HCV Forum:
Creating Supportive Health Care Environments

March 12, 2012
Vancouver, Nelson, Cranbrook, Smithers

www.pacifichepc.org
SUMMARY REPORT

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SUMMARY REPORT

1. Overview

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The Pacific Hepatitis C Network organized this one-day forum to bring together communities across BC to look at ways to create supportive health care environments for people living with and at risk for hepatitis C.

Thirty-seven people were involved in the HCV Forum in four sites: Vancouver (15 participants) and telehealth sites in Nelson (14), Cranbrook (4) and Smithers (4). Two other telehealth sites were planned in Victoria and Courtenay, but they weren’t able to connect on the day of the forum.

Forum participants included people living with and/or working in hepatitis C, in community-based organizations, health authorities, and provincial and federal governments. The forum was led by facilitators April Struthers and Christien Kaaij with Deb Schmitz, Executive Director of the Pacific Hepatitis C Network.

As our starting place we set out to answer this question: How, within the current context, do we do more of what works, together?

During the day we looked more closely at:

  o What makes supportive health care environments?
  o What keeps people from accessing hepatitis C care?
  o How can we counter stigma?
  o How can we work together to create more supportive health care environments?
  o What are our priorities for action?
  o What do we need to do next?

This report provides a summary of the forum activities and feedback plus the supporting materials we used. By the end of the day we had identified four overall priority areas: education, improve access to treatment, funding, and partnerships and collaboration. We will be determining specific priorities and actions to work on together next.

Many thanks to the Public Health Agency of Canada for their support to hold this forum, to the very large planning committee from communities across BC that worked out all the details, and to all those involved for their ideas, energy and commitment to take action in their own organizations and communities, and in the province, to make things better.

Abbreviations used in this report:

BCCDC  BC Centre for Disease Control
CBO   community-based organization
GP   general practitioner
HCV   hepatitis C
PHCN  Pacific Hepatitis C Network
2. Supporting materials

The planning committee for the forum pulled together a number of supporting materials that we reviewed, used and built on during the day. Our meeting package included handouts covering:

- Our activities for the day (forum agenda in Appendix A)
- Why we’re here and what we’re aiming to do at the HCV Forum (forum objectives in Appendix B and background in Appendix C)
- How we work together (guiding values and principles in Appendix D)
- Key documents that our work is building on (Appendix E)
- The role of community-based organizations in delivering hepatitis C care in BC (models in Appendix F and G)
- Values and principles reflective of the work and our approaches to it (Appendix H)
- A summary of the biggest issues from all these supporting documents (Appendix I)

3. Why is hepatitis C different from other “chronic” diseases?

To begin the forum we discussed and added to a list of factors that make hepatitis C different or more complex than other chronic diseases. The list below reflects what everyone needs to know about addressing hepatitis C:

- Not always considered a chronic disease
- Stigma at all levels / restrictions / psychosocial needs
- Multi-problem presentation or competing issues for people seeking help
- Disease of poverty
- Treatment not offered on diagnosis
- Provincial policies limiting treatment access
- Cure rate is higher the sooner treatment starts
- Someone has to be really sick before they can get treatment
- Very difficult to get re-treated if infected again, or the first round of treatment isn’t successful
- Treatment has severe side effects
- Disease course unique to individuals
- Need to see a specialist
- Not many specialists
- General physician awareness of disease and disease process not high
- Low level of education especially for health care system
- Slow appearance of symptoms
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- People do not know to get tested
- Lack of information and education to prevent transmission
- Harm reduction needed as part of the approach
- Likelihood and complexity of co-infection
- Fear of transmission high – this is an infectious disease
- Need for public education
- Advocacy required from sickest people
- Need more educated advocates to share information and an have impact on systems (many leaders are too sick to continue in this role)
- Very underfunded – if investments aren’t made now, we’ll have to pay a lot more later

4. Better practices: Improving models of care

Better practices and models of care for people living with hepatitis C are guided by the recognition that:

- Whole people with whole lives are looking for help, and they bring their whole experiences when trying to get help in their communities.
- Person-centered care makes a big difference in how someone is cared for over time, and not just in a technical way (i.e., medical treatment).

We looked specifically at the role of community-based organizations in improving hepatitis C services, care and support in BC (Appendix F and G). Community-based organizations are in a position to broker relationships and support people with hepatitis C and the people in their lives (people affected by hepatitis C). The diagram in Appendix F reflects a provincial service model for relating and being involved as peers, including health care providers, support providers, policymakers and others. The model in Appendix G shows how community-based organizations can extend and expand the reach and effectiveness of regional liver clinics. It reflects a determinants of health approach – encompassing all aspects and experiences in people’s lives. It also shows how people can influence and access services in their communities and in the province.

From these models we can see there are a variety of pathways into service, and how important it is to connect someone with community-based supports when they are accessing treatment or specialist services.

These service delivery models are from:

Managing the HCV Epidemic: A Practical and Cost-Effective Approach for BC Communities (Hepatitis C Council of BC, 2005)

http://www.larissaardis.com/Portfolio/Hep%20C%20Council%202005.pdf
5. Supportive care environments

Next we looked at what is needed for people living with hepatitis C to feel safe, accepted and welcome when they seek health care. All the sites discussed and contributed to this description of what makes a supportive care environment:

- Accessible (supportive, respectful, meets needs)
- Seeks and responds to patient feedback about design of care, i.e. pathways (people’s experiences of living with hepatitis C influence care and services)
- “Culture” in relation to treatment
- Range of support and psychosocial support (beyond a biomedical approach)
- Specific person-centered and goal-directed care approach (What makes a difference for each individual with specific needs and disease course?)
- Multi-level/multi-professional integration of health services (interprofessional and interdisciplinary care at all levels of system)
- Pathways into and through care system are well marked (clients know how to navigate the system)
- Self-care management and education, and health literacy taken into account (What can we do to take responsibility for our own health?)

