

Turning Research into Action

A Review of the Public Health Agency of Canada (PHAC)
and
the Canadian Institutes of Health Research (CIHR)
Research Initiative on Hepatitis C

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The views therein are those of the authors and do not necessarily reflect those of the Public Health Agency of Canada or the Canadian Institutes of Health Research.

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EXECUTIVE SUMMARY

In 1999, the Hepatitis C Prevention, Support and Research Program (Health Canada) and the Medical Research Council of Canada launched a joint initiative to fund hepatitis C research for a five-year period beginning in fiscal year 1999/00 and ending in fiscal year 2003/04. The Hepatitis C Program is now situated within the Public Health Agency of Canada (PHAC), while the Medical Research Council has become the Canadian Institutes of Health Research (CIHR). This original partnership was subsequently renewed for two consecutive one-year periods terminating in fiscal year 2005/06 and was known as the PHAC/CIHR Joint Research Initiative on Hepatitis C. Over the seven-year period of the joint initiative, \$16.5 million dollars Canadian has been committed to research operating grants, \$1.7 million to salary awards and \$1.1 million to training awards.

In order to evaluate the effectiveness of the joint initiative, PHAC and CIHR commissioned a review of projects funded through the initiative. The objective of the review was to describe the achievements of Canadian hepatitis C researchers and to measure the initiative's impact in a number of domains.

An email request to participate in the review was sent by CIHR staff to researchers funded through the initiative, namely:

- Principal Investigators of research projects funded through research operating grants;
- Investigators receiving salary awards;
- Trainees receiving fellowships; and
- Students receiving doctoral research awards.

In order to provide a truly comprehensive perspective on the breadth and depth of funding of hepatitis C research in Canada, other projects supported by PHAC and CIHR but funded outside of the joint initiative were also examined. The invitation to contribute to the review therefore was also sent to the principal investigators of:

- The Social and Behavioral Research Issues in HIV/AIDS and Hepatitis C: Interdisciplinary Capacity Enhancement (ICE) Team Grants Program (HIV/AIDS and HCV ICE Program); and
- The National Hepatitis C Research Training Program Grant, also known as the National Canadian Research Training Program in Hepatitis C.

Thirty-nine (66%) of the 59 researchers contacted participated in a telephone survey and twenty-two (56%) of these respondents completed a follow-up email survey.

In order to document the impact of the initiative on dissemination activities in the scientific literature domain, publications by principal investigators and co-investigators funded through the joint initiative, the HIV/AIDS and HCV ICE Program, and/or the National Hepatitis C Research Training Program Grant were examined at two points in time. The first measurement point, the years 1997 to 1999, was the baseline measure corresponding to the two years immediately before the implementation of the initiative. The second

measurement point, the years 2003 to 2005, was the follow-up measure.

Main Findings

- Initiative-funded HCV researchers are collaborating at a much greater level and with a greater number of disciplines compared with either the pre-initiative period or the start of their research career. Eighty-one percent stated that they were collaborating either more or much more, and a slightly lower proportion, 69%, stated that they were collaborating with more or many more disciplines compared with either the pre-initiative period or the start of their research career.
 - Engagement in this enhanced collaboration positively impacted research design and methodology, research support and dissemination of results.
 - The capacity building impact of HCV-funded researchers was high: 73% had supervised a graduate or post-doctoral student in the HCV domain and 92% had supervised other research personnel. In total, 126 students had received their primary supervision from a researcher funded under the PHAC/CIHR Research Initiative on Hepatitis C, the HIV/AIDS and HCV ICE Program and/or the National Hepatitis C Research Training Program Grant.
 - Impact through knowledge dissemination was also very high. Nearly all researchers had presented their HCV-related findings as either an oral presentation (82%) or poster presentation (90%) at a scientific congress, to a professional association, or at a national or an international conference. A total of 369 oral presentations and 247 poster presentations were made on the research findings both within and outside Canada.
 - Knowledge translation also took place through the publication of 72 peer-reviewed journal articles, three books, 11 book chapters, and 31 reports.
 - The number of journal articles accepted for publication increased substantially between the years immediately prior to the commencement of the joint initiative and the two years ending in March 2006. The percentage increase in the number of publications between the two time periods was 223%.
 - The percentage increase in the number of times these journal articles were cited by other authors in the two-year pre-initiative period compared with the two years ending in March 2006 was 190%.
 - Four main areas of challenge in conducting HCV-related research in Canada were identified: fiscal constraints; onerous ethical and clinical trials guidelines; overcoming a perceived emphasis on bio-medical and clinical research; and overcoming a perceived lack of interest by the public (including decision makers) in the group with the highest rates of hepatitis C infection.
 - Increased funding and increased personnel were considered essential to respond to the identified implementation challenges. Most particularly, researchers were overwhelmingly in favour of a reinstatement of the PHAC/CIHR Research Initiative on Hepatitis C to encourage and sustain Canadian HCV research.
 - The major challenges identified in disseminating HCV-related research in Canada were a perceived lack of support for dissemination activities; a lack of acknowledgement of the severity and therefore
-

