



Hep C We can change the conversation.



HEP C RESOURCES IN BC:
what we have - what's missing - and next steps

Pacific
Hepatitis C
Network 

TABLE OF CONTENTS

SUMMARY:

Demographics 2
Results 2
Recommendations 3

REPORT:

Acknowledgments 4
Executive Summary 5
Limitations 6
Background 6
Results 7
1. Respondents 7
2. Regional Representation 7
3. Urban/Rural Divide 7
4. Information Needs 8
5. Sources of Information About Hepatitis C 8
6. Qualitative Responses 8
 6.A Information needs not identified in the survey 8
 6.B Existing Helpful Resources 9
 6.C What has been working well 9
 6.D Where there are gaps 10
 6.E Opportunities for collective advocacy 11
 6.F Opportunities for individual advocacy 12
 6.G Other opportunities for advocacy 13
Discussion 14
Conclusion and Recommendations 15

This report 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

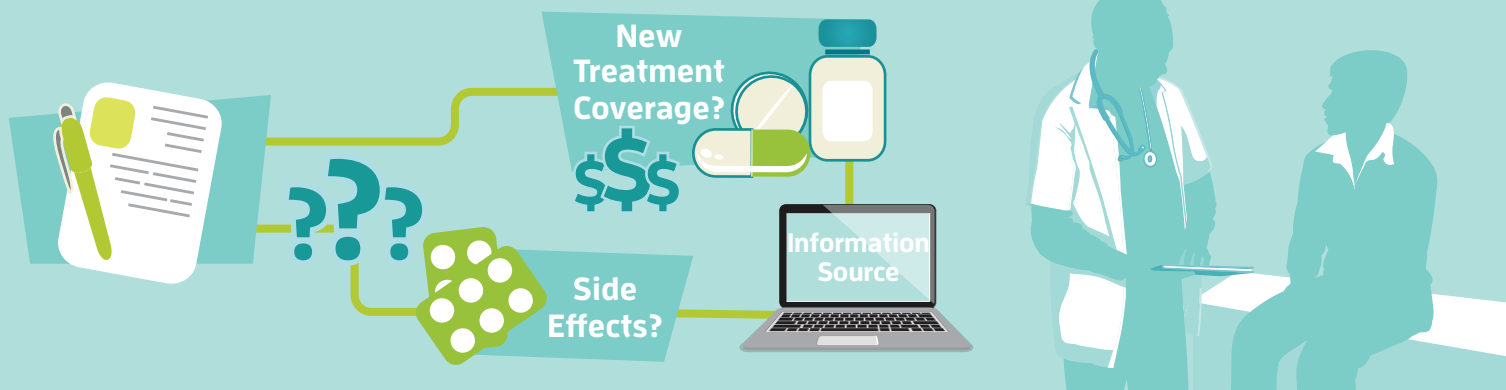
In total, 76 responses to the survey were accepted. (These responses had both completed demographics questions, and at least some of the information needs questions completed.) The largest group represented in those responses was people who self-identified as having lived experience, with 30 responses. 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.



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.

For more information, please contact Madeline Gallard at: madeline@pacifichepc.org

ACKNOWLEDGMENTS

The Pacific Hepatitis C Network gratefully acknowledges the contributions of the following:

- Our funder, the PHSA and the HIV and HCV Prevention, Care and Treatment Services Innovation fund, for supporting this important project;
- Gilead Sciences, for their contribution of an unrestricted grant that helped shape this project;
- Our peer evaluators, Alishia, Nick, and Laurel, who put so much time, effort, thought, and sheer work into this project as it developed and unfolded;
- The staff at the Pacific AIDS Network (PAN), including Janice Duddy, Simon Goff, Mona Lee, and Janet Madsen for their assistance in all areas and support;
- Liza McGuinness and Terri Buller-Taylor of the BCCDC for survey development help and excellent feedback;
- Members of the Collective Impact Network and in particular, DJ Larkin of Pivot Legal Society, for their feedback in the survey development phase, and
- Last, but not least, all who completed, promoted, and distributed the survey, as well as all the attendees of the Year of the Peer conferences that responded to and worked through some of the ideas presented here. **You help us grow!**

EXECUTIVE SUMMARY

From October 2017 to March 2018, the Pacific Hepatitis C Network undertook a broad needs assessment within British Columbia. The purpose of the needs assessment was to determine the accessibility of resources regarding hepatitis C and information needs of various cohorts of people connected with hepatitis C in BC. This needs assessment sought to determine:

- Where priorities exist in terms of information needs regarding hepatitis C in British Columbia,
- Where gaps exist in hepatitis C resources in British Columbia,
- Where further resource development is necessary and helpful in hepatitis C in British Columbia, and
- Where priorities for advocacy (both collective and individual) in hepatitis C lie in British Columbia.

