Strategic Review

CIHR-PHAC HEPATITIS C RESEARCH INITIATIVE

MARCH 2011

CONSULTATION & REPORT BY

gestalt collective

www.gestaltcollective.com

TASK

overview

The Hepatitis C Prevention, Support and Research Program was launched as a five-year initiative in 1999 as part of the government's response to the report of the Commission of Inquiry on the Blood System in Canada. Originally scheduled to terminate on March 31, 2004, the Program received three one-year extensions, the most recent of which expired on March 31, 2007. In 2008, the Canadian Institutes of Health Research (CIHR) and the Public Health Agency of Canada (PHAC) Community-Acquired Infections Division (CAID) signed an agreement to support a continued hepatitis C research initiative. The gestalt collective was contracted to assess the current research priorities, as identified by researchers and key stakeholders, to help determine how best to invest the remaining and possible future funds in this program.

This report reflects the compilation of feedback received from the engaged researchers and key stakeholders and offers recommendations for consideration during the next round of CIHR-PHAC strategic planning for the Hepatitis C Research Initiative.

REPORT

contents

DESIGN & METHODS

In order to access the knowledge and experiences of researchers and stakeholders with an interest in Hepatitis C research, a multi-method approach was taken to data collection that combined two means of gathering data in which no one primary method determined the use of the others (1). This two-pronged approach utilized the same set of research questions in two different ways:

- virtual knowledge exchange sessions, *and*
- an online survey.

Design of the virtual knowledge exchange session integrated a focus group approach with informal knowledge exchange concepts to facilitate the building of trust through mutual respect as well as create a safe space for sharing. Technology was leveraged with all but one participant open to using the online platform.

The facilitators encouraged peer-to-peer dialogue rather than a strict "question and answer" approach thereby generating interactive data, a better understanding of participants' own agendas, and the opportunity to observe the co-construction of meaning in action (2). The facilitators observed that constructive conflict increased participation and enhanced the depth of the data received (3).

An online survey was also made available to compliment the knowledge exchange sessions and broaden the reach within a short data collection time frame (the data collection phase, for both approaches, occurred over 4 weeks). Online surveys can help to speed up, or add another dimension to the process of data collection and provides for anonymity, which can lead to greater openness (4).

The two data collection mechanisms had a common set of goals, which were communicated to potential participants through online discussion and survey data collection. These activities aimed to learn from the opinions (i.e. the practice-based knowledge and lived experience) of the Hepatitis C researcher / stakeholder community, and to inform enhancements to future Hepatitis C Research Initiative strategic planning; to the extent that:

- current and future research priority areas are identified;
- knowledge translation and commercialization capacity is discussed (including methods, incentives, support required, etc.); *and*
- support for capacity development for the next generation of researchers is explored.

DESIGN & METHODS

Research questions were informed by, and findings were organized in the following themes:

1. **Content and Evidence**, including research and practice-based experience as it relates to Hepatitis C research, including knowledge gaps.
2. **Context and Culture** in which the evidence is being implemented, such as the context of the Hepatitis research community, and the context of existing networks or stakeholders that could support future Hepatitis C research.
3. **Facilitation**, including best or preferred practices and effective strategies to support knowledge translation (or transfer) that are appropriate to the needs of the situation.

These elements integrate the best practice thinking from the knowledge management perspective, as noted by Dubois and Wilkerson (5) and the knowledge transfer/ translation and exchange perspective via the widely accepted Promoting Action on Research Implementation in Health Services (PARIHS) framework (6,7). These two perspectives are often, but not always, defined within the context of an organization; however, Hepatitis C research spans organizations and sectors. As such, the knowledge network perspective is also considered in our approach to the data collection, themed results and subsequent recommendations (8). By nurturing integration (9) and awareness of these three constructs and making a concerted effort to achieve balance across them, future Hepatitis C research programs can expect greater impact and outcomes. This triad of perspectives has informed the development and organization of the data collection questions and results outlined herein.

In addition to considering content, context and facilitation constructs in their design, the data collection questions were themed to align with, and build on those identified in the Survey of CIHR-Funded Hepatitis C Researchers completed in 2001 and 2003 respectively (10). These themes include:

Theme 1: Profile of Research Areas (current and future)

Theme 2: Knowledge Translation and Commercialization

Theme 3: Capacity Development

DESIGN & METHODS

process

- A list of 74 stakeholders and researchers interested in Hepatitis C were identified by CIHR and used as the list of potential participants in the practice-based knowledge and lived experience data collection process
- Invitations to participate in either the online knowledge exchange sessions or complete the electronic survey were sent together on February 3, 2011 and reminders were sent on February 11th, 15th and 17th respectively
- The survey closed at 5:00 p.m. EST on March 1, 2011
- Registration for the online knowledge exchange sessions closed at 12:00 a.m. (midnight) EST on February 17th, 2011
- Upon registration, participation instructions for the knowledge exchange sessions were sent to registrants
- Two 90 minute, 18 question online knowledge exchange sessions were conducted with pertinent stakeholders

Technology:

- E-mail invitations were designed, distributed and tracked using an email service, Mail Chimp
- The electronic survey was designed using online survey software, Fluid Surveys
- Online Knowledge Exchange Sessions were conducted using:
  - audio by toll-tree teleconference line & visual by Adobe Connect Pro

DATA ANALYSIS

To analyze the data received through the knowledge exchange sessions, responses were read and notes were made to reflect the knowledge exchange session discussion and facilitator observations. These notes became the basis for raw data collected. It should be noted that as a participant-checking step, the facilitators transcribed the notes in the moment, in the online meeting room, visible to all participants. Through this approach participants were able to suggest corrections or additions. The facilitators then made the necessary changes to the notes as prompted by participants to ensure their thoughts and opinions were accurately reflected. After finalizing the notes, the facilitators organized and arranged all answers in relation to questions, and removed identifiers. The facilitators then reviewed all qualitative data sources (knowledge exchange sessions and online survey responses), and coded and themed the data using standard qualitative analytical techniques (11, 12, 13, 14).

Quantitative data collected via the knowledge exchange sessions and the online survey (demographics, closed ended survey and poll questions) were aggregated and analysed within using Microsoft Excel.