Participants also noted that there are so many barriers to any kind of care. Not just because services are far away, but also because people who are caught up in addictions don’t get this far in accessing care. There are too many other things that come first, like housing, drugs, food.... For many people, care starts at a community-based organization, not at a clinic or doctor’s office where there is still so much stigma (e.g., because they’re still using, they don’t deserve treatment or are not capable of seeing it through, or the doctor keeps putting off discussion till the next appointment).

One suggestion for overcoming some of these barriers: use more motivational interviewing at all levels of care. Recognize the stages of change – where a person is at and what you can do to encourage, educate and show options at each stage. So it’s not just that someone is in or out, or using so not eligible. Offer targeted approaches and steps so everyone is included.

It’s also important to remember that supportive care environments need to be everywhere and all the time: in prevention, harm reduction, care, treatment and support settings, in forums, at
6. Self-protection in the present environment

Contact info:

BCCDC Hepatitis Services:
www.bccdc.ca/resourcematerials/clinicsandprograms/programs/HepatitisServices.htm

e-mail: hepatitis.services@bccdc.ca

phone: 604-707-2423
toll free: 1-866-660-1676

Attendance for Hepatitis C Care Project:
Gail.Butt@bccdc.ca
Sandi.Mitchell@bccdc.ca

For information on hepatitis C:
http://www.bccdc.ca/dis-cond/a-z_/HepatitisC/default.htm

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community events ... in the whole range of services for people living with and affected by hepatitis C. Everywhere.

Gail Butt, from Hepatitis Services at the BC Centre for Disease Control (BCCDC), presented results from their research project that explored why people with hepatitis C do not go for care, put it off or delay it. Non-attendance rates range from 30-80%, so the project set out to identify what the issues are and what to do about them to increase attendance. The project team interviewed 84 people in six provinces: 55 people living with hepatitis C and 29 health and social care providers. They identified six reasons for non-attendance. The first four relate to individuals and their experiences with service providers, and the last two are systems barriers.

Self-protection: People avoided health care to protect themselves, because they were treated differently once they were diagnosed with hepatitis C, or they had seen how other people were treated. They described past experiences of rude or judgemental treatment, and assumptions that they were using or seeking drugs. Stigma after disclosure (revealed by going for care) was another big concern, especially in rural and remote areas.

Difficulty seeing the benefit of attendance: People said their health care providers didn’t provide any advice on monitoring or treatment, or didn’t know any more than they did as patients (and had to find out on their own). Also, if they didn’t have troublesome symptoms, the personal risks and costs of seeking care outweighed their expectations of success or readiness for change.

Competing priorities: For many people, hepatitis C gets put in the background. They have work or family obligations, or they’re dealing with other issues, like trying to find housing and food, transitioning from prison, or active drug use. They might have other health conditions to manage (e.g., arthritis), or they’re too sick to go for care (e.g., no energy or brain fog from hepatitis C means they miss appointments).

Knowledge gaps/health literacy: Health care providers need to learn more about hepatitis C. Many don’t know beyond diagnosis and treatment, lack information about monitoring and self-management, and sometimes pass along misinformation (like hepatitis C can’t be treated). Clients may have difficulty understanding medical terms or
assessing different sources of information, and they may be uncomfortable asking for explanations within the limited time in an appointment.

**Access to services:** The way health services are organized and delivered affect how people can access care. Although people don’t pay for health care, there are still costs like medications, childcare or transportation to be able to attend care. Services are very different depending on where you live, and rural and remote areas especially experience shortages of family doctors, specialists, social support services and medical/lab services. There’s often a lack of integrated and culturally appropriate services (e.g., for youth, Aboriginal or immigrant populations). There can be long delays before people can get care, such as long wait times or a series of tests and consultations with specialists before treatment can start. Sometimes clients are refused services because they’ve missed appointments or they’re using drugs.

**Restrictive policies:** Many project participants believed they had to abstain from drugs to be able to access treatment. Or they didn’t meet certain eligibility criteria for treatment. Other service provision policies also keep people from care, like requiring clients to call to confirm appointments (when they don’t have a phone) or get a referral (when they don’t have a family doctor).

Gail summed up the project results: current services focus on diagnosis and treatment, but people who are living with hepatitis C for years need chronic illness support services that include integrated health and social supports, self-care management and education. The BCCDC project is looking at developing resources to improve service delivery and encourage people to get care for hepatitis C (e.g., a tip card on tests someone with hepatitis C should be getting every year) and to partner with individuals and groups to help do this.

7. **Countering stigma**

The forum activities demonstrated that stigma has a huge impact on care. Stigma can be intentional or unintentional. Unintentional stigma can happen through disorganization, with a lot of different players at federal and provincial levels, and a lack of communication or information sharing. Intentional stigma happens through unequal power relations – when people see you as something “other” or less than, and behave towards you from that place.
The next activity provided an opening for us to think about at our experiences of stigma (that we witnessed or felt) and something we could do about it, as well as what we wanted someone in another role or sector to do. It also showed how we can collaborate, integrate and coordinate things differently to counter stigma. Some examples that participants shared from their experiences of stigma plus actions to change it:

**The lack of proper education on hepatitis C (especially for doctors) is huge for stigma.**

- Keep working on education, for health service providers and for raising public awareness.
- Include a practicum with frontline work in health professionals’ education – to challenge belief systems when we can have an impact on them, not 20 years later when their beliefs are entrenched.
- Work to provide more education with RCMP, nurses, doctors, pharmacists, schools, shelter, social services.

**Language that further stigmatizes people who use drugs: clean, junkies, crackheads, etc.**

- Work together to identify stigmatizing language, create a list and distribute it among health and social service providers (to identify the importance of language to all our contacts).

**When I told someone I have hepatitis C, they stepped back from me.**

- I’ll better inform myself and pass along information on a personal level to improve understanding of how it’s transmitted (e.g., blood, sharing needles, pipes, etc.).