The target populations of respondents of this needs assessment were people with lived experience of hepatitis C (treatment naive and experienced), family/friends/loved ones of people with lived experience, front-line workers at community-based organisations, peer workers in hepatitis C, and members of the general public interested in learning more about hepatitis C. Three peer evaluators were recruited and hired to aid in project activities throughout the entire span of the project.

The primary activity of this needs assessment was an online survey hosted on SurveyMonkey that ran from December 15, 2017, to January 31, 2018. (An optional additional incentive-based survey to enter a draw was hosted on LimeSurvey.) The link to the survey was distributed within the Collective Impact Network to disseminate within their contacts; distributed to contacts previously established by the PHCN, shared with outside organisations via email, and advertised in several e-newsletters. The survey used mixed quantitative and qualitative methods (including matrix-type questions and open-ended comment box-type questions) and took approximately 10 - 15 minutes to complete.

In total, 76 participants completed the demographics questions and at least some of the information needs-related questions of the survey. (Further explanation of these partial responses will be outlined in the limitations section.)

Basic information about hepatitis C (such as transmission, what activities put you at higher risk of contracting hepatitis C, and how hepatitis C is diagnosed), is largely well understood and available. 69.74% of respondents (n = 76) felt they had enough resources available to them on how hepatitis C is spread; 67.11% of participants (n = 76) felt they had enough resources available to them on high risk activities for transmitting hepatitis C, and 66.67 % of participants (n = 72) felt they had enough resources available to them on how hepatitis C is diagnosed.

Specific information about treatment and treatment options is both a large priority and not widely available. More than half of participants wanted to know more about whether people in BC pay for hepatitis C treatment; what the side effects of treatment typically are, and what someone can do if treatment is not an option for them. Nearly half of participants felt they needed more information about how long treatment typically takes.

Participants preferred to get their information on hepatitis C from health professionals, including health care providers specifically trained in hepatitis C (such as specialists) ranked as the first overall choice and primary care physicians and other health professionals not specifically trained in hepatitis C second. Beyond health care professionals, the Internet as a source of information about hepatitis C was ranked as the third overall most popular choice.

In terms of qualitative responses, participants confirmed that treatment-related questions were an information priority, as well as information about resources within their local community; availability of peer resources such as support groups, and addressing stigma (with an emphasis on education for healthcare providers, particularly primary care physicians).

Participants also affirmed the importance of Internet resources as useful for obtaining information about hepatitis C.

LIMITATIONS

Potential limitations of this needs assessment include the online-only format, its mixed methods approach, and its limited time frame.

Peer evaluators noted that an online survey may not reach individuals with lived experience of hepatitis C that are street-involved, currently in detox or other rehabilitation facilities, or otherwise do not have consistent access to Internet. Additionally, the text-based format created a barrier for those who may not be able to read in English. A caveat to the survey invitation was developed that informed organisations that survey questions could be emailed directly, printed, and returned in paper-based form; however, no paper-based copies were requested. Similarly, organisations were informed that potential respondents could be aided by a staff member in completing the survey.

For ethical reasons, paper-based copies were NOT directly distributed to front-line organisations. Therefore, future studies could emphasize the inclusion of these groups by following ethical protocols (including planning to seek informed consent from organisations prior to distribution) to distribute paper-based copies within front-line organisations; providing peer evaluator support to aid people who may struggle with literacy and/or reading and writing in English, and emphasizing other surveying methods such as focus groups. Such approaches may help to better engage populations that are traditionally “hard to reach,” such as people who use drugs.

Additionally, the mixed methods (qualitative and quantitative) approach may have contributed to the lack of respondents that answered every question on the survey. While mixed quantitative and qualitative methods were used in order to gain more detailed insights into the experience of accessing information about hepatitis C, respondents may have become burnt out or overwhelmed at being asked so many questions in different ways. (This is supported by the declining number of responses for subsequent questions in the survey.) Future approaches to remedy this could include supplementary information gathering methods such as focus groups and interviews as a follow up from a traditional quantitative survey, limiting the number of open-ended comment-box type questions, and broader piloting (to ensure the wording of questions does not rely on jargon or exclude those with limited literacy).

Finally, the limited time frame of the survey may have limited the number of responses. Slating a month and a half for the survey’s run time meant that advanced recruitment methods (such as going into organisations directly), could not be achieved in an ethical and well-executed manner. Future approaches to remedy this limitation could include simply extending surveying time, developing a more detailed recruitment plan from the project outset to ensure protocols are established for more advanced recruitment, and scheduling “reminders” about the survey to go out at pre-planned intervals.

