

A Nova Scotia Survey of Health and Health Care Costs For Hepatitis C

What is this survey about?

Thank you very much for agreeing to take part in this important study which is a survey of people who have Hepatitis C and how they consider cost issues when it comes to taking medication for this.

How to complete the questionnaire.

The questions inside cover a wide range of related topics, but most can be answered by placing a tick ✓ in one or more of the boxes . Sometimes you will be asked a question and your answer will be written in a box by the interviewer. No special knowledge is required and there are no right or wrong answers; we are simply interested in your own particular views.

The questionnaire should not take very long to fill in, about 30 minutes, and we hope you will find it interesting and enjoyable to complete. All your answers will be treated in the strictest of confidence, and will remain completely anonymous.

Questions or help.

If you have any queries about the survey please contact the researcher.

For Office Use:

ID Number: _____

Follow-up call made: _____

Consent given by participant: Yes Declined

Interview time scheduled: _____

Survey completed: _____

A. YOUR HEALTH, YOUR MEDICINES AND YOUR DOCTOR

First of all, a few questions about your general health.

A1. How would you say your health is in general?

- ¹ Very good
² Good
³ Fair
⁴ Bad
⁵ Very bad?
-

A2. Besides Hepatitis C, do you have, or have you ever had, any of the following conditions? [Tick all that apply]

<i>Have Now</i>	<i>Have had in past</i>	
---------------------	-----------------------------	--

- | | | |
|--------------------------|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> | Continuous back pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Asthma |
| <input type="checkbox"/> | <input type="checkbox"/> | Other breathing difficulties (e.g. chronic bronchitis) |
| <input type="checkbox"/> | <input type="checkbox"/> | Allergies |
| <input type="checkbox"/> | <input type="checkbox"/> | Cancer |
| <input type="checkbox"/> | <input type="checkbox"/> | Degenerative diseases (e.g. multiple sclerosis, arthritis, osteoporosis, Parkinson's) |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression |
| <input type="checkbox"/> | <input type="checkbox"/> | Diabetes |
| <input type="checkbox"/> | <input type="checkbox"/> | Feeling tired all the time (e.g. ME, chronic fatigue) |
| <input type="checkbox"/> | <input type="checkbox"/> | Heart disease (e.g. heart attack, angina etc.) |
| <input type="checkbox"/> | <input type="checkbox"/> | High blood pressure |
| <input type="checkbox"/> | <input type="checkbox"/> | Stroke |
| <input type="checkbox"/> | <input type="checkbox"/> | Other long-standing conditions, <i>please specify</i> _____ |
| <input type="checkbox"/> | <input type="checkbox"/> | None of these conditions |
-

A3. Do you take any regular prescription medicines?

- ¹ Yes
² No
-

A4. How many different regular prescribed medicines do you take? [Please enter the exact number]

A5. How often do you get a repeat prescription filled?

- ⁰ I do not get a repeat prescription
¹ About once a month
² About every two months
³ About every three months
⁴ Less than every three months
-

B. Hepatitis C AND WHAT YOU DO ABOUT IT

A few questions about your Hepatitis C condition.

B1. How long, overall, have you known that you have Hepatitis C?

- ¹ Up to six months
 - ² More than six months but less than one year
 - ³ One year to three years
 - ⁴ Three to ten years
 - ⁵ Longer than ten years
-

*B2. How many times have you been to see a doctor or nurse practitioner **on your own behalf** regarding your Hepatitis C in the last **three months**?*

- ⁰ Not at all
 - ¹ Once
 - ² Between 2 and 4 times
 - ³ More than 4 times
-

*B3. When you visit the Liver Diseases Clinic, do you **normally** get there by:*

- ¹ Walking/cycling
 - ² Driving yourself
 - ³ A lift (from family or friend)
 - ⁴ A taxi
 - ⁵ By bus / train
 - ⁶ Other, *please specify* _____
-

B4. How often would you say you get, or did get, a prescription or a repeat prescription directly related to your Hepatitis C from your doctor or nurse practitioner?

