



## REPORT SUMMARY

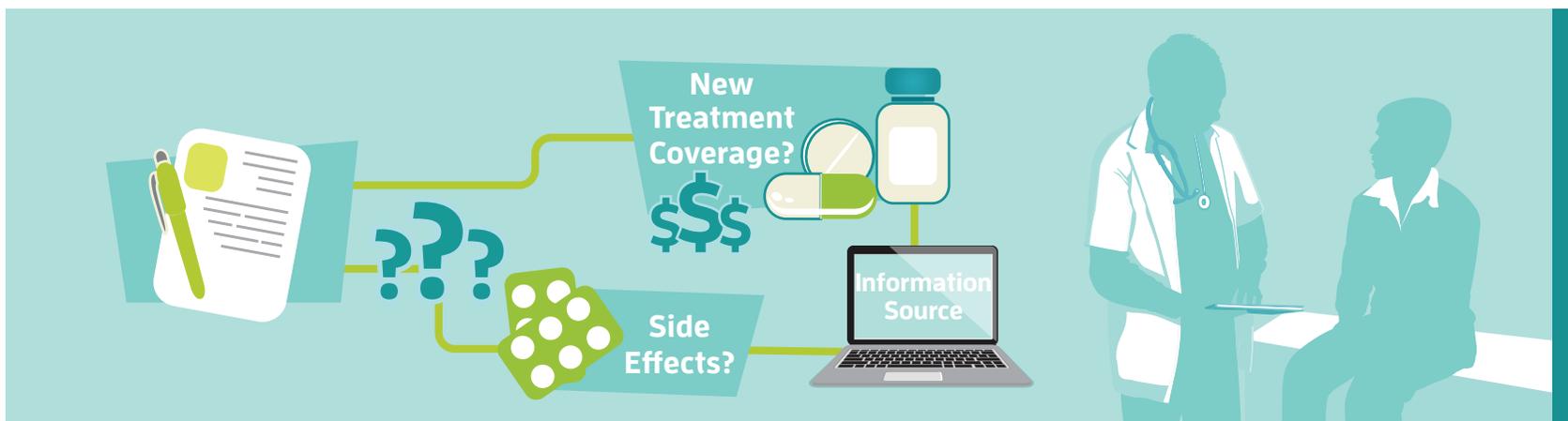
# HEP C RESOURCES IN BC:

what we have - what's missing - and next steps

This report summary outlines the results and recommendations from Pacific Hepatitis C Network's Hep C Resources in BC project. The project came about because we wanted to know more about where gaps exist in hepatitis C resources and advocacy across BC, as well as how people prefer to access information about hepatitis C and what kind of information needs they have, especially with the fairly recent advent of new, highly effective, publicly reimbursed hepatitis C treatments.

The focus of the project was a survey that ran from December 15, 2017, to January 31, 2018, and had both closed-ended matrix type questions, as well as open-ended comment box questions.





## DEMOGRAPHICS

In total, 76 responses to the survey were accepted. (These responses had both completed demographics questions, and at least some of the information needs questions completed.) The largest group represented in those responses was people who self-identified as having lived experience, with 30 responses. The next largest were self-identified healthcare providers, with 19 responses. In terms of regional representation, survey respondents lived and worked in all of the major health authority regions, and the majority lived in areas that were 'small urban', 'urban', and 'large urban.'

## RESULTS

Respondents' most preferred ways to get information about hepatitis C were from specially trained medical professionals (such as specialists), primary care physicians, and from the Internet. In the open-ended responses, the most commonly identified helpful resource was information from CATIE. Resources from the BCCDC and the Pacific Hepatitis C Network were also mentioned. However, groups of respondents had very different ideas about what resources were helpful to them. Service providers, such as health care professionals and frontline workers, saw CATIE and the BCCDC as more helpful than did people with lived experience, who mentioned peer supports (like groups and online forums) more often.

Respondents identified that basic information about hepatitis C, such as how it is transmitted and what activities put you at higher risk, is largely widely available. However, a majority of respondents wanted more information on whether you have to pay out of pocket for hepatitis C treatment in BC. Given that fibrosis staging restrictions have recently been lifted in BC, this is an important information need to address. More than half of respondents also wanted to know what the side effects of treatment typically are, and what an individual could do to stay healthy if treatment was not an option for them.

In the open-ended comment boxes, treatment-related issues were also regarded as a priority, including accessing treatment. Respondents also talked about issues addressing stigma (both outside of the hepatitis C community and within it) and particularly discussed issues of stigmatization stemming from health professionals. Many responses also affirmed the importance of peer supports, and reflected the desire of respondents to be connected with peer supports, long-term.

These themes are specific to people who use drugs, including the harm reduction community. The basis of hep C stigma largely lives here; addressing stigma towards drug use and people who use drugs in turn addresses the stigma experienced by any person living with hep C. Hence, we've drawn these comments from survey responses and highlighted them here as a start to addressing how stigma and criminalisation impact access to hepatitis C care and treatment. These statements will guide PHCN's work with key partners to address hepatitis C within this highly impacted group.

1. More supports for people who use drugs are necessary
2. There needs to be more dialogue between the harm reduction community and medical professionals
3. There is a need for education on how to discuss substance use with patients
4. Decriminalisation is a necessary advocacy step for hep C organizations

## RECOMMENDATIONS

Notes: 'In part' refers to both that the projects and activities outlined with each recommendation form part of what PHCN would do, as well as other organisations and groups. Further detail for each recommendation is available in the full report.

**Based on the results of this needs assessment, Pacific Hepatitis C Network recommends that:**

- 1. Treatment knowledge be expanded.** In part, this will be achieved by the development of a pilot project, led by PHCN, to provide population-specific treatment information in the form of a campaign. This project has received funding from a pharmaceutical partner (and may add other funders in the next few months). PHCN has identified several potential organisational partners to help tailor messaging and/or campaign material appearance for specific populations.  
**Timeline: April - September 2018.**
- 2. People living with hepatitis C take an active role in promoting, developing, and implementing peer-based supports.** In part, this can be achieved by the development of a peer "network" in hepatitis C, supported and coordinated by PHCN. This idea was suggested as part of a mind-mapping exercise at the Chilliwack date of the Year of the Peer conference. To start, existing peer navigators in hepatitis C across the province would be identified and brought together (in person, by phone, or other means) to identify key capacities and central responsibilities of hepatitis C peer navigators, along with supports and training needs, and to start sharing expertise and learning from each other. This work would also produce a training and support plan that PHCN would seek to operationalize.  
**Timeline: April - December 2018.**
- 3. Special concern be taken to address stigma that affects specific populations within the hepatitis C peer community.** In part, this can be addressed through additional project activities in the building of a peer network identified above could include development of in-person workshops/panels prioritizing the expertise of a diverse cohort of people with lived hepatitis C experience.  
**Timeline: as above, April - December 2018, some ongoing.**
- 4. Expanded resource development focusing on educating primary care physicians on hepatitis C - but not simply on its physical effects.** In the short term, this could in part be addressed by PHCN coordinating sit-down discussions with key expert hepatitis C treaters (who provide hepatitis C education to general practitioners) about how they would envision integrating lived experience into their training and mentoring work with GPs. These discussions would then facilitate the formulation of further steps to address this.  
**Timeline: Spring 2018 and on-going.**

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