somewhat important	43	14.5
Important	83	27.9
Very important	137	46.1
Total	297	100.0



Table 29. Factors associated with reporting information on how to tell others you have hepatitis C as important/very important

	%	P-value
<i>Age</i>		0.039
45 and under	80.9	
46 and older	70.1	
<i>Gender</i>		0.314
Man	72.1	
Woman	77.6	
<i>Aboriginal</i>		0.304
No	72.6	
Yes	78.5	
<i>Involvement in hepatitis C care decisions</i>		0.688
Very involved	73.7	
Somewhat involved/others make decisions for me	71.2	
<i>Treatment experience</i>		0.353
Never been on treatment/taken treatment and did not clear virus	75.9	
Currently on treatment/taken treatment and did clear the virus	70.6	
<i>Knowledge of hepatitis C</i>		0.489
Nothing/little	75.7	
Fair amount/a lot	72.0	

Table 30. Importance of information regarding: effects of alcohol and drug use on hepatitis C

	Frequency	Percent
Not at all important	25	8.4
Somewhat important	29	9.8
Important	80	27.0
Very important	162	54.7
Total	296	100.0

Table 31. Factors associated with reporting information on the effects of alcohol and drug use on hepatitis C as important/very important

	%	P-value
<i>Age</i>		0.728
45 and under	80.7	
46 and older	82.4	
<i>Gender</i>		0.705
Man	82.2	
Woman	80.4	
<i>Aboriginal</i>		0.957
No	81.8	
Yes	82.1	
<i>Involvement in hepatitis C care decisions</i>		0.994
Very involved	83.6	
Somewhat involved/others make decisions for me	83.6	
<i>Treatment experience</i>		0.851
Never been on treatment/taken treatment and did not clear virus	82.6	
Currently on treatment/taken treatment and did clear the virus	83.5	
<i>Knowledge of hepatitis C</i>		0.352
Nothing/little	79.2	
Fair amount/a lot	83.6	

Table 32. Importance of information regarding: personal experiences/stories of people with hepatitis C

	Frequency	Percent
Not at all important	28	9.8
Somewhat important	57	19.9
Important	94	32.9
Very important	107	37.4
Total	286	100.0

Table 33. Factors associated with reporting hearing personal experiences/stories of hepatitis C as important/very important

	%	P-value
<i>Age</i>		0.688
45 and under	68.9	
46 and older	71.1	
<i>Gender</i>		0.855
Man	70.4	
Woman	69.4	
<i>Aboriginal</i>		0.828
No	70.7	
Yes	69.3	
<i>Involvement in hepatitis C care decisions</i>		0.773
Very involved	70.4	
Somewhat involved/others make decisions for me	68.6	
<i>Treatment experience</i>		0.692
Never been on treatment/taken treatment and did not clear virus	68.8	
Currently on treatment/taken treatment and did clear the virus	71.2	
<i>Knowledge of hepatitis C</i>		0.166
Nothing/little	64.4	
Fair amount/a lot	72.3	

Table 34. Importance of information regarding: other (see below for responses)

	Frequency	Percent
Not at all important	11	22.9
Somewhat important	7	14.6
Important	12	25.0
Very important	18	37.5
Total	48	100.0

Responses: About cure; Any and all info is good; Cure comes with health risks; Dealing with treatment side effects; Had Hep C but not now; Information for women in menopause who wanted HCV treatment; Long term effects of having hep c; No drugs or alcohol; Support group; Waiting lists for treatment; What foods to eat or not to eat

Table 35. Most important hepatitis C information needs

	Weighted Sum	Ratio
How can I prevent transmitting hepatitis C to others?	378	0.91
How does hepatitis C affect my body?	417	1.0 (reference group)
What are the treatments for hepatitis C?	307	0.74
What things can I do to stay healthy?	381	0.91
How can I tell other people I have hepatitis C?	67	0.16
What are the effects of alcohol and drug use on hepatitis C?	85	0.20
Personal experiences/stories of people with hepatitis C.	72	0.17

Table 36. Importance of information regarding: how to get and pay for treatment

	Frequency	Percent
Not at all important	26	8.8
Somewhat important	38	12.8
Important	75	25.3
Very important	157	53.0
Total	296	100.0

Table 37. Factors associated with reporting information on how to get and pay for treatment as important/very important

	%	P-value
<i>Age</i>		0.145
45 and under	73.9	
46 and older	81.1	
<i>Gender</i>		0.546
Man	77.6	
Woman	80.6	
<i>Aboriginal</i>		0.411
No	79.7	
Yes	75.3	
<i>Involvement in hepatitis C care decisions</i>		0.043
Very involved	81.1	
Somewhat involved/others make decisions for me	69.4	
<i>Treatment experience</i>		0.098
Never been on treatment/taken treatment and did not clear virus	80.6	
Currently on treatment/taken treatment and did clear the virus	71.6	
<i>Knowledge of hepatitis C</i>		0.270
Nothing/little	74.5	
Fair amount/a lot	80.1	

