

Ministry of Health - Pharmaceutical Services Division

Welcome to B.C. PharmaCare's Public Input Questionnaire for drugs being reviewed under the B.C. Drug Review Process.

This questionnaire is for telaprevir (Incivek™).

Patient Groups have to register before completing the questionnaire. Not sure your group is registered? Check our list of [registered patient groups](#).

Your group can complete this patient group questionnaire only once. If you submit multiple questionnaires, only your last submission will be sent to the Drug Benefit Council for consideration.

Mandatory questions are flagged with an asterisk (*).

You do not need to answer all the questions. You need only answer those that you think apply to patients in your group.

To protect the privacy of members in your group, please do not include in your response names of individuals, companies, locations or any other information that might identify them or anyone else.

Confirm Your Eligibility

1. I am a resident of British Columbia, **AND**
I am an authorized member of a Patient Group that represents B.C. patients who have the condition or disease for which this drug is used*

Yes ()

No ()

Patient Group Information

You must complete this section of the questionnaire.

Your organization's contact information will only be used to retrieve your submission if you submit a request under the *Freedom of Information and Protection of Privacy Act (FOIPPA)*. It will not be used for any other purpose.

Your organization's name, however, will be included as part of your submission to the Drug Benefit Council.

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2. Patient Group Name and name of representative completing this questionnaire*

HepCBC Hepatitis C Education and Prevention Society (Rep

name REDACTED)

3. Patient Group's Address and Postal Code*

PO Box 46009 - 2642 Quadra St

Victoria, BC V8T5G7

Conflict of Interest Declaration

You must complete this section of the questionnaire.

To make sure the Drug Review process is objective and credible everyone who provides input has to tell us about any possible conflict of interest.

A conflict of interest exists if you, an immediate family member or your organization might benefit from the outcome of the review. For example, if you, an immediate family member or your organization owns stock in the company that makes the drug, they would be a financial benefit IF PharmaCare decides to cover the drug.

Examples of conflicts of interest include, but are not limited to, financial support from the pharmaceutical industry (e.g. educational or research grants, honoraria, gifts and salary) as well as affiliations or commercial relationships with drug manufacturers or other interest groups.

Even if you, an immediate family member or your organization has a conflict of interest, your input will still be considered as long as you declare the conflict of interest in your answers to the questions. All information you provide is protected under the *Freedom of Information and Protection of Privacy Act* (FOIPPA).

4. Do you have any Conflict(s) of Interest to declare? Yes, No

Yes (X)

No ()

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5. Describe any Conflict(s) of Interest below.
(Complete this question only if you answered "yes" to the previous question)

Will be receiving cheque for \$4000 from Vertex to cover travel expenses and food for doctors we brought to a March 2, 2012 public forum on hepatitis C in Victoria, BC.

6. Describe how the condition or disease for which this drug is used, affects the day-to-day life of patients in your group. Patients in our group often are asymptomatic for decades, though they still deal with stigma, uncertainty of when they will become symptomatic, and fear of the future for themselves and their families. Once the disease becomes symptomatic, they particularly deal with fatigue, muscle and joint pain, depression, concentration, irritability and digestive upsets. Later in the disease, they deal with cirrhosis symptoms including anemia vs. iron-overload, itchiness, susceptibility to infection and bleeding, lack of interest in outside world, headache, detecting strange tastes and smells, swelling of ankles/legs, then spleen or liver, and liquid buildup within entire abdominal cavity (ascites), moderate to severe brain changes (encephalopathy), nausea, anorexia, malabsorption, ischemic colitis, IBS, portal hypertension plus low platelets and consequential bleeding through nose, hemorrhoids, and eventually esophageal varices. Following this can lead to sudden bleeding to death, liver cancer, liver and/or renal failure, coma, and possibly liver transplant.

Questions on the Drug under Review

7. If the patients in your group have tried the drug under review, please tell us about the effects they experienced.
No one in our group has tried telaprevir, though we've been told about a lot of studies which show there are more side-effects with it than with current SOC (especially serious itching and skin thinning), but that it can be given during a shorter time period, and is significantly more successful (40% success with current SOC vs. 70% with telaprevir cocktail with interferon/ribavarin).

8. What drugs or other treatments have the patients in your group used, or are currently using, for the condition or disease for which this drug is used?

Please list all of the drugs and tell us about the experience of the patients in your group with each treatment.

AGGRESSIVE TREATMENTS:

Interferon only (many years back) – quickly relapsed.

Current SOC (interferon & ribavirin) – some successful, some not. Most genotype 1 were NOT cured.

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Boceprevir+interferon+ribavirin cocktail (in a trial) – all successful so far, including one genotype 1 retreated after failing current SOC two years ago.

BMS drug trial (probably a polymerase inhibitor+interferon+ribavirin) – 2 out of 2 were successful.

Chinese herbal formulations. ALT was successfully lowered from approx. 300 to 100, but plateaued at around 100; and HCV RNA still present. Side-effects too unpleasant for maintenance use – 2 patients tried over one year each before quitting for 6 months, then going onto SOC.

CHRONIC DISEASE (REGULAR SUPPLEMENTS):

Medical marijuana for reduction of insomnia, nausea, and depression plus stimulation of appetite.

Milk thistle for clearance of liver, bile ducts.

Cod-liver oil capsules.

Anti-depressants.

Thyroid (due to longterm SOC destroying thyroid function).

PHYSICAL TREATMENTS:

Acupuncture – seems to be helpful with general hepatitis-related problems.

Phlebotomy – temporary relief for hemochromatosis (iron-overload).

Banding of varices – temporarily successful while awaiting transplant.

Draining of ascites – temporarily successful but painful.

Liver transplant – (2 successful, 2 awaiting transplant)

Walking, biking, dancing, other exercise – good for everyone.

9. Please tell us why your organization believes this drug should be included in the B.C. PharmaCare program.

The main reason is that telaprevir is significantly more successful than current SOC, and also, of course, because it targets those with the most difficult-to-treat genotype 1, which is also the most common genotype in North America. Our group takes strong exception to some of the access guidelines used for current SOC, plus there are other issues we want to see handled differently, involving HCV screening and surveillance, genetic testing, non-invasive biopsy tools, better side-effect support including prophylactic mental health screening and treatment, and enhanced professional development of nurses, primary-care physicians, and rural medical staff. HepCBC will be publicly presenting our suggestions about how to lower the cost of hepatitis C in BC by using more current treatment management guidelines. However, the first step seems to be just getting telaprevir costs covered by Pharmacare, a step which we certainly support.

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Conclusion

Thank you for your organization's input to B.C. PharmaCare's review of this drug.

Once the survey period for this drug ends, we will send everyone's responses to the Drug Benefit Council for consideration when they make their drug coverage recommendations.

Before your input is forwarded to the Drug Benefit Council, we will remove all personal information, including the name(s) of patients and any other identifying details. The name of your organization, however, will be included as part of your submission.

Would you like to learn more about the drug review process? Visit the [drug review process overview](#) on the PharmaCare website.

Would you like to learn about drug review decisions? Visit the [PharmaCare drug coverage decision summaries](#) on the PharmaCare website.