FINDINGS

response rate

The invitation to participate in one of two online knowledge exchange sessions and/or an electronic survey was successfully delivered to 75 emails[1]. 10 stakeholders completed the electronic survey, eight participated in the first knowledge exchange session and six participated in the second knowledge exchange session for a total of 24 respondents. The response rate for this strategic review was 32%.

[1] 69 emails were delivered successfully; 5 emails bounced: 4 of the 5 email issues were resolved and these stakeholders were included in future communications; 2 additional emails were provided yielding a total of 75 up to date email addresses for potential respondents

FINDINGS

respondent profile

Figures 1 to 9 (n = 24)
*Figures 10 to 13 (n = 23)
one participant left a knowledge exchange session early and was unable to respond to questions 10 through 13

Figure 1.
Number of respondents by primary job title

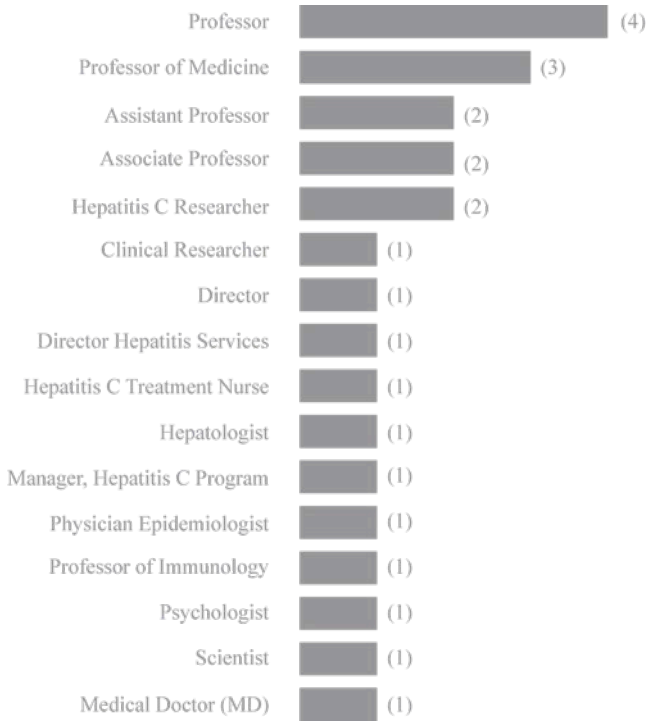
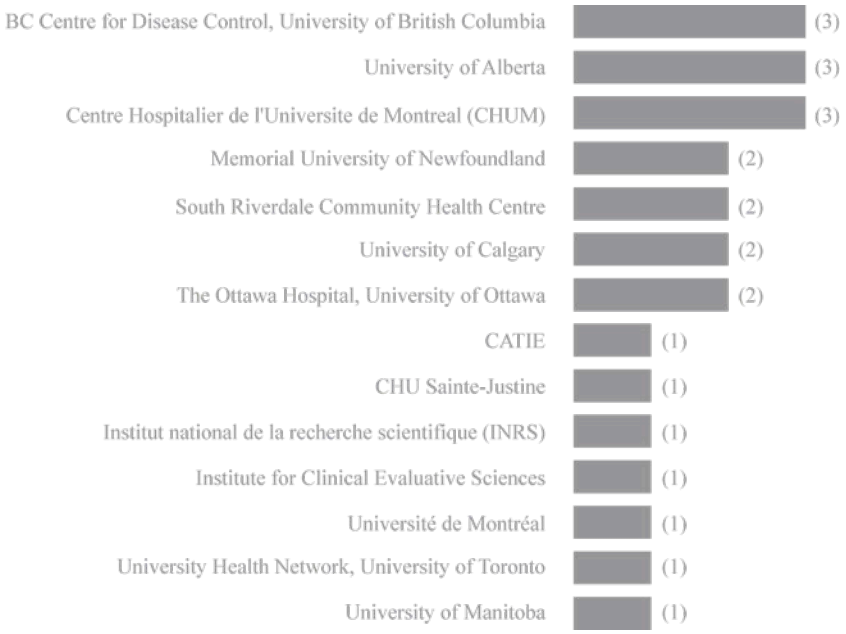


Figure 2.
Number of respondents by primary institution / organization



FINDINGS

respondent profile

Figure 3.
Number of respondents by Province / Territory

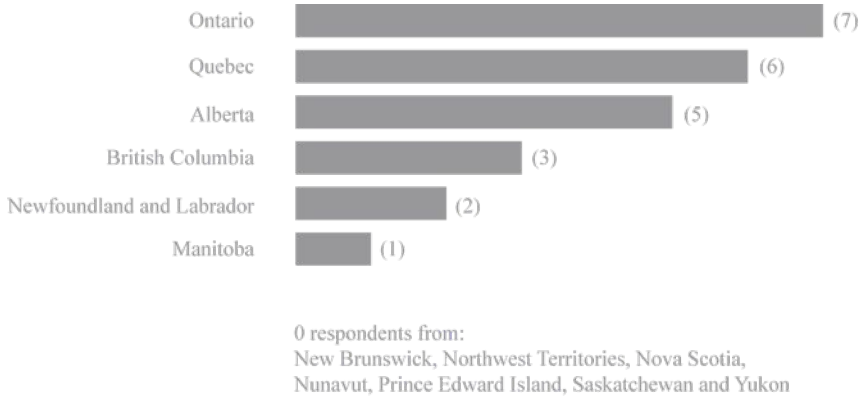
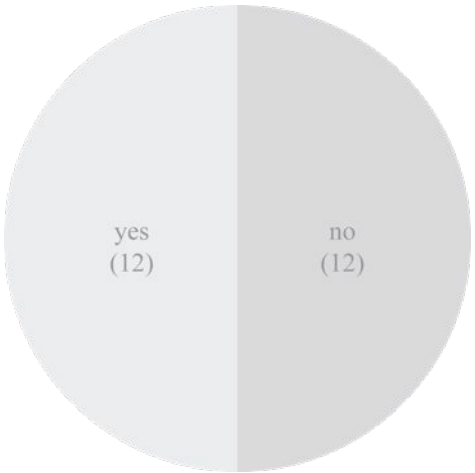


Figure 4.
Number of respondents who have received funding from the CIHR-PHAC Hepatitis C Research Initiative