**I’m shocked at how many people with hepatitis C are suddenly not allowed to have contact with relatives (e.g., babies).**

- Do a proper public education campaign with TV and radio ads letting people know that hepatitis A is contagious, hepatitis B less contagious, and hepatitis C not so much (and only blood to blood transmission). It’s essential and long overdue!

**People don’t always respect us when we try to tell them something.**

- Organize through peer groups and user groups, so people know we know what we’re talking about.
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When I was diagnosed, I wrote to the community newspaper, and that led to forming a local support group. But over time, when people around you are struggling with addictions, you’re losing your community and going through the grief process, you can internalize stigma.

➔ You need a strong basis of support and self-care (individual, peer group and community levels).

Involuntary disclosure (e.g., letter about hepatitis C diagnosis sent to ex-spouse).

➔ The province should have a unified approach to contacting people with hepatitis C through direct personal contact. You can’t take back disclosure.

Access to injection equipment, harm reduction supplies, injection sites and smoking rooms is often NOT seen as hepatitis C prevention.

➔ Bring people together in communities, including researchers, drug users, AIDS service organizations, needle exchange staff and the public, to ensure that education and support exists for people at risk for hepatitis C, people living with hepatitis C and providers who fear that they will be shut down.

➔ Broaden the discussion of hepatitis C prevention to include heroin-assisted therapy and safe crack smoking programs. Be firm, be evidence-based, let people let go of their hatred and biases in a supportive environment.

➔ Work with SFU, UBC, BC Centre for Excellence in HIV/AIDS, people who work with drug users, homeless shelters, medical clinics and the BCCDC to hold public forums on hepatitis C prevention.

A client accessing methadone maintenance therapy was not receiving adequate physician care for hepatitis C. This client has difficulty responding to his medical needs.

➔ Assign an advocate to attend medical appointments with vulnerable clients who may have cognitive issues and/or low literacy abilities.

➔ Make training available to physicians on cultural competency regarding people who use injection and/or inhalation drugs. Collaborate with other organizations and agencies to develop a curriculum for health care providers.
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The liver clinic routinely asks everyone, “How do you think you contracted hepatitis C?“ The client I accompanied did his best to answer in a way that would not stigmatize him further or disclose too much personal history. In a later conversation I had with the clinic coordinator, she held it against him that he didn’t answer the question properly. But there is no right answer. You can’t give a right answer to that question. If you say through drug use, there’s stigma. If you don’t say but it’s suspected through drug use, there’s stigma.

➔ We should stop asking how someone got infected – that’s not the issue but what should we do about it.
➔ Treatment providers can say they are sorry for treating drug users so badly and invite people with this stigma to be treated for hepatitis C. Many users think they cannot get treatment so they don’t approach to get treatment.

Plus some more actions identified during the group discussions:

➔ As part of monitoring: ensure that people get (1) testing, (2) referrals and (3) financial and mental health support (which is especially hard for a vulnerable community to access).
➔ Do a “Hepatitis C Challenge” with community-based organizations (and award a good prize) for “How does your organization work on preventing hepatitis C?”
➔ Hold an event in the park on World Hepatitis Day in July. This is a way for the entire community to learn about hepatitis C and to get good information out to lots of people. It’s also a way to show that hepatitis C isn’t something to be afraid of or to hide.

Everyone was encouraged to take the actions identified here home to our organizations, to share them with colleagues, and to make sure we have policies to address stigma in our organizations. By working well together, and by doing the things we’re doing but deliberately, we can affect stigma and create positive social change.

8. Heroes and assets

Another important part of creating social change is to link heroes and assets in our communities. There are always champions and advocates, working behind the scenes or publicly to bring change, and we need to recognize, support and renew them. In the next activity we identified our heroes in relation to hepatitis C, plus other
assets in our communities (e.g., people, organizations, history, successes, networks, space). Our combined list of heroes is very long; some examples include:

**Doctors** who give lots of their time, support and advocacy

**Nurses** – including hepatitis C support nurses, public health nurses, street nurses on the frontline helping people

**Pioneers and leaders** like Ken Thomson

**Individuals** in our organizations, communities and province who lead, volunteer, advocate, raise money and reach out to people; peers in the community that we don’t know about but who are filling the gap for organizations in our community

**Organizations and networks** – including HepCBC, Pacific Hepatitis C Network, PAN (Pacific AIDS Network), CATIE, ANKORS, Positive Living North, REDUN (Rural Empowered Drug Users Network), VANDU, BC/Yukon Association of Drug War Survivors, Pivot Legal Society, Salvation Army

**Needle exchange programs, harm reduction programs, supervised injection sites** – and the “guerrilla” (underground) needle exchange operators and injection sites

**Community-based groups/programs** like the Warm Zone in Abbotsford or Cool Aid Clinic in Victoria, Friendship Centres, church groups, homeless shelters, 12-step programs with open, safe hepatitis C and HIV-friendly meetings

**Local health and community services**, including Mental Health and Addictions, social planning committees, housing committees

**Cities/towns** with supportive councils, bylaws, police (e.g., for harm reduction)

**Funders/governments** that support hepatitis C work, and the bureaucrats (hidden at times) who work behind the scenes to ensure access (and therefore change attitudes)

So what makes someone a hero? Participants said that heroes:

- help others, with no ego or vested interests, and often little or no resources
- stand up for what they believe in – and aren’t afraid of the repercussions
- do what’s right
- take chances and risks to move things forward
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- go beyond status quo/conventions
- speak out and take positive actions (rather than just sitting and complaining)

In addition to heroes, another asset in communities can be found in service providers who provide their services for free to clients who normally can’t afford them (e.g., acupuncture, massage therapy, hair cuts) – by coming to local organizations or participating in a “Community Connect Day” where different services are shared among groups. Ways to build on this include expanding the number and variety of providers who participate, and sharing hepatitis C information with them for their use and dissemination to the public.