BACKGROUND

The recent broad availability of highly effective, shorter duration and minimal side effect treatments for hepatitis C, known as “direct-acting antivirals” (DAAs) has renewed interest in hepatitis C and the need for accessible and detailed information about hepatitis C.

Given the relatively new possibility of a cure for many of those living with chronic hepatitis C in BC as well as the ongoing need to educate the public about hepatitis C and chronic infection, the Pacific Hepatitis C Network began a province-wide needs assessment primarily funded by the PHSA and the HIV and HCV Prevention, Care and Treatment Services Innovation fund, and partially through a grant from Gilead Sciences. The purpose of this needs assessment can be summarized by the following:

- Determine what resources currently exist to inform the public about hepatitis C
- Determine where gaps exist in resources and broadly, information about hepatitis C
- Identify priorities in informational needs about hepatitis C
- Identify priorities in respect to advocacy to inform future efforts by the Collective Impact Network

The target populations for this needs assessment would broadly be described as those connected to hepatitis C, whether through lived experience; working as a health care provider, front-line worker, or in a community-based organisation; supporting a friend, family member, coworker, or other loved one living with hepatitis C; serving as a peer worker in respect to hepatitis C, or simply wanting to get more information about hepatitis C.

The priorities, resource gaps, and advocacy opportunities identified by this survey will be used by the Collective Impact Network to inform resource development and disseminate new resources.

RESULTS

I. RESPONDENTS

The bulk of respondents fell into one of two categories: people with lived experience and healthcare providers. Nearly two thirds of respondents fell into these two categories.

The breakdown of respondents by target respondent populations is as follows:

39.47% (30 respondents) identified as a "person who has or had hepatitis C"

9.21% (7 respondents) said they "do not have lived experience with hepatitis C but have an interest in learning more about it"

7.89% (6 respondents) identified as a "person with a family member, friend, or coworker who has or had hepatitis C"

17.11% (13 respondents) identified as a "front-line community-based worker (community-based organization, social worker, worker in a care facility, etc.)"

1.32% (1 respondent) identified as a "peer worker (a person with lived experience of hepatitis C who offers peer navigation and/or peer support)"*

25% (19 respondents) identified as a "healthcare provider (nurse, doctor, allied professional)"

It is worthwhile to note that although only 1 respondent identified as a peer worker in the initial demographics question, a follow up question asking respondents to affirm that they were a peer worker (included for survey branching purposes) had 3 respondents note they were peer workers. This difference could potentially result from differing definitions of a "peer worker" in this context (for example, someone who is a peer worker for an HIV organisation may have identified as such further in the survey).

People With Lived Experience

Amongst respondents who identified primarily as a person with has or had hepatitis C or primarily as a peer worker (**n = 31**) respondents who had achieved sustained virologic response (SVR) were overrepresented. (**58.06%, 18 respondents**) However, the second largest cohort was respondents who identified as having never had treatment for hepatitis C. (**25.81%, 8 respondents**) Additionally, nearly all of respondents (**87.097%, 27 respondents**) who self-described as having lived experience or as being a peer worker fell into the "baby boomer" age cohort (between 1945 - 1965).

2. REGIONAL REPRESENTATION

Respondents who identified as not working in a capacity related to hepatitis C (such as people with lived experience or with loved ones with lived experience) were asked "In which health region do you live?" (**n = 42**) The majority of respondents resided in either the Vancouver Coastal Health region (**33.33%, 14 respondents**) or the Fraser Health region (**26.19%, 11 respondents**).

Respondents who identified as working in a capacity related to hepatitis C (such as peer workers, front-line workers, and healthcare providers) were asked "In which health region do you primarily work?" (**n = 34**) The three most common regions for respondents were Island Health (**26.47%, 9 respondents**), Vancouver Coastal Health (**20.59%, 7 respondents**), and Northern Health (**20.59%, 7 respondents**).

Respondents of this question were also given the choice to identify that they worked provincially.

3. URBAN/RURAL DIVIDE

All respondents were asked, "How would you describe the area(s) you primarily live and/or work?" (**n = 76**)

39.47% described themselves as living/working in an area that is "Large urban - 175,000+ people, large city, highly developed with people living closely together, often include tall buildings such as skyscrapers. Easy access to a wide variety of medical services."

15.79% described themselves as living/working in an area that is "Urban - 75,000 - 175,000 people, small to medium sized city, lots of development and houses close together. Access to many medical services."

23.68% described themselves as living/working in an area that is "Small urban - 20,000 - 75,000 people - large town to small city, some development and houses may be more spread apart. Access to basic medical services and some specialized."