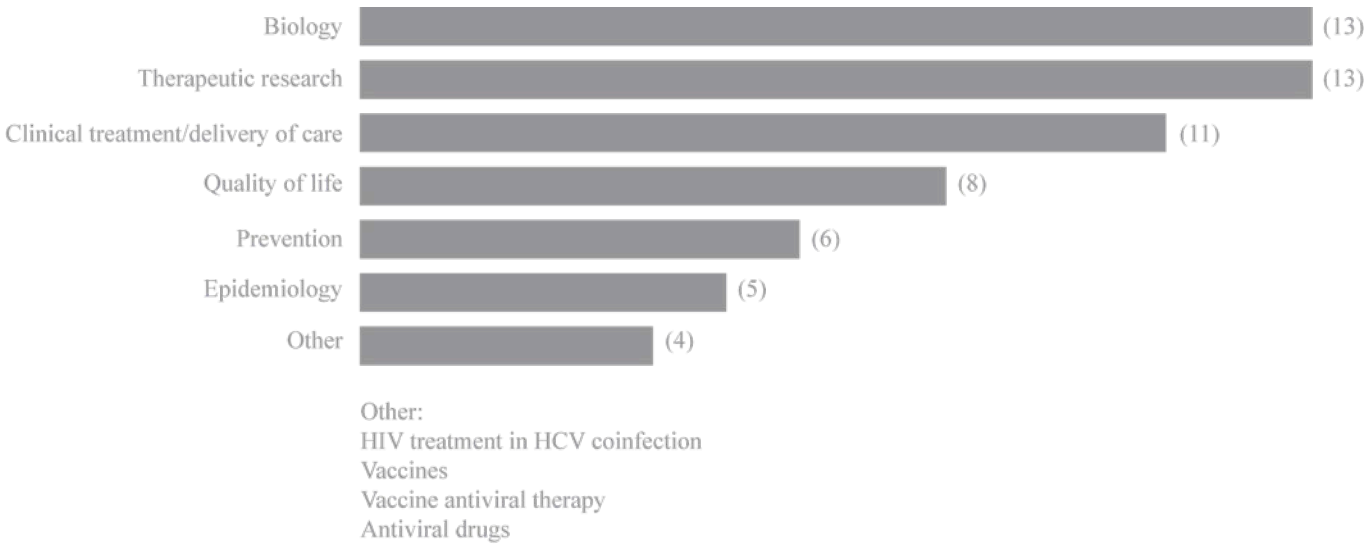
FINDINGS

theme 1

CONTENT

Profile of
Research Areas:
current and future

Figure 5.
Number of respondents by area of research/practice
Respondents chose all that applied



FINDINGS

theme 1

CONTENT

Profile of Research Areas: current and future

Survey respondents and knowledge exchange session participants (herein referred to as 'participants') identified three major gaps in the current funding profile. Firstly, participants identified a lack of funding for research related to high risk populations including those with co-morbidities such as HIV or liver disease, and marginalized populations such as aboriginals, recent immigrants, intravenous drug users, men who have sex with men and those living in rural/remote communities. Funding for research related to effective prevention (both vaccines and behavioural models) strategies was also identified as a gap. Finally, participants felt the knowledge associated with treatment and therapy outcomes and/or trends including those for high-risk populations, and for people with chronic HCV should be significantly strengthened.

In addition to these three gaps, the participants identified the following as their preferred funding priorities for any future Hepatitis C funding programs (funding themes align with those identified in the 2001 and 2003 survey of Hepatitis C researchers as published by CIHR (2009):

- **Biology**: vaccine and drug therapy development, research related to antivirals and immunobiology
- **Therapeutic research**: drug resistance, immune responses to treatment and secondary prevention strategies
- **Clinical treatment/delivery of care**: access to care for marginalized populations (particularly IDU) and supporting quality care practices
- **Epidemiology**: understanding high-risk populations and co-morbidities such as liver disease or depression
- **Prevention**: including specific issues such as mother-child transmission, prevention for high risk populations, behavioural interventions, application of consensus guidelines, and genetic testing
- **Quality of Life**: specifically understanding the burden of illness and whether or not treatment actually improves quality of life

The participants did not share a common perspective on weighting of funding. Some felt that equal funding for basic science and psycho-social research was inappropriate given the number of grants submitted for competition, while others felt that quality of life and prevention research as relates to behaviour was underfunded.

FINDINGS

theme 1

CONTENT

Profile of Research Areas: current and future

Subsequent to examining funding for current and future research topics, funding for research approaches (specifically participatory action research) was also discussed. Through this discussion, the majority of participants identified that participatory action research (PAR)[2] provides a valuable opportunity to engage the population of interest, build community capacity and gain insight as to how to develop policies, programs, and interventions that are informed by research-based evidence, practice-based evidence, and the knowledge from lived experience. The participants also identified that PAR can be effective in giving marginalized communities a voice and can break down barriers associated with stigma. There was a disparity of knowledge on the topic between basic science and psycho-social researchers which affected the ability of some to answer the questions about the extent to which PAR should be funded; the discussion centred around what it is and if/why it is valuable. As such, there were some questions related to participation criteria, systematic education and the outcomes associated with PAR. In summation, there were mixed feelings regarding the need to fund PAR:

> " [PAR should be] greatly [funded]; there is no point identifying what we need to do from our ivory towers if we don't explore what is acceptable and feasible from the perspective of people living with HCV "

> " I think, in general, that CIHR is over-emphasizing Request for Applications (RFAs) with community-based research initiatives "

CONTEXT

Profile of Research Areas: current and future

There appeared to be a lack of general awareness regarding the current funding priorities – researchers identified that they felt disconnected with the research outcomes of the last Hepatitis C funding initiative and were unsure as to where funds are being focused today. The researchers and stakeholders unanimously felt that a long-term, sustained funding commitment to Hepatitis C research would significantly contribute to closing the knowledge gaps and prevent losing the knowledge accumulated through established cohorts (i.e. resume commitment akin to the 1995-2005 grant initiatives). Further, there was a perceived lack of current support from funding agencies and government for Hepatitis C research, particularly when compared with HIV research funding relative to treatment options and prevalence.