visibility of HCV in comparison with HIV; and the perceived lack of public interest in the health of injection drug users, the population most affected by HCV.

- Enhanced funding to facilitate dissemination, protected time for dissemination activities, and national networking initiatives were suggested responses to the dissemination challenges identified.
 - Revisions to research funding opportunities and procedures, the creation of national networking initiatives, and a sustainable long-term program of research emphasising collaboration between researchers from all disciplines engaged in HCV research and enriched by a long-term funding program of resource allocation, training and resource development were identified as the key interventions for translating the initiative-funded research into action.
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1.0 INTRODUCTION

In 1999, the Hepatitis C Prevention, Support and Research Program (Health Canada) and the Medical Research Council of Canada launched a joint initiative to fund hepatitis C research for a five-year period beginning in fiscal year 1999/00 and ending in fiscal year 2003/04. The Hepatitis C Program is now situated within the Public Health Agency of Canada (PHAC), while the Medical Research Council has become the Canadian Institutes of Health Research (CIHR).

The objectives of this venture, known as the PHAC/CIHR Joint Research Initiative on Hepatitis C were:

- To effectively and efficiently select and fund a broad spectrum of scientifically meritorious and relevant research focused on the biology of the hepatitis C virus (HCV), the pathogenesis and epidemiology of HCV, screening and diagnostic technology, the natural history of the disease, treatment strategies, quality of life issues, and preventive measures, including a vaccine;
- To establish policies and priorities for the selection of investigator-initiated projects and for the launch of special initiatives;
- To expand Canada's research capacity and productivity on HCV through training programs; and
- To encourage the dissemination and uptake of research findings through the funding of special initiatives, workshops, colloquia, or other events designed to promote the synthesis of findings or to facilitate the uptake of research results by clients.

The Hepatitis C Program, and thereby its commitment to the joint hepatitis C research initiative, was scheduled to terminate in 2004. However in 2003, the then Minister of Health the Honorable Anne McClellan, made a commitment to provide additional funding for fiscal years 2004/05 and 2005/06. This commitment was to maintain the momentum that this partnered initiative had generated over the past four years and to ensure that multi-year projects started in 2003/04 would be supported at least until the end of the fiscal year 2005/06. Through this commitment the joint initiative was renewed for two one-year periods ending in fiscal year 2005/06.

In total, sixty-four research grants were awarded through the joint initiative. The research projects funded through these grants span the four pillars of CIHR research: biomedical research, clinical research, health services research and population health research. To date (March 2006), the total commitment to these research grants for the period 1999/00 to 2005/06 has been \$16.5 million Canadian.

In addition, five salary awards (three at the Investigator level, and two at the New Investigator level) and twelve training awards (nine fellowships, two doctoral research awards and one MD/PhD studentship) were granted through this initiative. The total commitment to these salary awards for the period 1999/00 to 2005/06 has been \$1.7 million Canadian. The total commitment to date to the training awards program for the same period 1999/00 to 2005/06 has been \$1.1 million Canadian.

Additional hepatitis C research has been undertaken in Canada as a result of funding awarded through other strategic and open CIHR programs. Two of these programs in particular - the National Hepatitis C Research Training Program Grant and the Social and Behavioral Research Issues in HIV/AIDS and Hepatitis C:

Interdisciplinary Capacity Enhancement Team Grants - were highly supported in principle by the Hepatitis C Program. However, these two programs of research funding could not be fully supported financially through the joint initiative due to insufficient funding. In view of the limited funds, the financial support from the joint initiative for these programs was limited to one year of funding in fiscal year 2003/04 for the National Hepatitis C Research Training Program Grant (\$200,000 from PHAC and \$100,000 from CIHR).