We can also look at where there are obstacles or resistance to our work and find ways to get people involved constructively. Perhaps we also need to include those who would be heroes though they don’t know it and bring them in to work in some way. It’s also important to celebrate our heroes in meaningful ways (and not just a plaque or gala dinner). Peer recognition is very important and encouraging – it gives us courage to continue in a very difficult field. Recognition can also be very useful for public education.

9. How to work together

To help build more connections, we did a sort of “speed dating” to meet as many people in the room in a short time and to find out how we can work together (including what each of us brings and needs). The Vancouver participants shared a lot of information about things everyone is doing, while the other sites said they already knew one another at their location, so they looked outside to see how they could better connect with activities and organizations in their communities and regions. Some of their plans include:

- Supporting a peer group to pass on information and education to various groups
- Encouraging attendance at user group meetings and building more capacity in the group (e.g., to do presentations to other organizations)
- Putting together a harm reduction community to share information, then pass it up to policymakers in the health authority
- Getting the hepatitis C message out there
- Increasing the focus on hepatitis C (in addition to HIV)
- Connecting with college nursing programs and human
services programs to educate students about hepatitis C and harm reduction
  o Being more proactive about connections to community services and becoming part of the conversation

10. Setting priorities for action

To provide direction for our work together, we each identified the two most important things we should do provincially on hepatitis C. We wrote down all the suggestions on sticky notes and sorted through them together to consolidate them into four main priority areas: education, improve access to treatment, funding, and partnerships and collaboration. Unfortunately the telehealth connections to the other sites stopped at 4 p.m., so we still need to review and decide together what priority actions to focus on next. Specific actions and issues in the four priority areas include:

EDUCATION
  o Education accessible to everyone
  o Public education campaigns (to increase awareness, reduce stigma, ensure knowledge exchange)
  o More education at the relevant level (e.g., community readiness model and what’s relevant to the area you live in)
  o “Ask Walter” (cartoon character to share basic information on hepatitis C)
  o Provide a forum for people living with HCV to dialogue with experts to get answers (treatment, disability issues, etc.)
  o Hepatitis C and input in programming

Additional comments on education:
  • Make people see it from a different angle – e.g., that needle exchanges won’t give drug users equipment to prevent hepatitis C.
  • Put a face on hepatitis C, so it’s not just a drug users’ illness, to make it more viable to raise awareness and funds. There are different avenues this disease can come from (e.g., blood transfusion, exposure for fire and police services).
  • HepCBC has done a remarkable job with tiny budget (FAQs). What could they do with more money? (e.g., teleconference, online site for dialogue/forum with experts)
IMPROVE ACCESS TO TREATMENT

- Improved integrated services: seamless transitions, flexibility, relative to individual’s needs (e.g., respite workers, childcare for single parent going through treatment)
- Early treatment
- Access to services / treatment access issues
- Ensuring access to service for people who use drugs
- GPs and nurses to provide treatment without judgement
- Excellent accessible prevention of hepatitis C (injection supplies, crack kits and education mystery shopped)
- Needle exchange in prisons
- Tattoo equipment in prisons
- Ensure police and prisons onside with disease prevention [also under Education for prevention]

Additional comments on access to treatment/services:

- *Treatment is cost-effective when done early = strong point for education/advocacy.*
- *Important to identify barriers to access (e.g., mental health, financial issues).*
- *Still need to examine stigma – and need very good strategies around that.*
- *There are functional barriers to treatment (e.g., Pharmacare).*
- *Peer organizations have no recourse when access or services are denied – it’s no use complaining to funders. There’s no accountability, no mystery shopping, no voice for people most at risk. Collaborations mask this problem, make it look like it’s working, but they’re not effective for people who can’t access services. Is there a legal strategy here?*

FUNDING: PRIORITIZE / INCREASE (OTHER SOURCES)

- More/enhanced funding
- Direct/separate funding to hepatitis C (i.e., from HIV/AIDS)
- Specific funding for peer organizing

Additional comments on funding:

- *Increase funding directly to groups working on hepatitis C (not lumped with HIV): amount, targeted, how allocated, federal/provincial levels.*
- *Keep hepatitis C funding separate – users don’t want to be outed or seen to have HIV.*
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- The reality that we as nonprofits have to face is that there’s not going to be more funding. What can we strategically do with what we have – to make it go as far as possible? There will be even more integration (with sexually transmitted infections, tuberculosis, other blood-borne infections). As groups, we can be ready for it or resist it (but it will happen).
- Need to prioritize or strategize funding if there’s not going to be more funding available.
- Also need to develop other sources of funding, expand our donor base so it’s not just government funding (finite).
- We still need to advocate for new funding – we still need to do it provincially to establish the need among other funders.
- If we reach out to the people doing most of the work in the province, and continue to be collaborative and creative, we’ll have a better chance of attracting funding when we make it clear that the best we have is already working, and we can’t do more without more funding. If we focus on doing what we can, then new resources will come.

PARTNERSHIPS & COLLABORATION

- Support networking
- Increase partnerships and collaborations
- Importance of building partnerships – one strong voice
- Work together to advocate for increased services, funding and education
- One go-to organization with all the answers instead of scattered resources
- Peer support
- Robust supported networks of people at risk (for treatment, prevention, support, advocacy)
- Legal strategy – i.e., to take legal action if discrimination occurs (bylaws against harm reduction)

Additional comments on partnerships/collaboration:

- A legal strategy may be supported through collaboration or partnerships – who would take it on?
- Ensure partnerships are ethical. Be very sophisticated about collaborations and partnerships. Sometimes you have to fire partners. Determine what you want, what minimum you’ll accept – do partnerships the way you want to do them.

“Should we consider partnerships and collaboration as the vehicle by which we address these and other priority areas?”