The participants felt that Canada excels at collaborative, multi-disciplinary research; however, that more support is required to better link centres of excellence that have a long-term interest in following cohorts and linking clinical data (investing in capacity maintenance).

Finally, from the perspective of basic science, it was felt that PAR was less relevant when conducting basic research and that engagement with those outside the research team should come from clinical trials associated with drug intervention and that the ability to facilitate this process may be limited if the pharmaceutical company is involved.

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[2] Participatory Action Research (PAR) is the "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education, taking action or effecting social change." (15) It focuses on working with people to identify problems in practice, implement solutions, monitor the process of change, and assess outcomes. (16)

FINDINGS

theme 1

FACILITATION

Profile of Research Areas: current and future

The participants had several specific and practical suggestions that could lead to improved Canadian research and innovation outcomes in Hepatitis C including:

- Access to comprehensive and well-organized Hepatitis C information and evidence databases, tissues banks and blood samples;
- Opportunities to connect with others to exchange knowledge and experiences and mobilize research community (e.g. it was mentioned that the last Canadian Conference was in 2007); *and*
- Through enhanced connectedness, researchers could contribute to a strong and united political voice to advocate for HCV as a national funding priority

It was strongly felt that knowledge networks are needed to facilitate connections between knowledge producers and knowledge users and that adequate funds are needed to support these opportunities for mutual learning. In addition, a series of team grants that complement the national training program and knowledge exchange infrastructures would support the various centres across Canada in continued collaboration to reduce current duplication, foster integration, and coordinate national perspectives.

FINDINGS

theme 2

CONTENT

Knowledge Translation and Commercialization

Figure 6.
Number of respondents by knowledge translation activity
Respondents chose all that applied

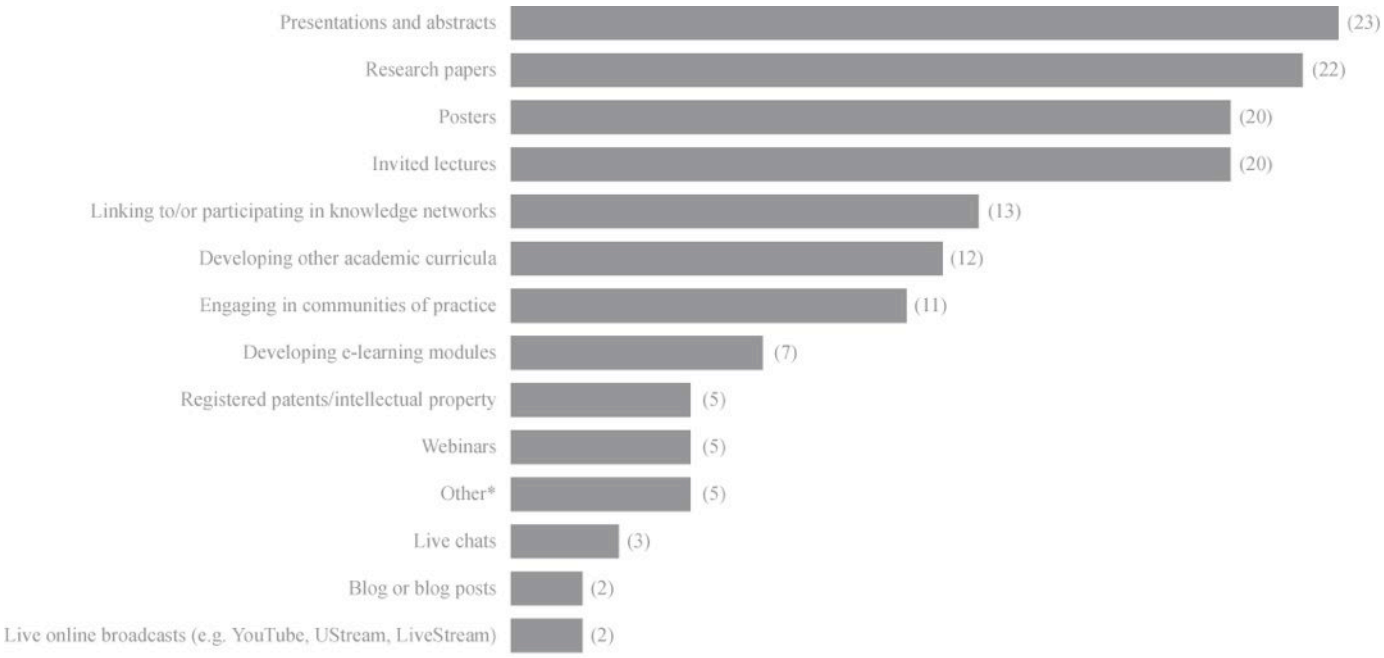
FINDINGS

theme 2

CONTENT

Knowledge Translation and Commercialization

Figure 7.
Number of respondents by methods used in the past, or currently in use to disseminate and or translate the knowledge generated from Hepatitis C research, at the end of a study
Respondents chose all that applied



FINDINGS

theme 2

CONTENT

Knowledge Translation and Commercialization

Figure 8.
Number of respondents by methods used in the past, or currently to include the intended users of the Hepatitis C research (or those could be affected by the research) throughout the research process
Respondents chose all that applied