10.53% described themselves as living/working in an area that is "Rural - 3,500 - 20,000 people - small to medium-sized town, less development, houses may be spread far apart. Basic medical services are largely accessible."

6.58% described themselves as living/working in an area that is "Small rural - 1,000 - 3,500 people - small town, not very developed, houses far apart. Some access to basic medical services."

No respondents described themselves as living/working in an area that is "Remote - 0 - 1,000 people - extremely small community, no or very little development, people living far apart from each other. Medical services are largely not available directly in the community because of how far people live apart."

3.95% described themselves as living/working provincially.

4. INFORMATION NEEDS

5 matrix-style question sections were developed to establish information needs. The sections included general information; prevention related topics; screening and diagnosis; care and treatment; and harm reduction. Respondents were asked to identify if they "need[ed] more information" on a topic; did not "need more information because [they] have resources already;" did not "need more information because it [was] not a priority" or simply did not know.

Across all sections, only three information need questions had a majority of respondents (more than 50%) identify the topic as a need. These three highest information needs were:

1. Information on "what someone can do if treatment is not an option;" (**67.61%, n = 71**)
2. Information on whether "people living with hepatitis C in BC pay for treatment;" (**57.75%, n = 71**) and
3. Information on "what the side effects of treatment typically are." (**53.52%, n = 71**)

5. SOURCES OF INFORMATION ABOUT HEPATITIS C

Respondents were asked to rank nine potential sources of information about hepatitis C in terms of how they prefer to receive their information. The top 3 resources ranked as the respondent's first choice for information were:

1. Health care professionals specifically trained and educated in hepatitis C (specialists, physicians, nurses, nurse practitioners, etc.) (**43.40%, n = 53**)
2. Primary care providers (physicians, nurses, nurse practitioners, etc.) (**22.92%, n = 48**)
3. The Internet (websites, online videos, webinars, etc.) (**18.00%, n=50**)

6. QUALITATIVE RESPONSES

6.A Information needs not identified in the survey

Respondents were asked if they "want[ed] to learn about anything else related to hepatitis C that ha[d] not been listed yet in [the] survey" in an open-ended comment box. 31 responses were recorded.

Responses could be broadly coded into 6 categories: **community/community involvement, treatment/treatment options, health, capacity, and other.**

Of the responses that could be coded as **engaging community and community involvement**, many emphasized the importance of peer supports and a desire to be involved in groups such as support groups - including groups for those that had achieved SVR but desire continued support. Some of these responses also implicitly

touched on stigma - issues surrounding finding an appropriate support group (perhaps reflecting on stigmatization of people who use drugs and other priority populations.) Some responses also asked for information about resources in local communities, as well as where to go with issues and concerns (effectively, advocacy.)

Of the responses that could be coded as **involving treatment/treatment options**, many reflected concerns about the lack of accessibility of treatment, as well as some capacity-related questions (such as where one can obtain treatment) suggesting that barriers to accessibility go beyond paying for treatment. Concerns about health from delaying treatment and post-treatment were also raised. Additionally, a few responses reflected a desire for transparency on the part of government on when treatment will become universally accessible, and what treatments will be available.

The responses that could be coded as involving **health**, broadly, were varied, but reflected a desire to achieve health in multiple areas of life. Some areas of health identified were concerns about health post-treatment; concerns about damage to the liver if one has not had treatment, and impacts to the body beyond the liver. Some responses also raised questions about resources related to health (such as availability of testing in some areas.) Additionally, some responses suggested a desire for mental and emotional health supports, particularly in the form of group supports.

Responses coded as engaging **capacity** frequently mentioned a desire to have current information about resources in local communities, such as testing availability, broad supports for people living with hepatitis C, group supports (including for people who use drugs) and accessing resources in rural communities where they may be limited. Many of these responses overlapped with community, treatment, and health. A few responses also suggested a need for information for the public, as well as one specific education-related question about hepatitis C itself.

Responses coded as other simply indicated that the respondent did not have thoughts about further information they needed.

6.B Existing Helpful Resources

Respondents were asked to list “any resources that [they] found particularly helpful in accessing information about hepatitis C” in an open-ended comment box. **42** responses were recorded.

Responses could be broadly coded into 5 categories: **Internet resources, peer groups/supports, in-person information sessions, clinics/medical staff, and other.** Resources coded as “other” included print resources such as brochures and mail outs and clinical tools available only to medical professionals, as well as responses that did not identify any resources.

In terms of specific resources, the commonly cited resource was information from CATIE (14 responses.) Also frequently mentioned were resources from the BCCDC (5 responses) and resources associated with the Pacific Hepatitis C Network (including the peer support helpline and web resources (6 responses). In some cases, organisations were named only, so it was unclear which resources specifically respondents found helpful.