Table 38. Importance of information regarding: how to get ready to start treatment

	Frequency	Percent
Not at all important	20	6.7
Somewhat important	26	8.8
Important	92	31.0
Very important	159	53.5
Total	297	100.0

Table 39. Factors associated with reporting information on how to get ready to start treatment as important/very important

	%	P-value
<i>Age</i>		0.467
45 and under	86.5	
46 and older	83.3	
<i>Gender</i>		0.678
Man	85.4	
Woman	83.5	
<i>Aboriginal</i>		0.809
No	84.0	
Yes	85.2	
<i>Involvement in hepatitis C care decisions</i>		0.034
Very involved	87.3	
Somewhat involved/others make decisions for me	76.7	
<i>Treatment experience</i>		0.402
Never been on treatment/taken treatment and did not clear virus	86.5	
Currently on treatment/taken treatment and did clear the virus	82.6	
<i>Knowledge of hepatitis C</i>		0.212
Nothing/little	87.9	
Fair amount/a lot	82.3	

Table 40. Importance of information regarding: how to deal with side effects

	Frequency	Percent
Not at all important	14	4.7
Somewhat important	14	4.7
Important	97	32.7
Very important	172	57.9
Total	297	100.0

Table 41. Factors associated with reporting information on how to deal with side effects as important/very important

	%	P-value
<i>Age</i>		0.826
45 and under	90.1	
46 and older	90.9	
<i>Gender</i>		0.899
Man	90.4	
Woman	90.8	
<i>Aboriginal</i>		0.899
No	90.6	
Yes	90.1	
<i>Involvement in hepatitis C care decisions</i>		0.411
Very involved	91.1	
Somewhat involved/others make decisions for me	87.7	
<i>Treatment experience</i>		0.607
Never been on treatment/taken treatment and did not clear virus	91.0	
Currently on treatment/taken treatment and did clear the virus	89.0	
<i>Knowledge of hepatitis C</i>		0.480
Nothing/little	92.5	
Fair amount/a lot	90.1	

Table 42. Importance of information regarding: help with taking medications on time

	Frequency	Percent
Not at all important	24	8.1
Somewhat important	38	12.8
Important	91	30.7
Very important	143	48.3
Total	296	100.0

Table 43. Factors associated with reporting information on how to keep adherent to medications as important/very important

	%	P-value
<i>Age</i>		0.210
45 and under	82.9	
46 and older	76.8	
<i>Gender</i>		0.252
Man	80.8	
Woman	75.0	
<i>Aboriginal</i>		0.027
No	75.9	
Yes	87.7	
<i>Involvement in hepatitis C care decisions</i>		0.506
Very involved	80.4	
Somewhat involved/others make decisions for me	76.7	
<i>Treatment experience</i>		0.586
Never been on treatment/taken treatment and did not clear virus	77.9	
Currently on treatment/taken treatment and did clear the virus	80.7	
<i>Knowledge of hepatitis C</i>		0.781
Nothing/little	80.4	
Fair amount/a lot	79.0	

Table 44. Importance of information regarding: concurrent infections (e.g. HIV)

	Frequency	Percent
Not at all important	46	15.6
Somewhat important	24	8.1
Important	66	22.4
Very important	159	53.9
Total	295	100.0



Table 45. Factors associated with reporting information on having other infections (like HIV) as important/very important

	%	P-value
<i>Age</i>		0.044
45 and under	82.7	
46 and older	72.4	
<i>Gender</i>		0.637
Man	75.6	
Woman	78.1	
<i>Aboriginal</i>		0.015
No	73.0	
Yes	86.4	
<i>Involvement in hepatitis C care decisions</i>		0.131
Very involved	78.7	
Somewhat involved/others make decisions for me	69.9	
<i>Treatment experience</i>		0.242
Never been on treatment/taken treatment and did not clear virus	75.4	
Currently on treatment/taken treatment and did clear the virus	81.7	
<i>Knowledge of hepatitis C</i>		0.913
Nothing/little	77.4	
Fair amount/a lot	76.8	

Table 46. Importance of information regarding: use of other drugs (including street drugs)

	Frequency	Percent
Not at all important	57	19.3
Somewhat important	27	9.1
Important	84	28.4
Very important	128	43.2
Total	296	100.0

Table 47. Factors associated with reporting information on using other drugs as important/very important