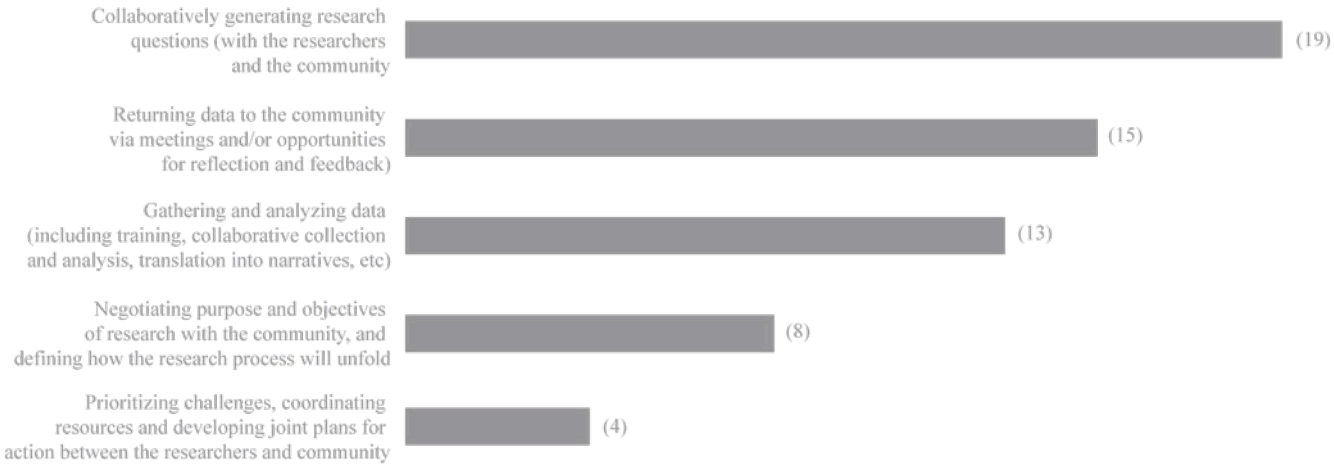


Figure 9.
Number of respondents who consider the commercial potential for their Hepatitis C research

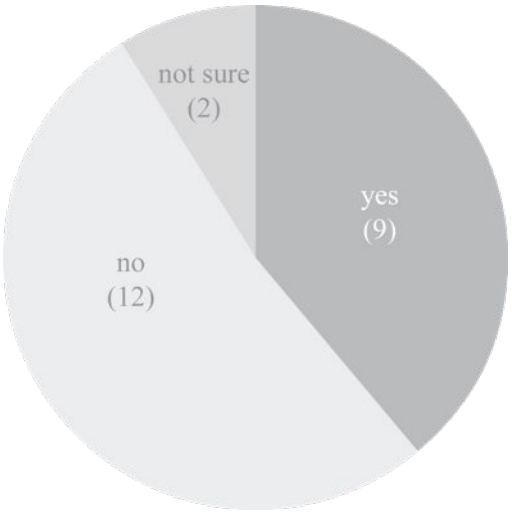
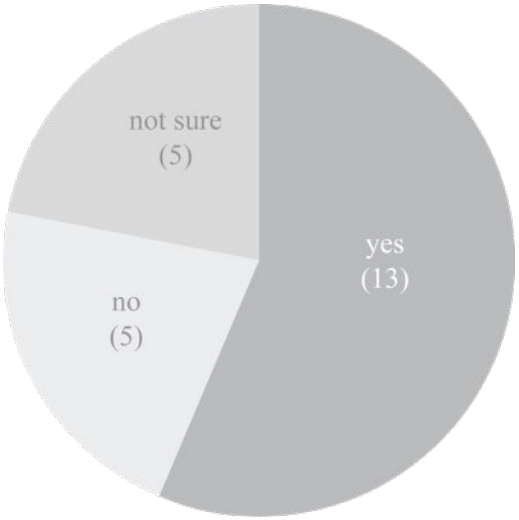


Figure 10.
Number of respondents who see value in considering the commercial potential for their Hepatitis C research



FINDINGS

theme 2

CONTENT

Knowledge Translation and Commercialization

Figure 11.
Number of respondents by participation in the CIHR Summer Institute

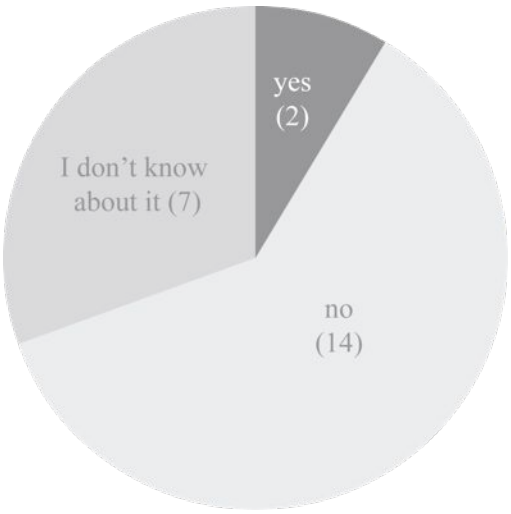


Figure 12.
Number of respondents by application for a CIHR Knowledge Translation Award

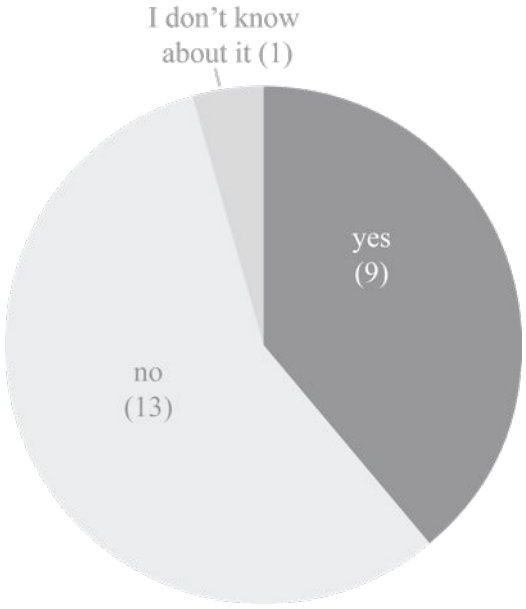
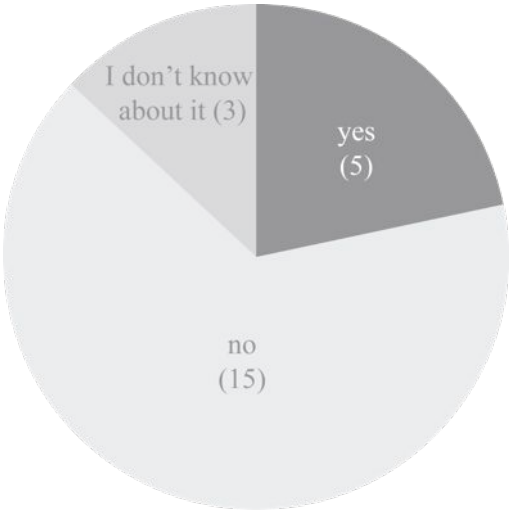


Figure 13.
Number of respondents by participation in a CIHR Café Scientifique



FINDINGS

theme 2

CONTENT

Knowledge Translation and Commercialization

As the participants embarked on the discussion around supports required to maximize the commercial potential of their research it became clear that many participants had concerns related to ownership of new knowledge and that, while most researchers do not have adequate access to support for commercialization, they felt that it was not a primary role for funding agencies like CIHR. The participants also identified that commercialization should not be the main issue, rather discovery and basic fundamental research; it was felt that good research will result in appropriate commercialization and spin-off companies. The current trend of commercialization via patenting of naturally occurring genes was identified as a questionable practice that could stall innovation and care.