“If so, does it make sense to prioritize building our capacity and skill for partnering and collaboration as we move forward?”
11. Action planning

A worksheet for creating your own action plan is in Appendix K

We then looked at what we (as individuals or our organizations) can do in the next few months or year to take action on one of these priorities. We identified what we want to achieve, key activities, strategies and resources, and a timeframe. Participants shared these examples from their action plans:

- Increase awareness of hepatitis C in the community by engaging service providers through a Hepatitis C Challenge, including a questionnaire filled with hepatitis C facts and questions to educate community members. Build community buy-in and support for prizes, etc.

- Connect with local doctors on the importance of hepatitis C treatment and support. Provide local doctors with hepatitis C information from CATIE, PHCN and other organizations.

- Provide monthly education sessions via PHCN telephone conference with doctors. (This may require funding or some other arrangement for doctor fees.)

- Hold at least two telehealth forums for people living with hepatitis C, community-based workers and health care providers in communities (PHCN to coordinate, working with community partners to identify topics and presenters). Include "Ask the Expert" rounds with a section for reciprocal learning – clients and their communities presenting their best practices, tools and tips to the same audience.

- Hold panel discussion through town hall meetings; provide links to information sites; plan for World Hepatitis Day.

- Organize a public forum for a robust discussion about hepatitis C prevention to ensure people at risk have education and support to reduce risk (involving participants and stakeholders in Surrey, Abbotsford, Burnaby and New Westminster).

- Integrate discussion about hepatitis C information and support needs with local drug user network(s), including a question-and-answer session with a guest speaker around hepatitis C (likely via Skype).

- Follow up with a social worker program at a local university to reach students earlier in their education (first and second years) with information on hepatitis C and harm reduction.

- Develop accessible (to everyone) hepatitis C education. Obtain specific education/information from BCCDC as
Observations and recommendations from the HCV Forum facilitator for moving the field forward and for organizing future learning forums like this one are in Appendix L.

12. Follow-up

Throughout the day we recorded other comments and questions that came up in the discussions. These other issues are sorted below into various themes for follow-up:

Need for information (patients, health providers, public)
- Ask Walter! (basic information on hepatitis C)
- What other organs does hepatitis C affect?
- Specific treatment issues

Advocacy
- Patients becoming their own advocates
- Disability benefits: policy and access for people living with hepatitis C
- AIDS services organizations are/were able to have fully funded advocates to ensure people could get disability, diet allowance, bus passes, etc. Hepatitis C patients need “real” advocates.

Person-centred supports and psychosocial care
- Tracking people referred by public health or GP

Ways to work together
- Use videoconferencing more, especially for rural areas
- Networking, communities of practice
- Asset mapping
- Recognize our heroes (share)
13. Next steps

For more information, updates or ways to get involved, check out the PHCN website at: www.pacifichepc.org

Following the forum, our first next steps will be to:

➤ Connect with the other sites (Cranbrook, Nelson, Smithers, Victoria and Courtenay/Campbell River) for their input on priorities and actions.

➤ Compile and share an email list among forum participants.

➤ Share this forum report widely – with the intention that it can be used for ongoing planning and direction towards creating supportive health care environments.
APPENDICES

A – Forum agenda
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F – Community-based organizations in HCV service delivery in BC (1)
G – Community-based organizations in HCV service delivery in BC (2)
H – HCV in BC values and principles
I – Biggest issues
J – Anti-stigma activity [worksheet]
K – Action planning activity [worksheet]
L – Recommendations for moving the field forward
## Creating Supportive Health Care Environments

### March 12 2012

**Communities participating via Telehealth**

<table>
<thead>
<tr>
<th>Location</th>
<th>Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vancouver</td>
<td>BC Children’s Hospital - Ambulatory Care Building, Rm. K0-156 (in basement), 4490 Oak Street. Main site with facilitators.</td>
</tr>
<tr>
<td>Smithers</td>
<td>Bulkley Valley General Hospital</td>
</tr>
<tr>
<td>Nelson</td>
<td>Kootenay Lake Hospital, Room 416</td>
</tr>
<tr>
<td>Cranbrook</td>
<td>Cranbrook Health Unit</td>
</tr>
<tr>
<td>Courtenay</td>
<td>Comox Valley Nursing Centre</td>
</tr>
<tr>
<td>Victoria</td>
<td>Memorial Pavilion on the Royal Jubilee Hospital campus, 3rd floor</td>
</tr>
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</table>

## PROGRAM

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00</td>
<td>Introduction/ground rules/warm up</td>
</tr>
<tr>
<td>9:30</td>
<td>Why Hep C is Different/ Guiding Principles</td>
</tr>
<tr>
<td></td>
<td>- Better Practices – Improving Models of Care</td>
</tr>
<tr>
<td></td>
<td>- Self Protection in the Present Environment (Gail Butt, Hepatitis Services, BCCDC)</td>
</tr>
<tr>
<td>10:30</td>
<td>BREAK</td>
</tr>
<tr>
<td>10:50</td>
<td>The Picture we would like/ Countering Stigma</td>
</tr>
<tr>
<td>12:00</td>
<td>LUNCH</td>
</tr>
<tr>
<td>1:00</td>
<td>Introductions-Review for our colleagues</td>
</tr>
<tr>
<td></td>
<td>- Heros and Assets</td>
</tr>
<tr>
<td></td>
<td>- How to Work together</td>
</tr>
<tr>
<td>2:30</td>
<td>Setting Priorities for Action</td>
</tr>
<tr>
<td></td>
<td>- Sorting</td>
</tr>
<tr>
<td>3:00</td>
<td>BREAK</td>
</tr>
<tr>
<td>3:30</td>
<td>Action Planning – What Is Next ?</td>
</tr>
<tr>
<td></td>
<td>- My part</td>
</tr>
<tr>
<td>4:30</td>
<td>Close</td>
</tr>
</tbody>
</table>
Appendix B – Forum objectives

FORUM OBJECTIVES

- Plan and coordinate 1 day forum
- Prepare key documents and expert findings
- Review what makes supportive health care environments for people living with and at-risk for hepatitis C infection and chronic hepatitis C
- Process: if we know what works (big picture), what steps can/do we take to create more supportive health care environments
- First next steps
- Document above during the meeting

We are looking at in this day:
- A potential better model of care
- Stigma
- How to work together

Follow up will include preparing and disseminating a report that documents the day with the intention that the document can be used for ongoing planning and direction towards creating supportive health care environments.