It is worthwhile to note, however, that identified “helpful resources” varied greatly when broken down by the cohort of respondents. Healthcare providers and frontline workers cited CATIE and the BCCDC as a helpful resource more often than people with lived experience. (Out of 20 responses from this cohort, 13 of these mentioned CATIE, and 5 mentioned the BCCDC.) Likewise, people with lived experience cited peer groups/supports (such as online groups, the peer-run and organized HepCBC, peer support workers through the PHCN, and forums) as helpful resources more often than healthcare providers and frontline workers. (Out of 19 responses, 6 referred to peer supports.)

6.C What has been working well

Respondents were asked, “in terms of information resources, what do you think has been working really well in BC in relation to hepatitis C prevention, testing, treatment, care, and support?” **41** responses were recorded.

Responses could be broadly coded into 5 categories: **promotions/campaigns, programs/resources, organisations, education, and negative/no response (no positive response and/or gaps assessed instead.)**

Responses coded as **promotions/campaigns** spoke positively of promotional materials (such as ads and posters) that brought awareness and provided information on hepatitis C. Some examples include television ads by Gilead Sciences and Generation Hep ads. Respondents also mentioned specific promotional activities their organisations are engaged in, such as presentations and handing out information, as well as broad promotion and education regarding hepatitis C with no reference to specific campaigns.

Responses coded as mentioning **programs/resources** were broad, and often overlapped with organisations and education. Some responses spoke positively of programs and resources that had been available to them personally, as well as programs that contributed to awareness of hepatitis C in various cohorts (both professionals and the general public.) A few responses referenced peer supports, both in the form of online resources and connecting directly with peers.

Responses coded as referencing **organisations** spoke positively of organisations working in hepatitis C and their activities broadly, including education, providing peer supports, and providing information. Specific organisations were also mentioned by name, including peer-led organisations, advocacy groups, and health units.

Responses coded as referencing **education** included positive experiences at educational events, opportunities to increase education including online informational resources (overlapping with organisations and programs/resources in some cases,) and general increased awareness of hepatitis C. Some responses also mentioned specific education-oriented programs facilitated by organisations.

Responses coded as **negative/no response** could either not identify anything that was done well (including "don't know" responses) or chiefly

identified gaps and areas for improvement. Many of these gaps are further explained and identified in the subsequent question (asking about existing gaps.)

6.D Where there are gaps

Respondents were asked, "in terms of information resources, where do you think there are gaps, challenges, or areas in need of improvement related to hepatitis C prevention, testing, treatment, care and support?" **44** responses were recorded.

Responses could be broadly coded into 5 categories: **stigma, capacity, medical professionals, testing, and treatment.**

Responses that mentioned **stigma** referred broadly to two kinds of stigma: stigma of living with hepatitis C in general, and stigma as it applies to priority populations of people living with hepatitis C. Some responses referred to issues throughout the entire continuum of care as a result of stigma (e.g. discomfort disclosing high risk behaviours and discomfort seeking information,) including lack of testing and poor treatment by medical professionals. Responses coded in this category overlap with medical professionals, testing, and treatment.

Responses that engaged issues of **capacity** were broad and varied, and overlapped with several of the other categories in this section. Several responses acknowledged a need for more/more accessible information (including information about direct acting antivirals, resources in the community, regarding priority populations, and platforms for sharing information.) Several responses requested more capacity for treatment - including improving accessibility. Several responses suggested capacity for screening must be increased, particularly in respect to priority populations. One issue of capacity that a few responses noted was in respect to rural/remote communities - inconsistent access to Internet and few resources limit the ability of service providers to provide information and help people living with hepatitis C move through the continuum of care.

Other specific issues of resources will be outlined in subsequent categories.

Responses coded as referencing **medical professionals** largely focused on two sub-categories: negative experiences with medical professionals (feeling ignored, devalued, etc.) and opportunities for further education (increasing capacity of primary care physicians to link with resources, current information about hepatitis C, etc.)

Negative experiences described in this category focused primarily on people with lived experience feeling excluded from their own care or experiencing a lack of opportunities to self-advocate. Stigma played a role in these responses also - one response suggested that there needs to be safety surrounding discussing hepatitis C with medical professionals.

Opportunities for further education for medical professionals ranged from the surface level (ensuring that primary care physicians have more info to give out) to deeper, more involved issues (such as ensuring primary care physicians have adequate and current information about who should be screened for hepatitis C, as well as information specific to working with patients that may be using drugs.) Specific concerns were relayed regarding primary care physicians working with priority populations - a few responses outlined the need to ensure primary care physicians know to screen groups at high risk of infection, including immigrants/newcomers and baby boomers.