The total funding commitment from the Public Health Agency of Canada to the PHAC/CIHR Research Initiative on Hepatitis C for the period 1999/00 to 2005/06 was more than \$12 million. Over this same period of time, CIHR contributed approximately \$9 million to grants and awards funded through the joint research initiative and these two other programs. Other partners, such as industry partners, contributed \$0.9 million to these same projects.

An additional \$11.9 million was committed by CIHR to the hepatitis C grants and awards offered under other CIHR programs. In some cases this contribution was made with other funding partners such as industry. CIHR has also made a commitment to continue support to those grants and awards funded under the joint initiative whose terms extend beyond the joint initiative end date of March 31, 2006.

In order to evaluate the effectiveness of this joint investment in hepatitis C research, PHAC and CIHR commissioned a review of the projects funded through the PHAC/CIHR Research Initiative on Hepatitis C. The objective of the review was to capture the accomplishments of Canadian hepatitis C researchers and to measure the impact of the PHAC/CIHR Research Initiative on Hepatitis C in a number of domains.

This report documents the outcomes of that review.

2.0 METHODS

2.1 Advisory Committee

In order to ensure that all aspects of hepatitis C research were considered and the patient perspective included, an Advisory Committee was established to oversee the design and implementation of the review. The Committee comprised researchers, patient group representation, PHAC staff and CIHR representatives and provided advice and guidance on the project design and methodology and reviewed an earlier draft of this report. The membership of the Advisory Committee is detailed in Appendix I.

2.2 Participant Recruitment

An email request to participate in the review of the initiative was sent by CIHR staff to the following four groups of researchers funded through the PHAC/CIHR Research Initiative on Hepatitis C:

- Principal investigators of research projects funded through research operating grants;
 - Investigators receiving salary awards;
 - Trainees receiving fellowships; and
-

- Students receiving doctoral research awards.

In addition, in order to provide a comprehensive perspective on Canadian HCV funding, and because the Hepatitis C Program supports the objectives of other programs to which it cannot provide direct funding support, the following two groups were also contacted:

- Principal investigators of research projects funded through the Social and Behavioural Research Issues in HIV/AIDS and Hepatitis C: Interdisciplinary Capacity Enhancement (ICE) Team Grants Program (HIV/AIDS and HCV ICE Program); and
- The principal investigator of the National Hepatitis C Research Training Program Grant (also known as the National Canadian Research Training Program in Hepatitis C).

The email request outlined the parameters of the review, requested participation in a telephone survey and permission to pass contact details to the researcher conducting the telephone survey. In giving their consent to be contacted for the sole purpose of the survey, researchers were also asked to indicate a preferred time for completion of the survey.

In order to maximize participation, CIHR staff sent the email request to each of the 64 researchers on two separate occasions and follow-up phone calls from CIHR staff were also made to each researcher on two occasions.

2.3 Survey Instrument: Telephone Survey

With input from the Advisory Committee, a questionnaire was developed which captured the following seven domains: respondent profile, research profile and impact through collaboration, impact through capacity building, impact through knowledge dissemination, impact through knowledge translation, respondents' perception of the impact of their joint initiative-funded research, and the respondents' perception of Canadian HCV funded research.

Respondent profile

The objectives of the questions in this section were:

- to characterize the research status and specialization of the respondent;
- to characterize the research focus and research location of the respondent; and
- to determine the extent and nature of all HCV-related research funding held by the respondent either through CIHR or other funding bodies.

Impact through collaboration

The objectives of the questions in this section were to characterize the extent and nature of the respondents':

- collaboration with other researchers, health care professionals, policy makers, program managers and people living with HCV in the formulation and design of their funded research;
 - collaboration with other researchers, health care professionals, policy makers, program managers and
-

- people living with HCV in the implementation of their research;
- perceptions of any impacts of this collaboration; and
- perceptions of any challenges experienced through the collaboration process.

Impact through capacity building

The objectives of the questions in this section were to characterize the extent of the respondents’:

- supervision / advising of graduate research students and post-doctoral students studying primarily in the HCV area; and
- supervision / advising of members of an HCV research team.