Outcomes: If participants feel they have had meaningful conversations, there was at least one useful thing (i.e. learning, insight, connection, idea, renewed energy or focus) and a next step for moving forward, this will have been a successful day. We sincerely hope that the day brings you this and more and that it is a worthwhile use of your time. Thank you for being here!

We know that those experiencing the problem must be a real part of the work to create supportive health care environments. We know that when we say “creating supportive health care environments” we mean supportive for everyone – staff, patients, advocates, family, supports.

The question is, “How, within the current context, do we do more of what works, together?"
Appendix C – Forum background

FORUM BACKGROUND

The background to this Forum really is our history together and our common desire to improve on things – our health, our ability to give and receive care, our communities.

This is true no matter how long you have been diagnosed and/or working in hepatitis C and regardless of whether you work in community-based organizations, health authorities, provincial or federal governments.

You will see a question at the bottom of this page. This is a place to start – not the only or the first place to start, just a place to start. Our hope is that we can continue in this discussion and in actions and in reflection on action – together, singly and in small groups, however those emerge.

We know the problem
People who are living with and at-risk for hepatitis C run the risk of being met with fear, stigma, discrimination, lack of knowledge, and assumptions about them, and their challenges, that can affect whether or not they can even access the care, every time they step into places where they should be met with care and concern.

And, we know that this isn’t true everywhere, nor is it true all the time.

We know what to do
When we talk to each other from our respective communities, desks and homes, we know what works and what is needed. We understand that while lives are complex and people are complex mostly what is needed is simple respect. We get that properly addressing prevention, care, treatment and support needs requires working together.

We understand that working together asks much of all of us: patience, skill, courage, a sense of humour, a willingness to believe in the best and the possible even in the worst of times. That, and more, is what is being asked of us.

We know that the people experiencing the problem must be a real part of the work to create supportive health care environments. We know that when we say “creating more supportive health care environments” we mean supportive for everyone – staff, patients, advocates, family, supports.

The question is, “How, within the current context, do we do more of what works, together?”.
Appendix D – Values and principles

VALUES

The values at the core of community development (one way to describe what we are doing) are:

• **Social justice**: The idea of creating a society or institution that is based on the principles of equality and solidarity, that understands and values human rights, and that recognizes the dignity of every human being.

• **Self-determination**: Self-determination has come to mean the free choice of one's own acts without external compulsion.

• **Working and learning together**: Whether we are giving or receiving care, we all have something valuable to offer in creating more supportive health care environments.

• **Sustainable communities**

• **Participation**

• **Reflective practice**: Reflective means to ponder, think about, review and analyze past activities because they were ineffective or troublesome – but to always try to make sense of them, evaluate them and learn from them. Reflective practice helps to bridge the gap between what we think will happen if we do something (theory), what actually does happen and what we actually do (practice).

PRINCIPLES

**Collaboration**: Process where two or more people or organizations work together to realize shared goals. This is more than the intersection of common goals seen in cooperative ventures, but a deep, collective, determination to reach an identical objective.

**Coordination**: Who does (1) what, (2) when, (3) where – and keeping each other informed. What are the roles? Who has what authority in which jurisdiction(s)?

**Integration**: Of services, perspectives, knowledge, experience, resources.

**Leverage**: Who do you know who knows someone who can tell someone else (someone with influence within a group, organization, community) about your issue, solution, process?
Appendix E – Key document summaries

Lots of studies, reports, strategies and frameworks exist that can be drawn from. The three summaries below were used because they are home-grown and, in the case of the third, speak to the importance of the meaningful involvement of people living with hepatitis C in successful models of care for them.

Summary 1

Managing the HCV Epidemic: A Practical and Cost-Effective Approach for BC Communities (HCV in BC: A Renewed Focus)
Hepatitis C Council of BC (HCCBC), 2005

Managing the HCV Epidemic: A Practical and Cost-Effective Approach for BC Communities was funded by the Public Health Agency of Canada and written by the HCCBC with professional writer/consultant Larissa Ardis, in 2005. The purpose of the document was, and is, a “contribution to the ongoing discussion about how BC should proceed in the absence of a clearly defined provincial or national strategy”.

The document broadly outlines the scope of hepatitis C in BC (epidemiology and cost) and challenges preventing and providing care, treatment and support.

The document identifies that community-based organization (CBO) and patient roles are critically important in the opportunity to address issues and points out that CBOs:

- support, extend and enhance the work of clinics
- ensure coordinated response within communities
- offer unparalleled access to at-risk, hard-to-reach populations
- offer real-world evaluations of program effectiveness
- identify emerging trends
- are cost effective

The conclusions and recommendations call for:

- provincial framework
- coordinated approach with high standards and equitable access
- integrated, coordinated, collaborative
- clear roles and authority within partnerships
- professional development and attracting specialists
- updated Pharmacare criteria
- research agenda with timely and appropriate knowledge exchange activities
- resources adequate to the task
Two diagrams illustrate a possible model of shared care that includes CBOs as equal and legitimate partners within a province-wide coordinated response to hepatitis C, HIV/HCV co-infection and liver disease.

**Summary 2**

**Healthy Pathways Forward: A Strategic Integrated Approach to Viral Hepatitis in BC**

*BC Ministry of Health, May 2007*

This document was developed with input from community, advocates, health care providers with the guidance of a steering committee with the intent of creating a “policy platform for implementation across the service system and is based on the assumption that the work will need to be done largely within the context of existing resources”.