	%	P-value
<i>Age</i>		0.351
45 and under	74.8	
46 and older	69.7	
<i>Gender</i>		0.423
Man	73.2	
Woman	68.8	
<i>Aboriginal</i>		0.050
No	68.7	
Yes	80.2	
<i>Involvement in hepatitis C care decisions</i>		0.888
Very involved	70.7	
Somewhat involved/others make decisions for me	71.6	
<i>Treatment experience</i>		0.909
Never been on treatment/taken treatment and did not clear virus	74.0	
Currently on treatment/taken treatment and did clear the virus	73.4	
<i>Knowledge of hepatitis C</i>		0.311
Nothing/little	75.7	
Fair amount/a lot	70.2	

Table 48. Importance of information regarding: what happens after treatment

	Frequency	Percent
Not at all important	12	4.1
Somewhat important	25	8.6
Important	91	31.3
Very important	163	56.0
Total	291	100.0

Table 49. Factors associated with reporting information on what happens after treatment as important/very important

	%	P-value
<i>Age</i>		0.755
45 and under	88.1	
46 and older	86.8	
<i>Gender</i>		0.717
Man	87.7	
Woman	86.2	
<i>Aboriginal</i>		0.582
No	86.5	
Yes	88.9	
<i>Involvement in hepatitis C care decisions</i>		0.354
Very involved	88.8	
Somewhat involved/others make decisions for me	84.5	
<i>Treatment experience</i>		0.320
Never been on treatment/taken treatment and did not clear virus	85.3	
Currently on treatment/taken treatment and did clear the virus	89.6	
<i>Knowledge of hepatitis C</i>		0.431
Nothing/little	89.6	
Fair amount/a lot	86.4	

Table 50. Importance of information regarding: other (see below for responses)

	Frequency	Percent
Not at all important	6	27.3
Somewhat important	3	13.6
Important	2	9.1
Very important	11	50.0
Total	22	100.0

Responses: Advertising more for CATIE to the public (e.g. buses and schools); I have cleared hepatitis C; My health is most important; Nutrition

Table 51. Most important hepatitis C treatment information needs

	Weighted Sum	Ratio
How to get and pay for treatment	377	0.91
How to get ready to start treatment	415	1.0 (reference group)
How can I deal with side effects	413	0.99
What will help me take my medicines when I'm supposed to?	90	0.22
What do I need to know if I have other infections, like HIV?	94	0.23
What do I need to know if I also use other drugs, including street drugs?	94	0.23
What happens after treatment?	207	0.50

Table 52. Preferred formats for receiving information about hepatitis C: internet

	Frequency	Percent
Not at all important	59	20.6
Somewhat important	43	15.0
Important	87	30.3
Very important	98	34.1
Total	287	100.0

Table 53. Factors associated with reporting the internet is an important/very important format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.001
45 and under	76.6	
46 and older	57.2	
<i>Gender</i>		0.022
Man	60.4	
Woman	74.2	
<i>Aboriginal</i>		0.960
No	64.9	
Yes	64.6	
<i>Involvement in hepatitis C care decisions</i>		0.027
Very involved	72.1	
Somewhat involved/others make decisions for me	57.7	
<i>Treatment experience</i>		0.483
Never been on treatment/taken treatment and did not clear virus	64.3	
Currently on treatment/taken treatment and did clear the virus	59.8	
<i>Knowledge of hepatitis C</i>		0.024
Nothing/little	56.3	
Fair amount/a lot	69.7	

Table 54. Preferred formats for receiving information about hepatitis C: brochures, booklets, or pamphlets

	Frequency	Percent
Not at all important	28	9.6
Somewhat important	59	20.1
Important	107	36.5
Very important	99	33.8
Total	293	100.0

Table 55. Factors associated with reporting brochures, booklets or pamphlets as an important/very format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.861
45 and under	70.9	
46 and older	69.9	
<i>Gender</i>		0.200
Man	67.7	
Woman	75.0	
<i>Aboriginal</i>		0.015
No	66.7	
Yes	81.2	
<i>Involvement in hepatitis C care decisions</i>		0.837
Very involved	70.7	
Somewhat involved/others make decisions for me	69.4	
<i>Treatment experience</i>		0.386
Never been on treatment/taken treatment and did not clear virus	72.7	
Currently on treatment/taken treatment and did clear the virus	67.6	
<i>Knowledge of hepatitis C</i>		0.542
Nothing/little	72.0	
Fair amount/a lot	68.5	

Table 56. Preferred formats for receiving information about hepatitis C: apps for mobile devices

	Frequency	Percent
Not at all important	110	39.7
Somewhat important	65	23.5
Important	62	22.4
Very important	40	14.4
Total	277	100.0