Testing-related responses focused on expanding screening, including priority populations (as described above.) Some responses also focused on ensuring the general public is aware of priority populations for hepatitis C screening. One response also noted that financial and political struggles can make accessibility of the entire continuum of care difficult in remote communities, including testing, while another simply stated that a gap existed in point of care testing (an area that is currently growing and developing in Canada.) One response also suggested that preconceived notions of who is at risk (primarily, people who use drugs) for hepatitis C contributes to stereotyping - and so people that have never used drugs are missed for screening.

Treatment-related responses largely focused on a theme previously identified: increasing the accessibility of treatment for hepatitis C. One response noted that many people living with

hepatitis C may not be aware of the benefits of direct-acting antivirals (a point that is supported by the matrix-question identified needs), while information about accessing treatment may not be accessible to the general public.

6.E Opportunities for collective advocacy

Respondents were asked, "Collective advocacy is defined as 'stakeholders and organizations working together to address issues that affect the larger community.' Some examples include working to reduce hepatitis C related stigma, working to improve access to treatment, and working to develop supports for people living with hepatitis C. Are there areas of collective advocacy that you wish to see more direct action across the province on? Please list any ideas below." **40** responses were recorded. (Examples were provided to differentiate between collective and individual advocacy, which is outlined below.)

Responses could be broadly coded into 5 categories: **treatment, education, capacity, stigma, and other.**

As in the above sections, responses coded as mentioning treatment focused primarily on collective advocacy to improve access to treatment. However, several responses expanded on this - one response suggested treatment needs to happen earlier in disease progression; two responses suggested that accessibility of treatment would eliminate some barriers to testing (reducing fear around a positive result.)

Responses coded as mentioning **education** largely overlapped with capacity related responses. As in previous sections, responses noted that medical professionals need to be better informed across the entire continuum of care for hepatitis C - from providing connections to resources, addressing stigma, and simply providing information to patients.. Education also covered responses that suggested medical professionals need education outside of information strictly including hepatitis C, including a better understanding of harm reduction and peer supports. Education-related responses also referred to a desire for greater public education, including expanding a presence on platforms such as social media.

Responses referring to **capacity** largely overlapped with other categories. Expanded access to treatment, connections to resources (including within the hepatitis C community and other references to peer support, as well as addressing health-related issues) and increased education (as referenced above). Other aspects of capacity included a response noting the need to address social determinants of health, such as housing. A need for collective advocacy to expand access to resources (including information) in rural communities was noted. One response noted a need for a provincial testing strategy for hepatitis C. Access to funding for advocacy in hepatitis C was also noted as a capacity issue.

Responses coded as referencing **stigma** acknowledged stigma broadly as affecting people living with hepatitis C, as well as priority populations within the community. This recurring theme will be discussed at length in the Discussion section.

Finally, the bulk of responses coded as **other** did not identify opportunities for collective advocacy, or suggested that all the examples identified were good areas for focus. Three responses stood outside of categorization: one mentioned safety measures to avoid workplace needlestick injuries, one commented on the need to empower individuals with lived experience and reduce the control professionals have over research, and one suggested self esteem was a potential area of focus.

6.F Opportunities for individual advocacy

Respondents were asked, "Individual advocacy is defined as 'support for individuals to get their needs met.' Individual advocacy typically happens with one person at a time. Some examples include helping individuals access disability benefits, helping individuals access harm reduction materials, and helping individual patients advocate for themselves in medical settings. Are there areas of individual advocacy that you wish to see more direct action on? Please list any ideas below." **33** responses were recorded. (Examples were provided to help differentiate between collective and individual advocacy, as described above.)

Responses could be broadly coded into 4 categories: **capacity, treatment, medical professionals, and other.**

Responses coded as mentioning **capacity** largely fit the same themes identified in earlier sections. They also frequently overlapped with responses in other categories. Many responses focused on ensuring supports were available for people living with hepatitis C, including addressing the social determinants of health (such as housing, food, and disability benefits;) ensuring supports are in place for those with advanced liver disease, and expanding accessibility of supports and care, including in rural areas and at the "street level." One response noted that funding needed to be expanded to support expansion of capacity. One response suggested that point of care testing needs to become widely available.

A few responses also noted that capacity for involvement of peers should be expanded.

Treatment-related responses followed trends identified in previous sections, and largely focused on ensuring individuals are able to access treatment, including those in priority populations (including people who use drugs and people in prison.)