- ⁰ I have never had a prescription for Hepatitis C
 - ¹ This was the first prescription I have had
 - ² About once a month
 - ³ About every two months
 - ⁴ Every three to four months
 - ⁵ Every five to twelve months
 - ⁶ If you no longer get a prescription for Hepatitis C, when was your last treatment? _____(Mo/yr)
-

B5. How often would you say you get a prescription or a repeat prescription for other treatments related to Hepatitis C (e.g. depression, water retention, other side effects)?

- ⁰ I have never had a prescription for other treatments related to Hepatitis C
 - ¹ About once a month
 - ² About every two months
 - ³ Every three to four months
 - ⁴ Every five to twelve months
-

B6. Do you know what your viral genotype is/was?

- ¹ Yes ² No *If yes, please specify (i.e. genotypes 1-6):* _____
-

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B7. Below please list the name(s) of the drugs for Hepatitis C that you get on prescription from your doctor and, if possible, the strength of the medicine.

	Name	Strength	Instructions for Use
1	_____	_____	_____
2	_____	_____	_____
3	_____	_____	_____
4	_____	_____	_____
5	_____	_____	_____
6	_____	_____	_____

Other Prescription drugs:

	Name	Strength	Instructions for Use
1	_____	_____	_____
2	_____	_____	_____
3	_____	_____	_____
4	_____	_____	_____
5	_____	_____	_____
6	_____	_____	_____
7	_____	_____	_____
8	_____	_____	_____
9	_____	_____	_____
10	_____	_____	_____
11	_____	_____	_____
12	_____	_____	_____

Other non- prescription drugs:

	Name	Strength	Instructions for Use
1	_____	_____	_____
2	_____	_____	_____
3	_____	_____	_____
4	_____	_____	_____
5	_____	_____	_____
6	_____	_____	_____
7	_____	_____	_____
8	_____	_____	_____
9	_____	_____	_____
10	_____	_____	_____
11	_____	_____	_____
12	_____	_____	_____

Herbal medicines/complementary medicines:

	Name	Strength	Instructions for Use
1	_____	_____	_____
2	_____	_____	_____
3	_____	_____	_____
4	_____	_____	_____
5	_____	_____	_____
6	_____	_____	_____
7	_____	_____	_____
8	_____	_____	_____
9	_____	_____	_____
10	_____	_____	_____
11	_____	_____	_____

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B8. How experienced or knowledgeable would you say you are about Hepatitis C? Please state how much you agree or disagree with each of the following statements.

¹ Strongly agree ² Agree ³ Not sure ⁴ Disagree ⁵ Strongly Disagree

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
I know all I need to know about how I can change my lifestyle to help with my Hepatitis C					
I know all I need to know about long term health risks associated with Hepatitis C					
I know all I need to know about the medicines I take for my Hepatitis C					
I know all I need to know about the side effects from taking my Hepatitis C medicines					
I know all I need to know about the long-term benefits of taking my Hepatitis C medication					

B9. Where do you get your information on Hepatitis C?

- ⁰ I have never received any information for Hepatitis C
- ¹ The Liver clinic
- ² Family physician
- ³ Other health care professionals
- ⁴ The internet
- ⁵ Media stories (e.g., tv, radio, magazines)
- ⁶ Government sources (e.g., websites, pamphlets, brochures, etc.)
- ⁷ Family/friends
- ⁸ Other _____

B10. Is there anything else you would like to tell us about your Hepatitis C?

C. PRESCRIPTION CHARGES AND COST OF MEDICINES

The next few questions are about the cost of medicines. This includes the prescription charge but also money you may spend when buying something over the counter at a pharmacy.

C1. Do you **ever** feel you have to think about how much money you have available to spend when you obtain medicines (either obtained on prescription or bought from a pharmacist (drug store/hospital)?

¹ Always

² Often

³ Sometimes

⁴ Never

⁵ Not applicable

C2. The next few statements are things that people commonly say about the cost of medicines and what they do to keep this cost down. Please say how often you would behave in such a way.