In terms of knowledge translation, participants identified several disincentives and incentives. The disincentives included:

- Health protection issues and permissions in Canada
- Lack of reconciliation of research with policy
- Lack of access to previous and current innovation (e.g. lack of an infrastructure to support exchange and collaboration)
- Loss of ownership/intellectual property

Participants also identified several incentives for knowledge translation activities. It was noted that the sharing of ideas leads to global uptake of knowledge and international collaborative potential. Several participants also acknowledged that knowledge translation can result in a greater likelihood of promotion and tenure in academic institutions as diverse knowledge dissemination methods brings profile to the institution. Measured respect ("giving back") as a result of knowledge translation activities was felt to be able to heal rifts between researchers and marginalized communities and enable the building of trusting relationships for effective two-way dialogue and enhanced internal validity of findings that increases general awareness of key issues; ultimately leading to better health/patient outcomes.

It was felt that while knowledge translation is important, it is time consuming, expensive, and requires a unique set of skills that researchers may not have.

CONTEXT

Knowledge Translation and Commercialization

The participants commented on a perceived shift away from internal research in the pharmaceutical industry. Now these companies are actively looking for new ideas, to come from researchers (or groups of researchers working together). However, they identified that Canadian universities do not have access to the same kinds of funds as those in the US for patent protection, therefore translation to a commercial product is challenging (lack of adequate funding for commercialization was a common concern). Currently, according to participants, the only route to patent is through universities; however, many do not have the expertise or capacity required to adequately facilitate the process. The participants also acknowledged that there seems to be a significant emphasis by government on the importance of translation and commercialization and funding has shifted accordingly. There was a perception that there is an increasing emphasis by CIHR on finding value through patents; however, patents do not necessarily ensure value and use. Finally, the participants identified that there are not sufficient go-to places for information or support for KT and/or commercialization, and while CIHR's online resources on knowledge translation are helpful, they aren't enough to raise the capacity level of researchers to engage in knowledge translation in effective and resource efficient ways.

FINDINGS

theme 2

FACILITATION

Knowledge Translation and Commercialization

Participants felt that there is limited access to knowledge networks and a national "bank" (or other infrastructure) of knowledge/expertise would facilitate collaboration and expand personal and professional networks to support commercialization and knowledge translation. It was identified that promotion of the new knowledge and support navigating relations with large pharmaceutical companies rather than direct involvement in the commercialization of knowledge would be an appropriate role for CIHR (and other funding agencies). Consistent and adequate funding is needed for institutions (such as university offices for technology transfer) to support translation and commercialization efforts including patent protection. In addition, CIHR knowledge translation grants and development initiatives like Café Scientifique enhance capacity and should be continued.

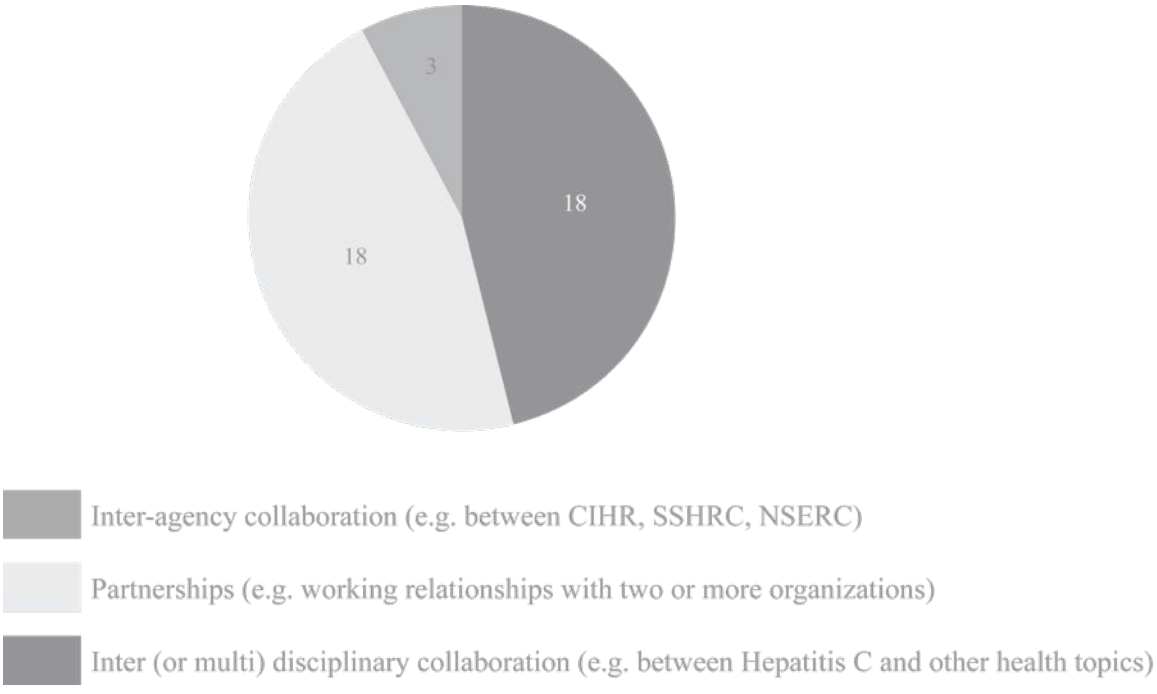
FINDINGS

theme 3

CONTENT

Capacity Development

Figure 14.
Number of respondents by partnership / collaborative activities in relation to current Hepatitis C research
Respondents chose all that applied



FINDINGS

theme 3

CONTENT

Capacity Development

The discussion associated with capacity development brought to light that universally, participants were engaged in a wide variety of activities or roles that develop capacity in new researchers such as teaching, tutoring, supervising and training of graduate and post graduate students and linking them with the existing knowledge base. However, they also identified that capacity building is challenging when funding and awards programs are ending and grant renewal rates are low. The National Canadian Research Training Program (NCRTP) in Hepatitis C was commonly cited as a successful source of support for strategic training initiatives (several of the respondents were directly involved in the program).