Impact through knowledge dissemination

The objectives of the questions in this section were to characterize the extent and nature of:

- published peer-reviewed articles / research papers resulting from research funded under the joint initiative;
- books or book chapters resulting from research funded under the joint initiative;
- published reports resulting from research funded under the joint initiative;
- patents and licenses resulting from research funded under the joint initiative;
- presentations (oral and poster) of research results to scientific conferences and professional bodies;
- presentations of research results to community organizations and people living with HCV; and
- media presentations (print, TV, radio) of research results at the local, provincial, national or international level.

Impact through knowledge translation

The objectives of the questions in this section were to characterize the extent and nature of:

- presentations / discussions of research results with policy makers at the regional, provincial, and federal level; and
- presentations / discussions of research results with fiscal policy makers at the regional, provincial, and federal level.

Respondents’ perception of the impact of their funded research

The objectives of the questions in this section were to characterize the respondents’:

- perceptions of the level of impact resulting from their research funded through the joint initiative (e.g. reduced suffering, increased years of healthy life);
- knowledge of the application of the research findings from their funded hepatitis C research; and
- knowledge of other research initiatives resulting from their funded hepatitis C research.

Respondents’ perception of Canadian funded HCV research

The objectives of the questions in this final section were to characterize the respondents’ perspectives on the:

- major challenges in conducting HCV-related research;
- major challenges in disseminating the results of their HCV-related research; and
- the further work that is required to translate research into action.

The questionnaire was amended for researchers receiving training awards. For research trainees, additional questions covered their current employment or educational status and the relationship to their funded training in the HCV domain. The questionnaires used in the telephone survey of researchers and research trainees are available on request.

Data entry of questionnaire responses was completed using SPSS 11.0. Verification of the entered data was completed by comparing all records against the original questionnaire responses. The statistical analysis of the collected data was performed using SPSS 11.0.

2.4 Survey Instrument: Email Survey

On completion of the telephone survey, researchers were also asked to complete a short email survey designed in collaboration with the Advisory Committee. This survey asked researchers to describe their research in lay terms, to describe their most significant research finding and to describe in detail challenges that they may have experienced in conducting HCV research in Canada. In addition, researchers were asked to indicate their permission to have details of their successful research findings published in CIHR or PHAC reports.

The email survey is available on request.

2.5 Bibliometric Analysis

In order to characterize the dissemination of Canadian HCV research results through the publication of manuscripts in scientific journals, an examination of publications by principal investigators and co-investigators funded through the joint initiative, the HIV/AIDS and HCV ICE program and/or the National Hepatitis C Research Training Program Grant was undertaken at two points in time. The first measurement point, the years 1997 to 1999, was the baseline measure corresponding to the two years before the implementation of the initiative. The second measurement point, the years 2003 to 2005, was the follow-up measure. In addition, in order to obtain a comprehensive picture of the degree to which these researchers have published, the publication search captured information on all articles published from 2000 to 2005.

Reference library technicians in the Health Sciences Library in the Faculty of Medicine at the University of Ottawa conducted the search using the electronic Web of Science database². The search strategy involved entering the names (last name and initial(s)) of the principal Investigators (n=64) and co-investigators (n=85) and the term “hepatitis C”. The search strategy was limited to scholarly journals. The total number of journal publications for each investigator was determined, along with the year of publication, the title of the journal and its respective journal impact factor (JIF). A journal was classified as *international* if it was listed as a Medical Sciences journal published outside of Canada in Ulrich’s Periodicals Directory³.

² ISI, Web of Knowledge, 2005.

³ Ulrich’s Periodicals Directory, 2006

In addition, the number of articles subsequently citing each original piece of work was documented (excluding self-citations), along with the year of publication, the title of the journal and its respective impact factor. This citation analysis was restricted to citations within two years of the publication date of the original article.

2.6 Information on Other National Hepatitis C Research Funding Programs

In order to situate the Canadian PHAC/CIHR Joint Research Initiative on Hepatitis C within the context of activities to support HCV research existing in other developed countries, the terms ‘hepatitis C’, and ‘Australia’ or ‘United Kingdom’ or ‘United States’ were entered into the Google search engine. Results of each search were reviewed and information detailing national hepatitis C research strategies or funding programs was extracted. The same terms were also entered into the PubMed search engine and resultant publications were examined for additional descriptions of national funding.