Table 57. Factors associated with reporting apps as an important/very important format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.025
45 and under	45.2	
46 and older	31.8	
<i>Gender</i>		0.923
Man	36.9	
Woman	37.5	
<i>Aboriginal</i>		0.533
No	35.7	
Yes	39.7	
<i>Involvement in hepatitis C care decisions</i>		0.529
Very involved	39.1	
Somewhat involved/others make decisions for me	34.8	
<i>Treatment experience</i>		0.113
Never been on treatment/taken treatment and did not clear virus	42.6	
Currently on treatment/taken treatment and did clear the virus	32.4	
<i>Knowledge of hepatitis C</i>		0.251
Nothing/little	32.7	
Fair amount/a lot	39.6	

Table 58. Preferred formats for receiving information about hepatitis C: phone/email

	Frequency	Percent
Not at all important	84	29.7
Somewhat important	49	17.3
Important	83	29.3
Very important	67	23.7
Total	283	100.0

Table 59. Factors associated with reporting phone/email as an important/very important format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.123
45 and under	58.9	
46 and older	49.4	
<i>Gender</i>		0.406
Man	54.7	
Woman	49.5	
<i>Aboriginal</i>		0.596
No	54.2	
Yes	50.6	
<i>Involvement in hepatitis C care decisions</i>		0.637
Very involved	55.5	
Somewhat involved/others make decisions for me	52.2	
<i>Treatment experience</i>		0.962
Never been on treatment/taken treatment and did not clear virus	54.0	
Currently on treatment/taken treatment and did clear the virus	54.3	
<i>Knowledge of hepatitis C</i>		0.100
Nothing/little	59.4	
Fair amount/a lot	49.1	

Table 60. Preferred formats for receiving information about hepatitis C: text messages

	Frequency	Percent
Not at all important	117	42.2
Somewhat important	57	20.6
Important	60	21.7
Very important	43	15.5
Total	277	100.0



Table 61. Factors associated with reporting text messages as an important/very important format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.060
45 and under	44.2	
46 and older	32.9	
<i>Gender</i>		0.244
Man	39.5	
Woman	32.2	
<i>Aboriginal</i>		0.627
No	37.8	
Yes	34.6	
<i>Involvement in hepatitis C care decisions</i>		0.202
Very involved	40.7	
Somewhat involved/others make decisions for me	31.9	
<i>Treatment experience</i>		0.129
Never been on treatment/taken treatment and did not clear virus	43.2	
Currently on treatment/taken treatment and did clear the virus	33.2	
<i>Knowledge of hepatitis C</i>		0.289
Nothing/little	41.6	
Fair amount/a lot	35.1	

Table 62. Preferred formats for receiving information about hepatitis C: workshops

	Frequency	Percent
Not at all important	50	17.8
Somewhat important	55	19.6
Important	90	32.0
Very important	86	30.6
Total	281	100.0

Table 63. Factors associated with reporting workshops as an important/very important format to receive information on hepatitis C

	%	P-value
<i>Age</i>		0.952
45 and under	62.9	
46 and older	62.5	
<i>Gender</i>		0.507
Man	63.7	
Woman	59.6	
<i>Aboriginal</i>		0.006
No	58.0	
Yes	75.6	
<i>Involvement in hepatitis C care decisions</i>		0.025
Very involved	66.1	
Somewhat involved/others make decisions for me	50.7	
<i>Treatment experience</i>		0.929
Never been on treatment/taken treatment and did not clear virus	65.3	
Currently on treatment/taken treatment and did clear the virus	64.8	
<i>Knowledge of hepatitis C</i>		0.771
Nothing/little	61.8	
Fair amount/a lot	63.5	

Table 64. Preferred formats for receiving information about hepatitis C: other (see below for responses)

	Frequency	Percent
Not at all important	8	16.7
Somewhat important	4	8.3
Important	7	14.6
Very important	29	60.4
Total	48	100.0

Responses: A support group; Canadian Liver Foundation; Communications between health authority regions regarding stats for any particular area; Doctor; Doctors; Group at Pender; Groups, hep C nurse, herbalist, books, personal stores; Hep c group at my clinic and with the doctors here; hep c support at Pender Clinic; Information from my liver specialist; My best way of receiving the importance of treatment and shared dialogue was with my hep c nurse in explaining everything from preventing to dealing with and coping with side effects and the treatment; one on one with nurse, building a safe relationship; Personal meetings; Regular weekly group; Speaking to professionals; Support group for HCV; Support group VIDC; Support groups; Support groups and one on one consults; Support groups for HCV positive people; Support groups etc.; TV; Weekly group at Pender.