Specific to hepatitis C, Healthy Pathways Forward “presents a strategic approach that can act as a ‘roadmap’ for a coordinated and integrated response that addresses multiple vulnerabilities - thereby improving the overall health outcomes related to viral hepatitis and beyond”.

The Healthy Pathways Forward strategic framework goals are:

- **Goal 1:** Prevent new hepatitis infections and reduce the risk of those infected progressing to serious liver disease.
- **Goal 2:** Enhance program reach and engagement of vulnerable populations in the health promotion, prevention, care, treatment and support service continuum.
- **Goal 3:** Strengthen the system’s capacity to respond.
- **Goal 4:** Create seamless service delivery. “Improved integration, coordination and collaboration are achieved by implementing a service delivery model rooted in the principles of community development, consumer involvement and shared care”.

The recently released Healthy Pathways Forward Progress Report, May 2007 - 2010 states that, “community-based prevention and care initiatives suggest that strong effective partnerships are needed to carry out effective health promotion, prevention, care, treatment and support activities”.

**Summary 3**

**Oral presentation: Nothing for us, without us: The meaningful involvement of clients in HCV treatment and prevention**

*NCRTPHC (Research) Program and Abstracts, February 2012*

Conclusions: The ETHCP [East Toronto Hepatitis C Program] is a model of care that improves access to HCV treatment by addressing many of the complex needs and barriers face by people living with hepatitis C. The meaningful involvement of people living with HCV has been vital to the integrity and ongoing success of this program.
Appendix F – Community-based organizations in HCV service delivery in BC (1)

**Fig. 1: A Model For a Province-Wide Organization**

**PROVINCIAL HEALTH SERVICES AUTHORITY**

- **Health Region**
  - CBO
  - Regional Liver Clinic
  - CBO

- **Coordinated HCV, Co-infection and Liver Disease Treatment Program**
  - COMMUNITY-BASED ORGANIZATIONS (CBOS)
    - support, extend and enhance work of clinics
    - ensure co-ordinated response within communities
    - offer unparalleled access to at-risk, hard-to-reach populations
    - offer real-world evaluations of program effectiveness
    - identify emerging trends
    - are cost effective*

* Note: endnotes dedicated to cost effectiveness can be referenced on p33 of this document.
Appendix G – Community-based organizations in HCV service delivery in BC (2)

**Fig. 2: How CBOs Can Extend and Expand the Reach and Effectiveness of Regional Liver Clinics**

Community-based organizations expedite referral pathways: Capacity is developed in communities through the education of existing service providers about HCV treatment issues, the roles that each can play within this extended team and the importance of timely access to these services, particularly during treatment. This collaborative, cross-educational process can only increase the percentage of successful treatment outcomes as well as the health outcomes of HCV positive people not on treatment but it can also broaden awareness and cooperation among service providers and community groups on a range of challenges and determinants of health that affect the community as a whole.

**Diagram: Diagram adapted from North Island Liver Services Diagram**

**HCV IN BC**

A RENEWED FOCUS
Appendix H – *HCV in BC* values and principles

The B.C. Hepatitis Collaborative Circle submits that any effective strategy, or combination of strategies, must also reflect B.C. values of compassion, equal opportunity, and equitable access to healthcare. Realizing these values requires clear commitment to the fundamental principle that all citizens deserve:

> A reasonable level of funded services for HCV prevention, support and education, treatment and care, consistent throughout B.C.

> Accurate, appropriately presented and readily available information about HCV.

> Treatment and care for HCV in a respectful, confidential manner.

> Treatment regimes which are supported by current best practices knowledge.

> Meaningful input into the design, delivery and evaluation of programs meant to benefit them.

> Recognition that addiction is a health issue, with implications for individuals, their families and communities.
Appendix I – Biggest issues

- Time bomb demographic trend.
- Specific care as well as specific treatment indicted as most effective.
- Stigma holds back dealing effectively with this issue on many fronts.
  - Human rights issues
- No overall coordinated strategy yet.
- This is not just a biomedical epidemiological and treatment issue.

Summary of documents

1. There has been progress.
2. Not many of population tested.
3. Indicators (are they the best?).
4. Using a whole picture approach, with the role of all recognized is important, especially the role of community-based organizations and patients.

Implications

- Collaboration, coordination, integration required.
- Criticality of issue needs to be brought home to policymakers, politicians and large service organizations.
- Everyone has a role to play.
- Progress needs to be assessed in the “big” picture as well as within sectors and organizations.
Appendix J – Anti-stigma activity [worksheet]

✓ Check mark for self. “X” for other area.

<table>
<thead>
<tr>
<th>ANTI - STIGMA</th>
</tr>
</thead>
<tbody>
<tr>
<td>PREVENTION/ HARM REDUCTION HEALTH CARE (ANY)</td>
</tr>
<tr>
<td>SPECIALIST CLINIC</td>
</tr>
<tr>
<td>SCREENING, ASSESSMENT AND REFERRAL PRACTICES</td>
</tr>
<tr>
<td>RESEARCH, DATA COLLECTION SYSTEMS AND PROTOCOLS</td>
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</tbody>
</table>

Identify one example of stigma:

To counter the stigma I will:

To create anti-stigma in ________________, they should:

To apply one of these principles I will:

**Principles**

- Collaboration
- Leverage
- Integration
- Coordination

**Anti Stigma**

- Which area do you work in?
- What will you do to create anti-stigma aspects there?
- Choose one other area - what should happen there?
## Appendix K – Action planning activity [worksheet]

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Key Activities</th>
<th>Action Points</th>
<th>Resources</th>
<th>Timeframe</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do we want to achieve? (Priorities?)</td>
<td>What do we need to do?</td>
<td>How do we do it?</td>
<td>What supports do we Need?</td>
<td>When will we do it? (Who will check?)</td>
</tr>
</tbody>
</table>

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**HCV Forum Summary Report (March 2012)**
Appendix L – Recommendations for moving the field forward

Following the HCV Forum, facilitator/consultant April Struthers provided these observations and recommendations:

1. The Big Picture

Getting focus on the issue

“The progression of this largely curable disease among people infected over the past 30 years – including those who have not been diagnosed or treated – is expected to result in an explosion of costly liver-related complications.”