2.7 Ethical Approval

Ethical approval to conduct this review was granted by the Ottawa Hospital Research Ethics Board.

3.0 RESULTS

3.1 Response Rate

The response rate to the telephone survey was 66%.

Among the 64 researchers who received funding either through the PHAC/CIHR Research Initiative on Hepatitis C, through the HIV/AIDS and HCV ICE Program or through the National Hepatitis C Research Training Program Grant, current contact information could not be obtained for five researchers.

Among the 59 researchers with current contact information and thus eligible to participate:

- 13 researchers did not reply to two CIHR emails and two follow-up phone calls soliciting participation;
- 3 researchers declined to participate;
- 4 researchers were not available at the time of the survey; and
- 39 researchers completed the telephone survey.

The response rate to the email survey was a little lower at 56%.

Among the 39 researchers who completed the telephone survey:

- 15 researchers agreed to participate but failed to return the email survey subsequent to follow-up phone calls and emails;
- 2 researchers declined to participate in the email survey; and
- 22 researchers completed and returned the email survey.

3.2 Respondent Profile

As shown in Table 1, the greatest proportion of respondents, 46%, reported that their primary research focus

was basic science; 21% stated their primary research focus was social, cultural, environmental and population health; with 8% of respondents describing their primary research focus in each of the two areas of clinical research, and health services and health systems research. Eighteen percent of the respondents stated their research spanned more than one of the above research foci.

In terms of research domain, for those researchers identifying only one domain, approximately one quarter of respondents (26%) stated biology was their main domain of research, 15% epidemiology, 3% quality of life and 3% therapeutic research. Interestingly, no researchers surveyed stated that either prevention alone or clinical treatment and delivery alone were their single main research domain. However, the majority of researchers (54%) stated that their research spanned more than one domain; for example, six researchers characterized their research in the prevention and at least one other research domain, and seven researchers characterized their research in the clinical treatment and delivery of care and at least one other research domain.

Table 1 Respondent Profile: Research Focus and Research Domain

Research Focus and Research Domain	
Research Focus	N (%)
Basic science research	18 (46.2)
Clinical research	3 (7.7)
Health systems / services	3 (7.7)
Social / cultural / environmental / population health	8 (20.5)
Other*	7 (17.9)
Research Domain	N (%)
Biology	10 (25.6)
Clinical treatment / delivery of care	0
Epidemiology	6 (15.4)
Prevention	0
Quality of life	1 (2.6)
Therapeutic research	1 (2.6)
Other**	21 (53.8)

* 2 participants indicated 'basic science & clinical research', 1 participant indicated 'basic science, clinical research & social', 1 participant indicated 'clinical research & health systems', 1 participant indicated 'clinical research & social', 1 participant indicated 'health systems & social' as their primary research focus.

** Participants classified as 'Other' selected more than one of the categories specified, with the most frequently selected combination being 'Biology, Therapeutic research' (8 participants). Various combinations 'Clinical treatment' with 'Prevention', 'Quality of life' and 'Epidemiology' were accounted for many of the remaining respondents in this category. 'Psychosocial/determinants of health' and 'Pharmacology' were additional research domains defined.

The researchers surveyed were well established in their research career. As shown in Table 2, the greatest proportion, approximately one-third of respondents (31%), were independent investigators with more than 15 years experience, approximately one quarter (26%) had between six and ten years experience, and 23% eleven to fifteen years experience. One respondent was a post-doctoral fellow. University was the research location for the greatest proportion of respondents (44%) followed by a teaching hospital (33%). The research locations of the others included a pharmaceutical company, integrated public health facility, provincial government laboratory, public health department and an academic health centre.

Table 2 Respondent Profile: Stage of Research Career and Research Setting

Stage of Research Career and Research Setting		
Stage of Career	N	(%)
Post-doctoral fellow (post graduate trainee)	1	(2.6)
Independent investigator (1 - 5 years)	7	(17.9)
Independent investigator (6 - 10 years)	10	(25.6)
Independent investigator (11 -15 years)	9	(23.1)
Independent investigator (> 15 years)	12	(30.8)
Research Setting	N	(%)
Teaching hospital	13	(33.3)
University / College	17	(43.6)
Other	9	(23.1)

3.3 Impact through Collaboration

PHAC/CIHR-funded HCV researchers are now clearly collaborating at a much greater level and with a greater number of disciplines compared with either five years ago or the start of their research career. As shown in Table 3, the majority of respondents, 80%, stated that they were collaborating either more (33%) or much more (47%), and a slightly lower proportion, 69%, stated that they were collaborating with more (44%) or many more (25%) disciplines demonstrating an increase in the cross-disciplinary nature of research collaboration.