Table 65. Most preferred formats for receiving information about hepatitis C

	Weighted Sum	Ratio
Internet	519	1.0 (reference group)
Brochures, booklets or pamphlets	469	0.90
Apps for mobile devices	66	0.13
Phone/email	225	0.43
Text messages	67	0.13
Workshops	309	0.60

Table 66. How do you get your hepatitis C information?

	Frequency	Percent
Doctor/nurse	262	90.0
Community organizations	80	27.5
Internet	104	35.7
Family/friends	67	23.0
Support groups that meet in person	83	28.5
Media (e.g. Television, radio, newspapers)	46	15.8
Peers (talking to other people who have hepatitis C)	78	26.8
Other (please specify)	11	3.8

'Other' responses: Brochures; Case manager; Education; Everywhere; Literature; My hep c nurses; My own research; Regeneration staff; Support group in Vancouver; Infectious disease centre; Support group at VIDC; Support group at Saint Paul's;

## Appendix C – Qualitative responses

### What is your greatest concern about living with hepatitis C?

- Be calm and do what the doctor recommends to you.
- Being able to be productive.
- Being tired
- Can it come back after being cleared for years?
- Cancer
- Cirrhosis
- Cleared but might come back
- Clearing and getting cured
- Cure
- Cured
- Dealing with the chronic effects of Hep C
- Death
- Death; Serious liver damage
- Depression
- Developing cancer and passing it on to others
- Did not want to die from liver disease
- Did treatment... Hep C free
- Diet, drug free, alcohol free
- Do I need treatment?
- Dying
- Dying
- Dying
- Dying
- Dying alone
- Dying from HCV
- Dying of liver disease
- Dying too young
- Dying too young. I want to be with my family as long as possible
- Dying
- Early death
- Eating properly
- Effects of treatment (both during and after)
- Fatigue
- Fatigue & anger
- Fatigue and disorientation. Pessimism.

- Get well
- Getting better
- Getting better.
- Getting coverage for medications
- Getting cured
- Getting rid of it
- Getting rid of it.
- Getting sick
- Getting tired, not being able to walk and do daily exercise
- Getting treatment
- Giving hep c to people and the fact of not feeling good
- Giving it to family.
- Giving it to other people
- Giving it to someone else
- Going to treatment
- Health
- How can I improve my quality of life while waiting for funding for the newest treatment?
- How can I live a healthy life
- How carcinogenic is HCV?
- How do I pay for my medication and how I can help myself to feel better
- How fast is my liver going to deteriorate
- How fast will it progress without treatment
- How it could affect your liver
- How it affects my body
- How it makes me feel
- How long before it will affect my body
- How long can I live
- How long can one live with the virus
- How long do I have to live
- How long I would live? I want it cured, I want it gone.
- How long I'm going to have it for, and will I get better?
- How long my lifespan is
- How long that I can live with hepatitis C
- How long will I survive without treatment
- How long you're going to live.
- How not to get it again
- How to deal with it and side effects of treatment
- How to get rid of it
- How to get rid of it.
- How to get treatment
- How to keep from infecting other people

- How to not infect others; treatment, nutrition, staying healthy after treatment.
- How to stay healthy
- How will I survive
- How will it affect the rest of my life?
- I am cured, so no worries any more. I am just to focus on lifestyle/personal choices
- I am cured now
- I am now clear of the virus
- I do not know
- I do not want to suffer
- I don't want to spread it around
- I get very scared when I am drinking
- I have a fear of going into stage 4 before treatment works for me
- I have cleared the virus but I am concerned about the effects of hep c and alcohol interaction
- I have cleared the virus, but I am seriously scared of hep. C coming back
- I have no concerns. I just want to be aware.
- I just want to make sure that I get cured and I am pleased that I was diagnosed just after FDA approval of Sovaldi
- I never thought about it
- I really don't care; it only comes up as an issue when a roommate is concerned about catching it and I wonder about fatigue
- I was very concerned that I would infect a loved one. I myself was infected by sharing an extremely hard bristled tooth brush with my spouse. My gums bled significantly, and shortly after that I had symptoms and was diagnosed with HCV.
- I will die
- If and when it will attack my liver.
- If I can get better or worse
- Lack of energy (a chore to daily living)
- My main concern is funding for hep c treatment. The second issue is hep c awareness at the community level. The public needs to have good reliable information presented other ways than through the news media. Consequently, community hep c awareness workshops would be a good idea.
- My mind and body,
- Needing a transplant
- Never feeling well or healthy. Ongoing fatigue
- No concern
- No concern! Doing treatment!
- No concerns.
- None
- Not being 100%
- Not being able to heal it from my blood stream