CONTEXT

Capacity Development

It was generally expressed that Canada is good at coming up with new programs but poor at maintaining them when they are successful (e.g. the CIHR-Health Canada HCV program was effective but did not continue). As a result, researchers who are mid-career seem to have greater difficulty getting grants than early researchers; **"first renewal is more difficult than first grant"** which leads to a detrimental lack of security regarding funding. The participants felt that this not only affects current researchers but also kept students from pursuing research in Hepatitis C given a perceived lack of job security and compensation incentive. An additional contextual pressure cited as affecting the ability to build capacity in early researchers include taxes on awards received by post doctoral fellows which was felt to have a significant impact on the sustainability of programs and may have a negative impact on Canada's future science.

FACILITATION

Capacity Development

As a result of this discussion, the participants felt that there was a need for more mid-career awards to sustain investments in innovations and complement the work of new researchers. It was identified that programs like the NCRTP need to continue. Participants also felt that a research network could promote the development of collaborative team projects across Canada resulting in integrated centres of excellence and outstanding research as illustrated by other disease areas.

Consistent, long-term, sustainable grant money for early and mid-career researchers was identified as being needed to ensure innovation in Canada is continued and that a career as a scientist is "liveable". Funding in the form of team grants and knowledge exchange networks, within and across disciplines, would help accelerate innovation and knowledge sharing and support capacity development.

It was also suggested that accelerated programs for known issues related to Hepatitis C, based on widely agreed upon scientific evidence, would better support innovation and subsequent translation.

RECOMMENDATIONS

Given that the purpose of this project was to engage current Hepatitis C researchers and stakeholders for their opinions on issues related to future Hepatitis C research, the following recommendations are a starting point for informing subsequent CIHR-PHAC Hepatitis C Research Initiative strategic planning. These recommendations should be considered within the context of other data (e.g. CIHR and PHAC organizational priorities, external literature, international Hepatitis C research programs, etc.) to ensure a comprehensive approach is taken to inform the future CIHR-PHAC Hepatitis C Research Initiative strategic planning.

The following eight (8) recommendations have been taken directly from the data received by the 24 participants who opted to engage in either the opportunities for knowledge exchange or the online survey. The rationale for each recommendation can be found in the "Findings" section of this report.

1. Funding streams should follow those from the 1999 – 2004 CIHR-Health Canada Hepatitis C initiative including (as defined by the participants):

    - **Biology:** vaccine and drug therapy development, research related to antivirals and immunobiology
    - **Therapeutic research:** drug resistance, immune responses to treatment and secondary prevention strategies
    - **Clinical treatment/delivery of care:** access to care for marginalized populations (particularly IDU) and supporting quality care practices
    - **Epidemiology:** understanding high-risk populations and co-morbidities such as liver disease or depression
    - **Prevention:** including specific issues such as mother-child transmission, prevention for high risk populations, behavioural interventions, application of consensus guidelines, and genetic testing
    - **Quality of Life:** specifically understanding the burden of illness and whether or not treatment actually improves quality of life

    with a special focus on three overarching themes:

    - **High risk populations**
    - **Effective prevention strategies**
    - **Treatment and therapy outcomes and/or trends**

2. Given the divergent opinions and ideas regarding the relative weighting of funding per research stream and the value of participatory action research as a method, it is recommended that **more research and consultation** with the Hepatitis C research community take place prior to making decisions related to future CIHR-PHAC initiatives.

3. Future CIHR-PHAC initiatives should include **long-term, sustained funding** both for the research initiative itself and for the individual grant awards to maintain capacity whilst continuing to invest in innovation, specifically providing grant opportunities for both early and mid-career researchers.

4. Future CIHR-PHAC initiatives should consider **team grant opportunities** to facilitate continued collaboration between researchers, reduce the perceived current amount of duplication, foster integration, and coordinate national perspectives so the Hepatitis C research community can speak with a united voice.

5. Future CIHR-PHAC initiatives should indirectly **support commercialization by enhancing the capacity of academic institutions** rather than direct involvement in the commercialization process. Support for commercialization could be offered by creating or providing access to skill building opportunities by connecting both academic institutions and researchers with experience in the commercialization process, as well as through CIHR grant funding opportunities by specifying that portions of grant funds, when applicable, be allocated to support researchers commercialization efforts.

6. Future CIHR-PHAC initiatives should **continue to support knowledge translation (KT)** through grants and grant criteria related to KT and also provide access to coaches, mentors and/or peers with experience related to KT skill building (e.g. other researchers, knowledge translation professionals, etc.), help build personal and professional networks and compliment the information CIHR currently makes available about KT. Finally, it is recommended that research grant timelines adequately take into account the time required to engage in effective integrated knowledge translation, end-of-grant knowledge translation or participatory action research, etc.

7. CIHR, in partnership with PHAC, should engage in **continuous environmental scanning** in order to understand contextual factors that affect capacity development and maintenance and adjust Hepatitis C funding programs accordingly.

8. CIHR, in partnership with PHAC, should **develop and implement a knowledge exchange infrastructure**, including access to people, resource databases, and resource links for Hepatitis C researchers to support continuous learning, foster innovation and collaboration and to establish new partnerships through the development of personal and professional networks.