Table 3 Research Collaboration

Research Collaboration		
<i>Degree of Collaboration</i>	N	(%)
<i>(Compared with 5 years ago or earliest date in HCV career)‡</i>		
Much more	17	(47.2)
More	12	(33.3)
About the same	3	(8.3)
Less	2	(5.6)
Much less	2	(5.6)
<i>Degree of Collaboration with Other Disciplines</i>	N	(%)
<i>(Compared with 5 years ago or earliest date in HCV career)‡</i>		
Many more	9	(25.0)
More	16	(44.4)
About the same	11	(30.6)
Fewer	0	
Far fewer	0	

‡ Data missing for three participants.

As shown in Table 4, biomedical scientists (82%) and clinical researchers (72%) were the two groups with whom the majority of respondents reported that they had collaborated at the design and formulation stage of their research. This finding is not surprising considering the majority of respondents were basic scientists. Health care providers (56%) was the third-ranked group with whom respondents had collaborated and approximately one third of respondents had worked with either community groups (39%), population health researchers (39%), private sector researchers or managers (31%), or provincial health policy makers (31%) during the design and formulation stage of their research.

Table 4 Collaboration at the Research Design and Formulation Stage

Collaborative Groups	
	N (%)
People living with, or at risk of, HCV	10 (25.6)
Aboriginal peoples	7 (17.9)
Biomedical scientists	32 (82.1)
Clinical researchers	28 (71.8)
Community groups	15 (38.5)
Federal health policy makers	5 (12.8)
Health care providers	22 (56.4)
Health services researchers	10 (25.6)
Population health researchers	15 (38.5)
Private sector researchers or managers	12 (30.8)
Provincial health policy makers	12 (30.8)
Other	6 (15.4)

As shown in Table 5, the pattern of collaboration during the research implementation stage was very similar. However, nearly one-third (31%) reported collaborating with people living with, or at risk of, infection with hepatitis C in this stage compared with only one quarter (26%) who had collaborated with this group in the earlier design stage.

Government decision makers and consumers were the two groups least likely to be engaged as collaborators in both the design and the implementation of the funded research. Researchers reported limited consultation with federal health policy makers at the research design and development stage (13%) and even fewer had consulted with them during the implementation stage of their research (8%). Similarly, Aboriginal peoples and people living with, or at risk of HCV were minimally engaged as collaborators at either the research design and development stage - 18% and 26% respectively or the during the implementation stage of the research - 13% and 31% respectively

Table 5 Collaboration during Implementation Stage of Research

Collaborative Groups	
	N (%)
People living with, or at risk of, HCV	12 (30.8)
Aboriginal peoples	5 (12.8)
Biomedical scientists	28 (71.8)
Clinical researchers	26 (66.7)
Community groups	10 (25.6)
Federal health policy makers	3 (7.7)
Health care providers	20 (51.3)
Health services researchers	7 (17.9)
Population health researchers	13 (33.3)
Private sector researchers or managers	11 (28.2)
Provincial health policy makers	10 (25.6)
Other	7 (17.9)

As shown in Table 6, in addition to collaboration with these groups, almost all of the researchers surveyed (90%) stated that they had collaborated with academic colleagues from other departments in their own institution. Similarly, the majority had collaborated with academic colleagues in either their own (64%) or other provinces (56%). Over one-third had collaborated with academic colleagues in the United States (39%) and other countries (41%).

Table 6 Academic Collaboration

Academic Collaborative Groups	
	N (%)
Other departments in researcher's own institution	35 (89.7)
Other institutions in researcher's province	25 (64.1)
Other provinces	22 (56.4)
Federal government laboratories	7 (17.9)
Provincial government laboratories	15 (38.5)
United States	15 (38.5)
Other countries	16 (41.0)

In the process of conducting their PHAC/CIHR-funded HCV research, researchers developed a key relationship or a partnership with a variety of organizations. As shown in Table 7, Hospitals and Health Centers (47%), an HIV/AIDS organization (45%), an educational institution (42%) and a pharmaceutical company (42%) were the organizations identified by the greatest proportions of researchers. Social Services agencies (8%), local community groups (24%), Public Health Units (26%) and local organizations addressing hepatitis C (27%) were the organizations partnered by the lowest proportions of researchers.