- Not being completely healthy and dying young
- Not clearing the virus post treatment. Not knowing how virus will impact my quality of life.
- Not contaminating others
- Not drinking
- Not giving it to anyone else
- Maintaining my health
- Not having enough energy to get through the day. Passing it on to my partner.
- Not knowing what is going to happen
- Not living
- Not living out my life as long as I can... And having to live my life without my full potential
- Not spreading the disease
- Not to spread it to others
- Nothing
- Ongoing liver damage progressing to liver failure. Wanting to connect with people opting out of western treatment. How to keep my liver healthy without doing treatment
- Organ failure and feeling lack of energy and ill effects
- Other people's reactions and the mixed information or misinformation about it
- Pain
- Passing HCV to others
- Passing it on to someone unintentionally. Having it take time from my miserable existence.
- Progressive liver damage. Ability to clear virus is questionable (Failed interferon & interferon/Riba treatments x4)
- Quality of life
- Quality of life. Always feeling weak and tired
- Receiving treatment after a certain age (70+). I was unqualified for treatment.
- Recurrence
- Reinfection
- Short life
- Side effects
- Spreading the virus
- Spreading it
- Spreading it to others
- Starting treatment as soon as possible.
- Starting treatment can aggravate my chronic liver disease
- Staying sick
- Staying alive
- Staying healthy
- Staying healthy
- Taking treatment
- Telling people I have it
- That I can be cured

- That I do not pass to anybody
- That I don't pass it on
- That I will get sick and die
- That I will die from it
- That I will die or pass it on
- That I'm going to die earlier
- That it will progress and my health will be at jeopardy
- That liver stage 4 can be treated
- That my hep c doesn't get bad and that I stay healthy
- That my kidney will fail and I will die
- The damage that it does to my body and the effect that the treatment will have on my body
- The long term goals for eradication of this devastating disease.
- The most important thing right now is my gallbladder as I have gallstones and have to have a cholecystectomy, and because this is something I had no idea of, it has deteriorated my liver to the 3rd stage of cirrhosis, and this is of great concern to me the longer I have to have this infected organ in my body.
- The state of stamina in everyday living and the stamina at work.
- Tiredness
- To be cured
- To be healthy
- To be treated
- To get cured
- To get cured
- To get rid of it
- To infect another person and my health
- To not drink alcohol because it can damage your liver and not to use other drugs
- To prevent it from transmitting to my family
- To try and get rid of it
- Transferring to other people
- Transmission
- Transmission
- Transmission.
- Transmission and dying soon
- Transmission to another person, like husband and kids.
- Transmitting it
- Transmitting to someone else, fatigue.
- Transmitting to someone else
- Transmitting it
- Treatment
- Treatment failure
- Unknown health



- Very afraid of transmitting hep c to baby.
- Want to get rid of it
- Weight loss and brain loss
- What can be helpful other than drugs and doctors? Is junk food really bad for my health?
- What will it do to me
- What would be the consequences (e.g. shorter lifespan)
- When does chronic infection turn into liver cirrhosis
- When will I get treatment and how hard will it be on my body
- Will it affect my health even after a successful treatment?
- Will it get worse
- You do not have a choice

**Please name any specific resources you have found helpful in managing your hepatitis C.**

- 601 north
- Access center
- Access place
- After the initial outbreak, I didn't have ongoing symptoms so I didn't look for resources.
- AIDS Vancouver; Native Health
- All the information from the internet and my doctor and nurse
- All of the resources at Pender, the doctor, nurse, counsellor, peers, and myself
- Alternative modalities like Chinese medicine and acupuncture, plus doctors who use complementary protocols
- Asking questions
- Bible
- Bloom clinic
- Brampton Healthcare
- Brochure
- Brochures and internet
- Brochures, booklets, internet
- Case manager and CATIE
- CATIE
- CATIE pamphlets given to me by my nurse
- CATIE stuff I see at my doctor's office
- CHC hep groups
- Clinicians with whom I work.
- Coming here to this group.
- Common sense
- Community health clinic, doctors and nurses, because I sometimes need clarification.
- Consulting doctor
- CUPS
- CUPS Calgary

- CUPS has been most awesome support.
- CUPS health. My Doctor and nurse
- CUPS hep c program
- CUPS medical clinic
- CUPS nurse
- CUPS, blogs
- CUPS, Dream center
- Diet was a useful way to treat the side effects
- Doctor
- Doctor
- Doctor, Vancouver Infectious Diseases Centre
- Doctor & internet
- Doctor Alenezi
- Doctor and the brochures at the office
- Doctor and hep C group
- Doctor, internet
- Doctor
- Doctor's office and reading
- Doctors
- Doctors & nurses
- Doctor's advice
- Doctor's advice, internet
- Doctors and nurses.
- Doctors, nurses
- Don't know
- Dr. Brian Conway
- Dr. Conway
- Dr. Conway and Shawn
- Dr. Conway and VIDC
- Drs.
- Eating healthy
- Family and friends. Brochures. HIV outreach clinics
- Friends
- Going to meetings
- Going to weekly groups that meet in person.
- Group
- Group at clinic, doctors at clinic, literature at clinic.
- Group help
- Group
- Group environment
- Groups