Responses coded as referring to medical professionals overlapped frequently with capacity. One response referred to specific education needs for primary care physicians, including up to date information about advanced liver disease. A few responses also referred to the need for individuals to be able to advocate for themselves in medical settings, particularly in asking a primary care physician for a diagnosis. One response also noted that supports need to be in place to help individuals find a primary care physician.

Responses coded as **other** largely either indicated the respondent did not have ideas for individual advocacy, or agreed with the examples given. One response that was not categorized commented on the problematic nature of tokenistic peer involvement in research.

6.G Other opportunities for advocacy

Respondents were asked, "Do you want any other forms of advocacy included in hepatitis C resources? Please list ideas here." **24** responses were recorded.

Responses could broadly be coded into 3 categories: **resources, continuum of care, awareness, and other**. Continuum of care encompasses both testing and treatment in this question.

Responses focused on expanding **resources** were rather broad and varied, but overlapped with the other categories. A few responses suggesting advocacy could be oriented to developing resources focused on case studies - in one case, to inform the public about the benefits of hepatitis C treatment, and in another, ensuring access to the continuum of care while in transition. Resource related responses also encompassed increasing access to treatment and external supports for health during treatment; access to peer supports; education for medical professionals and the public; legal support, and increased access to testing. One response suggested that web resources could be improved.

Responses that referred to aspects of the **continuum of care** encompassed prevention, testing, and treatment. This included educating priority populations (including people in prison and youth, including in schools) ensuring peer supports are in place; advocacy to ensure that people remain healthy post-diagnosis; access to testing; and access to treatment.

Responses that mentioned **awareness** focused on both educating the public, and educating medical professionals. In line with previous questions, responses focused on broadly educating the public on the entire continuum of care (including encouraging screening) and educating medical professionals about hepatitis C and working with patients through the entire continuum of care.

Responses categorized as **other** largely did not indicate opportunities for advocacy. One response noted a desire to advocate at the policy level, while another suggested advocacy surrounding working with medical professionals was needed.

DISCUSSION

Several connections could be drawn between the quantitative and qualitative results of this survey.

Firstly, the reported high priority of information about treatment and how it could be accessed was reflected in the prevalence of treatment-related comments in several of the open-ended response questions. Given that relatively short duration, low side effect but highly effective treatments are now widely available for hepatitis C, this suggests that broad dissemination of information specifically on the various DAAs approved in Canada could be beneficial for people living with hepatitis C; their loved ones, and those working with people living with hepatitis C.

Additionally, the importance of access to treatment cannot be overstated. Respondents felt that information about whether BC residents had to pay for hepatitis C treatment was extremely important. Respondents also felt that lack of equal access to treatment was a significant gap. Given that the BC government has announced the end of fibrosis staging restrictions on treatment, accessible, frequently updated information about how affordable treatment can be accessed is clearly critical.

Most importantly, however, many responses reflected that the experience of living with hepatitis C does not end with achieving SVR - it is a lifelong journey, and the need for support and information on how to stay healthy continues beyond successful treatment. Many responses also reflected a desire for holistic health to be achieved for people living with hepatitis C. In data analysis activities with the peer evaluators, this sentiment was echoed. The quantitative section suggested that information about options beyond treatment for those living with hepatitis C that want to remain healthy is a high information need priority- and many qualitative responses focused on wanting more information about physical health impacts (including post-diagnosis), resources for securing the social determinants of health (such as housing and healthy food), and resources to reach and meet the health needs of priority populations (such as immigrants/newcomers, youth, people in prison, and people who use drugs).

Several qualitative responses also indicated there is a gap in information resources regarding health after achieving SVR - for example, recommendations and statistics regarding ongoing monitoring of liver health. A focus on successful treatment as the "end goal" of the hepatitis C

continuum of care may have had the result of creating this gap - as opposed to seeing treatment as a step within a lifelong journey.

Concretely, this could suggest that a gap exists in the form of a directory of resources across the province that is frequently updated and broad (not just focused on treatment and testing, but also resources that support health broadly, such as harm reduction services, supports for advocacy in medical settings, and supports for housing and food, as examples). Two such directories exist, but ensuring that resources are broadly reflected and are kept up to date is crucial.

On both sides of the coin, with both service providers and people with lived experience, a sense that it was difficult to know what resources were available in their immediate community was pervasive. Given that, across the board, respondents felt positively about organisations working to address hepatitis C, and also considering that some responses suggested that unified messaging and action plans across the province would help address gaps in resources and information, a centralized resource directory regularly contributed to and updated by organisations could prove beneficial in addressing these concerns.