Table 7 Organizations with whom a Key Relationship or Partnership was Established

Key Relationship or Partner Organization	
	N (%)
Public health unit†	10 (26.3)
Hospital / Health Centre†	18 (47.4)
Social services agency†	3 (7.9)
Local community group†	9 (23.7)
Provincial / territorial government†	11 (28.9)
National organization addressing hepatitis C†	15 (39.5)
Local organization addressing hepatitis C§	10 (27.0)
HIV/AIDS organization†	17 (44.7)
Educational institution†	16 (42.1)
Pharmaceutical company†	16 (42.1)
Other†	8 (21.1)

† Data missing for one participant.

§ Data missing for two participants.

Researchers reported a range of impacts on their research as a result of the collaboration in which they had engaged. Engagement in collaboration had several impacts on the respondent’s research; primarily in the areas of research design and methodology, research support and dissemination.

Changes to the methodology of the research project as a result of collaboration included changes in the way study participants were approached; changes in consent forms; an increase in the sample size available to the researcher e.g., recruitment could take place nationally rather than restricted to a local sample; and a refinement of techniques:

Collaboration has brought in different disciplines and different perspectives which have had an impact on research design, provided advice on methodology and increased the scale of the project.

Researchers also described the benefits of collaboration in terms of the enhanced research support they had received. Some researchers had received statistical and modeling advice, analysis assistance, and help with interpretation of results. Provincial researchers reported access to local databases to analyze policy directions:

This initiative has enabled great collaboration between the provinces and researchers.

Other researchers felt that their collaborative endeavours had accelerated the research process, whereas for others the impact was in the dissemination domain in terms of manuscript development and for one researcher the collaboration had led to the development of a new research proposal.

Perhaps the most compelling commendation for the initiative in this collaboration domain was the following comment by one researcher, which was echoed by many:

The initiative has led to focused attention on this area. (I) would not have done this collaboration without the initiative.

In addition to the positive side of collaboration, researchers were asked to describe any challenges they may have encountered in undertaking collaborative work. Not all respondents reported that they had experienced challenges while collaborating on their PHAC/CIHR-funded HCV research. Among the minority that did report challenges specific to collaboration, general difficulties in bringing people together and collaborating with a new community as a result of initiative funding were identified. For example:

(The challenge) is working to ensure researchers from different research perspectives work respectfully together and to ensure researchers are well connected with community groups so that they can work closely with these groups.

Before this strategic program, I was not involved in hep C research. One of the important consequences of the program was to bring me as well as many other Canadian scientists to the field. Clearly, it permits to build a Canadian scientific community interested in hep C. Therefore, one of the challenges that I faced was to take my place in this community as well as start a new project.

The other challenges identified were issues perhaps more closely aligned to conducting research overall rather than specific to collaboration. Among this group, the common theme was a lack of protected research time and a lack of funding:

The University's emphasis on covering teaching eats into research time – we need protected research time.

Retaining and training staff was also identified by some researchers as a major collaboration challenge, but again an issue that perhaps applies more widely to the general conduct of research as well as to research collaboration.

Some respondents identified the lack of research material or research resources as a significant challenge in undertaking collaboration. For example, “*the very limited access to animal models*” in Canada on which to study HCV and thus requiring work to be undertaken in the United States where work on chimpanzees is possible, collecting blood samples at remote sites, and “*a lack of tools to investigate this virus*” had made collaboration difficult for some researchers.

3.4 Impact through Capacity Building

Over the period of the initiative 27 researchers, nearly three-quarters of the researchers surveyed (73%) had supervised a graduate or post-doctoral student studying primarily in the HCV area.

As shown in Table 8, of these 27 researchers who had been supervisors, the majority (96%) had been the principal supervisor of at least one graduate student and 59% the principal supervisor of at least one post-doctoral student. In total, 126 students had received their primary supervision from a researcher funded under the PHAC/CIHR Research Initiative on Hepatitis C, the HIV/AIDS and HCV ICE Program and/or the National Hepatitis C Research Training Program Grant.