- Having a television
- Healthcare providers
- Health centres
- Hep C central
- Hep C support group
- Hep C support group, doctors, personal friends,
- Hep c weekly group and brochures
- Herbalist book and my herbalist
- I found that a good doctor and group takes the pressure off
- I found that my treatment nurse was very supportive. The second person was my hepatologist. I feel that the doctors should have the time for each person, so a person can be properly oriented to important concerns.
- I have been taking milk thistle and eating healthy foods
- I have found that Dr. Meggdy was helpful in managing my hepatitis.
- I have none
- I have not done treatment
- I have refused all written information
- I haven't really looked for any resources
- I used naturopathic medical treatments before and during the interferon treatment. I did 3-week whole foods, liver cleanse diet along with castor oil, and using hot water bottle treatments. Also did acupuncture every week, especially targeting hep C and interferon side effects. It worked very well on reducing side effects and the hep C was gone within 3 weeks of starting the treatment. My doctor was very impressed and asked what I'd done as I was one of the best he'd seen come through the interferon so well.
- Info
- Information from others
- Internet
- Internet browsing
- Internet searches
- Internet. Hep c workshops.
- Learning how to stop drinking
- Living
- Many of CATIE's newest pamphlets and website
- Medical nurse team
- Medical pamphlet
- Mental health
- Milk thistle
- Morphine
- My doctor

- My Doctor is very informed as he is a specialist, and he is kind, so because of his excellent care of me, he lets me know everything that's going on and all the latest information on hep c.
- My doctors
- My family
- My hep c nurse Leslie
- My medical team
- My nurse
- My nurses at CUPS will always be my nurses because of the efficiency of every department.
- My wonderful nurse, Kelly Hurd, at Dr. Elkashab's office.
- Native Health (P.O.P.)
- Nurse at the clinic.
- Nurse Darlene at Bloom clinic
- Online groups
- Online info, regular emails from the hep C BC group, my own research
- Outreach workers
- Pamphlets have helped
- Peer support groups
- Pender clinic
- Pender Clinic and hep c team
- Pender Clinic staff, group.
- Places like Pender clinic; life skills
- Quit doing drugs and eating healthy
- Quit drugs and eat healthy
- Recovery center offering me second chance at life, anyone who brings out the truth about hep c and frontline health care workers.
- Resting, reading, speaking with others who have gone through the treatment
- Sexual health clinic
- St. Paul's hospital, Royal Oak Clinic
- Staff at the Pender clinic in Vancouver
- Staying as healthy as I am able to
- Support group
- Support group at Vancouver Infectious Diseases Centre and Clinic
- Support group at VIDC
- Support group at VIDC
- Support groups
- Support groups are really helpful!
- Support groups for people living HCV
- Support groups for people living with hep C
- Support groups that i attend.
- Support staff

- Talk about it with friends
- The clinic
- The clinic. The doctors. Dr. Mark Hall.
- The group and talking with my doctor
- The hep c support group provided me with all kinds of very helpful information.
- The most helpful resource in managing my hep c and treatment is the groups that are offered at Pender clinic.
- The Pender group
- The support group and medical team
- This doctor office
- This group at Pender
- This group, my doctor, the team, the food, being treated with respect.
- This weekly group
- Threat to life
- Treatment
- Treatment. I'm so happy that I got treatment
- Trying to eat right
- Trying to get in shape. To be healthy to deal with side effects
- V.I.D.C
- Vancouver Infectious Diseases Centre
- Vancouver Infectious Disease Clinic; my social worker
- Vancouver Infectious Diseases Centre
- Vancouver infectious diseases centre
- Vancouver infectious diseases centre and internet
- Vancouver infectious diseases centre
- VIDC
- VIDC support group
- WebMD
- Websites
- Women's group; hep c nurse
- Workshops, support groups

**Is there anything else you would like to tell us about your needs?**

- 
- A phone number to call for information
- Antidotes and description of drugs (e.g. what's in the medication)
- Be more receptive to the power of the individual and the choices they make for themselves.
- Alternative protocols have been the key to why I am doing so very well
- Financial support for treatments
- Doctor was extremely helpful
- Everything is going well