	<i>Always</i>	<i>Often</i>	<i>Some-times</i>	<i>Never</i>	<i>Not Applicable</i>
If I can't afford my prescription I don't get my medicine dispensed at all					
Knowing that I will not be able to afford the prescription stops me from going to see my doctor or nurse practitioner					
If I'm worried about money I take less of my medicine to make it last longer					
I have to wait to get my prescription filled until I get paid (or social assistance cheque)					
If I have a number of different items on my prescription, I don't get them all filled, because I can't afford them all at once					
I have in the past borrowed money to pay for my prescription medicines					

C3. People sometimes ask their doctor or nurse practitioner for help or advice in order to keep the cost of medicines down. These statements are **not only** about your Hepatitis C medicines, but also other medicines that you may be taking for **other conditions**, including things that you may be able to **buy from a pharmacy**. Please say how often you would do any of the following.

	<i>Always</i>	<i>Often</i>	<i>Some-times</i>	<i>Never</i>	<i>Not Applicable</i>
I ask my doctor or nurse practitioner to prescribe a longer supply of my medicine to help me when I haven't got enough money					
If I can't afford my prescription I ask my doctor or nurse practitioner to recommend something cheaper to buy <i>without</i> a prescription					
I ask the doctor or nurse practitioner for a free 'sample' of medicine to save me having to pay for it on prescription					

C4. The next few statements are again **not only** about your Hepatitis C medicines, but other medicines that you may be taking for **other conditions** too, including things that you may be able to **buy from a pharmacist or other shop**. Please say how often you would behave in such a way.

	<i>Always</i>	<i>Often</i>	<i>Some-times</i>	<i>Never</i>	<i>Not Applicable</i>
I get a prescription, if it is covered, because buying an over the counter remedy tends to be too expensive					
If I can't afford my prescription I ask the pharmacist to recommend something cheaper to buy					
I consider the price of a medicine before I buy it without a prescription					
I prefer to buy something from the pharmacist/ drug store in order to avoid going to see a doctor or nurse practitioner					
I don't take anything, because I cannot afford to buy medication from a pharmacist or drug store					
If I cannot afford an expensive over the counter product I ask for something else cheaper at the drug store/pharmacy					

C5. This question concerns **your views** about prescription costs and whether you feel able to discuss cost issues with your doctor. Because nurse practitioners do not sign your prescriptions, we are only going to ask you about doctors, which would include a specialist and/or your family doctor. Again, this is about **any medicine**, not just your Hepatitis C medicines. Please state how much you agree or disagree with each of the following statements.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Not sure</i>	<i>Disagree</i>	<i>Strongly Disagree</i>	<i>N/A</i>
When my doctor writes a prescription s/he does not consider how much it is going to cost me						
The doctors are more worried about what the medication costs the hospital or government than what I have to spend						
My doctor is not aware of the problems I have with paying for my prescriptions						
I don't tend to talk to my doctor about the cost of my medicines and whether I can afford them or not						
My doctor sometimes advises me to buy a medicine over the counter rather than give me a prescription						
The doctor should take more of an interest in whether I can afford to pay for the medicines s/he prescribes						
It is not a doctor's job to check if I can afford to pay for the medicines						
I know how the cost of my prescription compares with what I have to pay when I buy something from the pharmacist/drug store						
The copayment I need to pay for the prescription charge is too high						

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C6. Does the Liver Diseases Clinic team help you obtain coverage for Hepatitis C medication (e.g. interferon, etc.)?

- ¹ Yes ² No

If yes, please explain _____

C7. What is your drug coverage currently?

- ¹ I am covered under my parents
² I have a private drug insurance plan Specify: _____
³ I am 65 years of age and covered by Nova Scotia Senior Pharmacare Plan
⁴ I am a client of Community Services and have coverage through Pharmacare
⁵ I have a Non-Insured Health Benefits Plan
⁶ I have a Veterans Affairs plan
⁷ I don't have any coverage
⁸ Other _____

C8. Are your prescriptions free or do you have to pay for them?