The “ticking time bomb” aspect of hepatitis C as a public health issue needs amplifying. Suggest presenting at all professional meetings, symposia, conferences possible to get the message across of the need to invest and organize now because of the nature of the demographic epidemic. Common message and material could be developed to be presented everywhere.

Creating effective and sensible strategies

There are strategies from other jurisdictions that could be a basis for strategy in BC. The issue has lots of common features in other places and the shopping lists of needs are virtually the same (e.g., www.correlation-net.org/hepatitis).

The principles implicit in the community-based organization model presented in the forum need to drive the work moving forward to create effective and sensible strategies and to be embedded within the strategies themselves.

Person-centered wraparound care

Make the case for the critical need for the total person wraparound care model because of unique features of this disease and its symptoms, medication side effects, extremely marginalized population, the high potential for stigma in people’s illness experiences.

Use community-based organizations that know how to engage the whole person in care to teach other organizations and settings how to do that.

Reduce stigma

Stigma is a central feature of dealing with this disease. Work needs to be done at every level to recognize, and counter, the dynamics and effects of stigma. A public health approach to this feature using bias and diversity policies and existing lens can be used.
Ratify and make practical the principles espoused in the background material

“Nothing about us without us”; high service user / illness experiencer participation and peer-to-peer relationship building between service users and practitioners, health care professionals, staff at community-based organizations, researchers, bureaucrats, epidemiologists and others.

2. High Participation/High Engagement Forums and Educational Experiences

This hepatitis C field appears to be information and education deficient at several levels: general public, service user/family/community, health care professionals. Public and health care education have well established pathways and frameworks. To move the field forward in a collaborative, participatory way requires the development of service user, family and community pathways, including in: planning, implementing and critiquing efforts, sharing technical information and advances with these levels, and getting all the players in the picture to work together within defined roles.

This requires creative and suitable use of technology and learning formats. Recommended ones include:

- small-scale methods: communities of practice, action learning sets, etc.
- forums, panels, facilitated meetings

Continue to use technology to make education and knowledge sharing and collaboration cost-effective in the huge geography of BC. Media to do this include:

- telehealth
- teleconferences
- Skype VOIP telephone- and video-conferencing
- Ustream TV-free private or open Internet webcasting
- produce training videos or other media through low-cost video production software (e.g., Screenflow optimized for Mac computer costs $99)

Facilitating telehealth or distributed learning forums

Facilitating several remote locations and an in-room group is a challenging situation at any time. For participative work two-way connections need to be maintained and neither technology nor other environmental conditions should intrude on or limit conversation, communication, multi-channel learning (kinesthetic, visual, oral, etc.) – especially when it is critical to include all input, show people working together as peers, and give equal time to all who want to speak. Size of room, access to natural light, cleanliness and smoothness of the service aspects are all really important to success working collaboratively and remotely this way.

While this particular day lacked some of that, participants showed great persistence and poise on focussing on important aspects of what did happen, and worked collaboratively to move through the program (which was fragmented by technical interruptions). The will to contribute, to stay present, to interact and to make learning accessible was notable and appreciated. Having the cooperation of skilled site coordinators, the intense preparation
beforehand, and a common will made the outcomes of the day possible (along with appropriate facilitation and well thought-out and customized exercises).

The facilitator suggests that future forums have a parallel complete plan to switch to in the light of future possible technical problems, and that remote sites know both plans. This requires even more preparation.

This forum, in spite of considerable challenges, was a success in meeting the avowed objectives and in having collaboration happen in real time around the province.

Future forums

To pull together this field and coordinate efforts and provide cost-effective use of limited funds, the recommendation is that the forum format with similar invitation lists be continued. In thinking about the field of hepatitis C prevention/support/treatment, the facilitator (putting on her consultant hat) would recommend this series of topics in forum format over the next one to two years:

*Treatment Information:*
- Panel of experts talks about latest treatment, treatment challenges and solutions, and answers questions or refer to other sources of information.
- People need both general level information and consultations for individuals.
- This event could be a straightforward format or be conducted as a forum (possibly built as a progressive dialogue).

*Care Forum:*
- Explore the difference between illness and disease, treatment and care.
- Explore how to incorporate the elements of care listed in the March 12 forum.
- Explore the kinds of ongoing supports that are required with this disease and its progression.
- Think about how to use “heroes” and “assets” in your community.
- Have community-based organization staff demonstrate “care”.

*Stigma:*
- Precede this forum with a project where a couple of highly regarded organizations (consider a high-level organization to be one) undertake the NGO Code of Good Practice self-assessment (http://hivcode.org/silo/files/final-sandd.pdf) and then present on their learning around how to recognize, counter and monitor progress on controlling stigma.
- Have community-based organization staff demonstrate stigma-free care.
- Review some stories of stigma and do a case conference review of how things could be different in one case.

*Partnership and Collaboration Skill Building:*
- The “nitty-gritty” of working together effectively over time. Interprofessional working; stages of collaboration, creating learning teams, etc.
- Facilitate a cross-role participatory design group to apply best practices to create an experiential forum to spread collaborative practices.
Using the same kind of approach as in this forum …

- where the facilitator meets with an advisory group over time, with additional small key individual meetings
- where site supervisors are coached and act as mini-facilitators/coordinators and animators
- where there is a cross-role invitation list
- where participation and capacity building are as important as the content
- where content is accessible and concise
- where there is considerable background material developed and distributed before the event
- where mixed media are used for engagement (in-room groupings, remote site video connections, separate and joint mini-sessions throughout the day)
- and facilitation pulls it all together

will make these powerful opportunities.