- Fear of living with Hep C
- Fears of living with Hep C
- Feeling better
- From my experience of being on the treatment, the most important need is the living arrangements. Having my own bathroom and kitchen makes a big difference in being stable while I was on treatment and coming to group every week kept me on top of my health and was very informative.
- Healthy food that I can eat when I have hep C
- Hep C support groups would be good to attend if there are any. Meeting other people living with hep C talking and about it in groups, and more workshops in the community to raise awareness are needed.
- Hoping to continue working while on treatment,
- How can I manage hep c as well as several other chronic conditions such as heart problems, cirrhosis, and diabetes, and how to stay mentally and physically healthy
- How can I reduce all the side effects while I am on treatment
- How should deal with it in future
- How to deal with living with the hep c virus
- How to deal with side effects
- How to follow a good diet with low budget
- How to get treatment
- How to reduce the stigma of having Hep C. More fundraising and community support
- How to stay healthy and eat right.
- I cannot afford the treatment costs
- I had episodes of being sleepy and disoriented while cooking. I had fallen sleep and woke up from smoke... Would like to know how it can be related to my HCV.
- I have no money for treatment.
- I need a hug. Nah, just good influences to keep my hope alive. Thanks.
- I need clean and well maintained living quarters
- I need help with my down addiction
- I need more money and prescription for medicinal pot
- I need stable housing and steady income
- I need to be careful about my needle use
- I need to be more informed to be prepared for treatment
- I need to eat healthy and do not have money to get it
- I need to get rid of it
- I think more information in schools about infection and what it is.
- I would like more information about aging and what affects hepatitis C will have on me later in life even after clearing the virus
- I would like to join your study group
- I would like to try a new treatment that may work for me. I have tried two rounds of interferon and ribavirin

- I'd like to get medication in January so I can visit sister. My health.
- If I can get better and how to get the help that I need
- If there are better supports and help for the ones who can't access medical help
- Information about hepatitis in general; vaccination if they exists
- Ipad survey not easy to use. I have other health concerns that are more pressing than hep c
- It would be nice if there was nutritional support to go along with treatment
- It would make things a lot better if we had better food to go along with our illness
- Just have the usual apprehension of having an illness
- Just that I would like to be able to live life as long as I can
- Last month of treatment was hard. All patients should know what to expect before they start
- Live life to the fullest
- Liver cirrhosis
- Looking forward to treatment being over.
- MOH should make mandatory testing as part of annual check ups to minimize the progression of virus. If I was tested earlier in life, I would have not progressed to the current stage of my disease.
- More awareness
- More education on side effects of medication
- More help about needs to treat hep c
- More home support
- More info about treatment
- More info to educate
- More information
- More information about current available treatments of HCV
- More services and awareness that there is treatment for hep C
- More support groups with people I feel comfortable with
- More information about hepatitis so that people know there is treatment and where to get it
- More vitamins like vitamin c tablets
- My main concern was having adequate nutrition, adequate housing and a proper support network.
- Need for retraining and increased access to education
- Need information
- Need more money
- Need more peers to share
- Need more workshops about co-infection. Need to know why some people clear the virus and some people don't.
- Not really, but I want to know why beginning treatment takes so painfully long
- Not yet.
- Nothing

- Nothing in particular.
- Pamphlets tend to be too basic. After living with HCV for 30yrs, I know the basics :)
- Please talk with me about my needs
- Should receive more benefits under the special diet with Alberta works. Also help with phone through Alberta works to ensure appointments are made
- Simply that I sincerely feel that I have been receiving awesome help, info, support, and understanding here at the Pender clinic. I am thankful and constantly encouraged to continue forward in my little journey of healing that I am now on.
- Stay visible and do not be afraid of stigma
- Support groups in my city (Mississauga). There are no organizations for hep c in Mississauga
- Support throughout my treatments
- Thank YOU
- The relationship between HIV and HCV; infected gallbladder.
- The symptoms have been worse than expected - severe headaches and depression.
- There are no physicians
- They should make it easier to get access to vegetables and yogurt. Dietary needs.
- They've been met.
- This health clinic
- To get help and go through addiction treatment
- To help de-stigmatize the illness
- Treatment options
- Treatments available
- Unable to access the best medications as my liver is not bad enough, so I am constantly worried
- Want to start treatment, want to get back on Ativan.
- We need more help with the money for the medication.
- We need more nurses with the same protocol as Linda, Rachel, Dr. McPhail and Christina of the lab.
- Where to get healthy food when living on a low income
- When can I win the Lotto 649 to pay for my own treatment?
- Why would I be refused treatment just because my fibrosis level was 0.1
- Wonder if I have to be concerned about my liver health moving forward.