- ¹ Free
² Have to pay **all** prescription charges
³ Partially covered Specify: _____ % coverage:

C9. Some drug benefit plans require that you meet certain criteria before approval for drug coverage or reimbursement of drug purchases (e.g. forms filled out, signatures of physicians and others, drug receipts or proof of purchase). Please identify any of the following requirements that you have experienced in seeking access to your drugs:

- ¹ Have to pay a fee to the physician to fill out forms for the drug benefit plan
² Have to collect forms and mail/email/fax/deliver them to the drug benefit plan
³ Have to pay for the drug first and then seek reimbursement with receipts
⁴ Have to collect forms and send them to a reimbursement system, e.g. Pegassist or Pegcare

C10. Have there been situations where you have not claimed for the reimbursement of your drug costs from your benefits plan?

- ¹ Yes
² No

If yes, identify any of the following reasons that explain why you have not claimed for reimbursement of drug costs:

- ¹ Lost paperwork or forms
² Lost receipts
³ Unable to get appointment with doctor to fill out forms
⁴ Didn't understand the process
⁵ Other _____ --

D. IMPORTANT BACKGROUND INFORMATION

In this final section we would like to ask you a few questions about yourself. This gives us an idea of differences between people.

D1. What is your current clinic status (date): _____

- ¹ On treatment
² Previously on treatment, but no longer
³ Not on treatment, although eligible.
 Specify reason, if known _____
⁴ Organ recipient

D2. a) What is your age? _____

b) What is your date of birth? [day, month and year.] Day: ____ Month: ____ Year: _____

D3. Are you male or female?

- ¹ Male ² Female

D4. Ethnicity:

- ¹ Caucasian ² African-Canadian ³ Asian ⁴ First Nations
⁵ Other (please specify) _____

D5. Which of these descriptions applies to what you were doing last week? [Tick more than one if necessary]

- In full-time paid employment or self employed full-time
 In part-time paid employment or self-employed part-time
 In full-time education or training
 Looking after the family, home or dependants
 Waiting to take up paid work already obtained
 Looking for work
 Temporarily unable to look for work – on sick leave due to illness or injury
 Permanently unable to work because of long-term sickness
 Retired
 Doing something else, please specify _____

D6. If applicable, please give the title of your present or most recent paid job (or period of self-employment), and describe what you actually do /did.

a) Job title: _____

b) Job description: _____

c) Do/did you work in:

- ¹ a large organisation (25 or more employees)
² a small organisation (less than 25 employees)
³ on your own (self-employed and no employees)

d) *Has or did your treatment impact your employment or ability to work?*

¹ Yes ² No *If yes, please explain:*

D7. *What is your highest level of education?*

- ¹ Not yet finished
² I never went to school
³ Some elementary
⁴ Completed elementary
⁵ Some high school
⁶ Completed high school
⁷ Some Community College/Technical Institute/Trade School
⁸ Completed Community College/Technical Institute/Trade School
⁹ Some University/Teacher's College
¹⁰ Completed University/Teacher's College
¹¹ Don't know

D8. *What is your best estimate of your HOUSEHOLD total gross income (before any deductions for Income Tax) that you usually receive from **all** sources during the past 12 months? By all sources we mean income from main job(s), but also additional occupations, interest on savings, etc.*

Per year

- ¹ No income
² Less than \$9,999
³ \$10,000 to \$19,999
⁴ \$20,000 to \$29,999
⁵ \$30,000 to \$39,999
⁶ \$40,000 to \$49,999
⁷ \$50,000 to \$69,999
⁸ \$70,000 to \$89,999
⁹ \$90,000 to \$119,999
¹⁰ \$120,000 to \$149,999
¹¹ \$150,000 or more

D9. *How many people live in your household that are aged 18 or older? [Please write in the number, including yourself]*

Aged 18 or over _____

D10. *How many people live in your household that are aged 17 or younger?*

Aged 17 or younger _____

D11. *What is your current marital status?*

- ¹ *Single*
² *Married or living with partner*
³ *Separated*
⁴ *Widowed*
⁵ *Divorced*