REFERENCES

1. Morgan DL. Focus groups as qualitative research (2nd ed.). Thousand Oaks, CA: Sage; 1997.
2. Wilkinson S. Focus groups in health research: exploring the meanings of health and illness. J Health Psychol. 1998;3(3): 329-348.
3. Greenfield G, Campbell, J. Communicative practices in online communication: a case of agreeing to disagree. JOCEC. 2006;16(3-4): 267-277.
4. Edmunds H. The focus group research handbook. Lincolnwood, IL: NTC Business Books/Contemporary Publishing; 1999.
5. Dubois N, Wilkerson T. Knowledge management: background paper for the development of a knowledge management strategy for public health in Canada. Background paper shared at Knowledge Management in Public Health: Exploring Culture, Content, Process and Technology Conference; 2008 Nov 3-4 Hamilton, Canada.
6. Kitson A, Harvey G, McCormack B. Enabling the implementation of evidence based practice: a conceptual framework. QHC.1998;7:149-158.
7. Rycroft-Malone J, Harvey G, Kitson A, McCormack B, Titchen A. Getting evidence into practice: ingredients for change. Nurs Stand. 2002;16(37):38-43.
8. Consoli D, Ramlogan R. Scope, Strategy and structure: the dynamics of knowledge networks in medicine. MPRA Paper 12791, University Library of Munich, Germany. 2009.
9. Heeseok L, Byounggu C. Knowledge management enablers, processes, and organizational performance: an integrative view and empirical examination. J Manage Inform Syst Archive 2003;20(1):179-228.
10. Survey of CIHR-Funded Hepatitis C Researchers. Canadian Institutes of Health Research; 2009 [updated 16 March 2009; cited 12 March 2009]. Available from: http://www.cihr.gc.ca/e/38861.html
11. Creswell JW. Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage; 1999.
12. Hammersley M, Atkinson, P. Ethnography: Principles in Practice, (2nd ed.). London, Routledge; 1995.
13. Lincoln YS, Guba, EG. Naturalistic Inquiry. Newbury Park, CA: Sage Publications; 1985.
14. Merriam SB. Case study research in education: A qualitative approach. San Francisco: Jossey-Bass Publishers; 1988.
15. Green LW, George MA, Daniel M, Frankish CJ, Herbert CJ, Bowie WR, et al. Study of participatory research in health promotion: review and recommendations for the development of participatory research in health promotion in Canada. Vancouver, BC: University of British Columbia report for the Royal Society of Canada; 1995.
16. Ramsden VR and Cave AJ (2002). Hypothesis: The Research Page. Participatory methods to facilitate research. Canadian Family Physician; Vol 48, 548-549.

APPENDIX

Research Questions

Theme 1: Profile of Research Areas (current and future)

1. Current areas of Hepatitis C research – where you have or are at present, spending your time (please indicate all that apply).
    - Biology
    - Therapeutic research
    - Clinical treatment/delivery of care
    - Epidemiology
    - Prevention
    - Quality of life
    - Other

2. Comment on any gaps that you think exist in the current funding profile.
3. Comment on the extent to which you think participatory action research should be funded in the future. (Optional follow-up: What supports do you think would be necessary to better enable this type of research?)
4. In your opinion, what should the Hepatitis C research funding priorities be for the next 10 years and why?

Theme 2: Knowledge Translation and Commercialization

1. When you engage in knowledge translation, you do which of the following (please indicate all that apply)

    - **Synthesis** - Synthesis, in this context, means the contextualization and integration of research findings of individual research studies within the larger body of knowledge on the topic.

    - **Dissemination and public outreach** – Dissemination/public outreach involves identifying the appropriate audience and tailoring the message and medium to the audience.

    - **Exchange** - The exchange of knowledge refers to the interaction between the knowledge user and the researcher, resulting in mutual learning.

    - **Apply knowledge in an ethically-sound way** - Ethically-sound KT activities for improved health are those that are consistent with ethical principles and norms, social values, as well as legal and other regulatory frameworks - while keeping in mind that principles, values and laws can compete among and between each other at any given point in time.

2. Please indicate which methods you have used in the past, or are currently using to disseminate and or translate the knowledge generated from your Hepatitis C research, at the end of your study:
    - Presentations and abstracts
    - Posters
    - Invited lectures
    - Research papers
    - Registered patents/intellectual property
    - Webinars
    - Blog posts
    - Pod casts
    - Live online broadcasts (e.g. YouTube, UStream, LiveStream)
    - Live chats
    - Linking to/or participating in knowledge networks
    - Engaging in communities of practice
    - Developing e-learning modules

- Developing other academic curricula
- Other

3. Please indicate the methods you have used in the past, or are currently using to include the intended users of your Hepatitis C research (or those could be affected by your research) throughout the research process:

   - Negotiating purpose and objectives of research with the community, and defining how the research process will unfold
   - Collaboratively generating research questions (with the researchers and the community)
   - Gathering and analyzing data (including training, collaborative collection and analysis, translation into narratives, etc)
   - Returning data to the community via meetings and/or opportunities for reflection and feedback)
   - Prioritize challenges, coordinate resources and develop joint plans for action between the researchers and community

   *Anchors based on: Ramsden VR and Cave AJ (2002). Hypothesis: The Research Page. Participatory methods to facilitate research. Canadian Family Physician; Vol 48, 548-549.

4. When submitting grants for new Hepatitis C research projects, do you consider the commercial potential for that research?

   - Yes
   - No
   - I'm not sure

5. Do you see value in considering the commercial potential for your Hepatitis C research?

   - Yes
   - No
   - I'm not sure

6. If you would like to consider the commercial potential of your Hepatitis C research, what might you need to do so?
7. What, if any, incentives are there for you to translate your Hepatitis C research? Are there any disincentives?
8. What are your go-to places for information or support in your knowledge translation and/or commercialization activities?
9. Have any of you ever participated in the CIHR Summer Institute?

   - Yes
   - No
   - I don't know about it

10. Have you ever applied for a CIHR Knowledge Translation Award?

    - Yes
    - No
    - I don't know about it

11. Have you ever participated in a CIHR Café Scientifique?

    - Yes
    - No
    - I don't know about it

Theme 3: Capacity Development

1. Comment on the extent to which you currently support capacity development in the next generation of Hepatitis C researchers?
2. What support would help you develop capacity in the future?
3. Do any of your current Hepatitis C research activities involve any of the following (please indicate all that apply):

   - Inter-agency collaboration (e.g. between CIHR, SSHRC, NSERC)

- Inter (or multi) disciplinary collaboration (e.g. between Hepatitis C and other health topics)
- Partnerships (e.g. working relationships with two or more organizations)

Survey Question Only:

Have you received funding from the CIHR-PHAC Hepatitis C Research Initiative?

- Yes
- No
- If yes, please use the space below to share your thoughts on how to enhance this Research Initiative.