Further, this desire for holistic health was reflected in the clear emphasis on the benefits and importance of peer supports. While the quantitative responses did not result in a definitive preference for information coming from peers (perhaps due to the limited ability of service providers to assess the importance of peer supports). Many qualitative responses reflected on either the benefits the respondent had received from peer supports, or a desire for peer support (such as wanting information about local peer support groups, or discussion of searching for a support group). It is evident that a community exists amongst those living with hepatitis C, and a desire for connection and support within this community could be an important way for people living with hepatitis C to feel more mentally and emotionally healthy, even after achieving SVR.

This ties into an emphasis on stigma that was evident through qualitative responses. Living with hepatitis C seems to mean that stigma leeches into every part of life - in the doctor's office, for example, or in the workplace. The experience of stigma restricts information seeking and comfort disclosing to medical professionals, potentially limiting the care and treatment that individuals could receive. Stigma also impacts those in small communities, given that knowing medical staff and other service

providers personally may limit comfort in information-seeking or disclosure of health information.

Interestingly, the ubiquitous nature of stigma exists even in the hepatitis C community itself. Stigma experienced particularly by people who use drugs contributes to stereotyping surrounding who is affected by hepatitis C, and could contribute to a lack of screening - but it also seems to drive divisions in the efficacy of peer supports. Some responses indicated that a sense of "us" and "them," (particularly towards people who use drugs), meaning that some people living with hepatitis C would not be comfortable or even experience a sense of common experience with others within their community. Such beliefs indicate more work must be done to bring various groups (as some responses indicated, particularly with the harm reduction community and others) together, and facilitate conversation and sharing.

Stigma also led to many responses focused on the need for continued education of healthcare providers. The importance of this is reflected in the emphasis placed on healthcare providers as sources of information on hepatitis C. Stigma meant that some respondents felt they could not or were actively discouraged from participating in treatment and care, and even had difficulties obtaining a diagnosis from a primary care physician. Stigma also meant that service providers sometimes failed to adequately screen individuals for hepatitis C based on a preconceived notion of who is affected by it. This could also mean that a focus should be placed on developing resources that focus on information about and working with particular priority populations, such as immigrants/newcomers, and people who use drugs.

Further, this could indicate an ongoing opportunity for peer engagement. Many responses noted that primary care physicians do not always have up to date information or the connection to people affected for adequate follow-up and care. Peer evaluators further noted that the language of many resources is effectively "like a doctor" - using terminology that is inaccessible and confusing (for example, referring to SVR as opposed to simply 'the cure'). This could mean that emphasizing peer involvement in resource development could result in resources that are more generally useful to the broader public, and disseminate information more readily than existing high-level resources. Additionally, responses and discussion with peer evaluators frequently reflected a need for continued education of healthcare providers that emphasizes lived experience.

Some newer programs and resources (such as a medical student/person with lived experience education program at the University of British Columbia) have focused on bringing healthcare providers and people with lived experience together, in order to provide opportunities for education that are based in lived experience, and tackle stigma head on - by building relationships.

CONCLUSION AND RECOMMENDATIONS

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

- I. 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.

Rationale: A focus be taken on expanding resources and knowledge of resources available to both people with lived experience and service providers on information related to treatment available for hepatitis C. This includes side effects and duration, as well as how it can be accessed from a financial perspective. This could also provide an opportunity to engage lived experience, as many respondents are interested in knowing what options are available outside of treatment; given the positive impacts of peer supports, peers could be engaged to help develop resources that emphasize healthy living with living with hepatitis C. Given that many respondents felt positively about campaigns such as the Generation Hep ads and the Gilead TV ads and many people access resources about hepatitis C on the Internet, a visually oriented information campaign may be the best approach to addressing these issues.

- 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 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.

Rationale: Peer-based supports have not only been identified as positive and helpful in supporting health, but may present opportunities to address stigma both within the hepatitis C community and the general public. This could be achieved by dually promoting existing peer supports (such as groups and other resources) and focusing on expanding opportunities for hepatitis C peer involvement.

- 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.

Rationale: Stigma not only affects people living with hepatitis C, but it causes distance between people within the community itself. Opportunities to come up with strategies to address this expression of hepatitis C stigma could be created in the form of focus groups or workshops.

- 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.

Rationale: Education should include information about screening (including within priority populations, such as immigrants/newcomers) community resources, and how to engage patients in a way that deliberately destigmatizes the experience of care for patients. (i.e. addressing stigma.) Existing programs to match medical students with people with lived experience are a positive step forward, but there must be parallel continuing education programs in place to ensure that primary care physicians have current information and are comfortable with sharing it with patients.

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**

**For more information, please contact
Madeline Gallard at:
madeline@pacifichepc.org**



madeline@pacificepc.org

www.pacificepc.org