Table 8 Supervision of Graduate and Post-doctoral Students 1999-2005
(N = 27 Researchers as Supervisors)

Student Supervision	
	N (%)
Number of Researchers Supervising Graduate Students	26 (96.3)
Total number of students	97
Median (range)	2.0 (1, 30)
Number of Researchers Supervising Post-doctoral Students	16 (59.3)
Total number of students	29
Median (range)	1 (1, 4)

As shown in Table 9, among the 97 graduate students supervised by researchers funded through one of the research programs above, the top three categories of full or partial funding were through their own PHAC/CIHR or CIHR training award (42%), through a PHAC/CIHR HCV research initiative grant (42%) and through other funding sources such as internal studentships and scholarships, pharmaceutical companies, the Alberta Heritage Fund, the Canadian Network for Vaccines and Immunotherapeutics (CANVAC) and Fonds de la recherche en Santé du Québec (FRSQ). Twenty-seven percent were either fully funded or partially funded through a CIHR training program grant.

Table 9 Sources of Funding for Graduate Students Supervised by a Joint Initiative-funded Researcher

Source of Funding	
	N (%)
<i>Number of researchers with at least one graduate student funded through a CIHR training program grant</i>	7 (26.9)
Number of graduate students completely or partially funded	7
<i>Number of researchers with at least one graduate student funded through student's own PHAC/CIHR or CIHR training award</i>	11 (42.3)
Number of graduate students completely or partially funded	14
<i>Number of researchers with at least one graduate student funded through a PHAC/CIHR Hep C Research Initiative Grant</i>	11 (42.3)
Number of graduate students completely or partially funded	24
<i>Number of researchers with at least one graduate student funded through their supervisor's own CIHR research operating grant (ROG)</i>	9 (34.6)
Number of graduate students completely or partially funded	17
<i>Number of researchers with at least one graduate student funded through someone else's CIHR ROG</i>	1 (3.8)
Number of graduate students completely or partially funded	1
<i>Number of researchers with at least one graduate student funded through other funding sources, besides CIHR</i>	11 (42.3)
Number of graduate students completely or partially funded	52

As shown in Table 10, among the 29 post-doctoral students, the top two categories of full or partial funding were through a PHAC/CIHR HCV research initiative grant (44%), or through other funding sources (44%) such as CANVAC, the Alberta Heritage Fund, the American Liver Foundation and industry. Thirteen percent were either fully-funded or partially-funded through a CIHR training program grant.

Table 10 Sources of Funding for Post-doctoral Students Supervised by a Joint Initiative-funded Researcher

Source of Funding	N (%)
<i>Number of researchers with at least one post-doctoral student</i>	2 (12.5)
Number of post-doctoral students completely or partially funded	3
<i>Number of researchers with at least one post-doctoral student funded through student’s own PHAC/CIHR or CIHR fellowship</i>	4 (25.0)
Number of post-doctoral students completely or partially funded	5
<i>Number of researchers with at least one post-doctoral student funded through a PHAC/CIHR Hep C Research Initiative Grant</i>	7 (43.8)
Number of post-doctoral students completely or partially funded	14
<i>Number of researchers with at least one post-doctoral student funded through supervisor’s own CIHR research operating grant</i>	2 (12.5)
Number of post-doctoral students completely or partially funded	3
<i>Number of researchers with at least one post-doctoral student</i>	0
<i>Number of researchers with at least one post-doctoral student</i>	7 (43.8)
Number of post-doctoral students completely or partially funded	9

Similarly, over the period of the initiative, between 1999 and 2005, most of the researchers (92%) had supervised research assistants or technicians employed on HCV research projects. Fifty-nine of these assistants were employed full-time on HCV projects under the general direction of the researcher, and 53 were part-time. Over three-quarters (79%) of these assistants were paid through the researcher’s own PHAC/CIHR Hep C Research Initiative Grant. Six percent were paid through a CIHR training program grant (data not shown).

3.5 Impact through Knowledge Dissemination

As shown in Table 11, nearly all researchers funded under the PHAC/CIHR Joint Research Initiative on Hepatitis C had presented their HCV-related findings as either an oral presentation (82%) or poster

presentation (90%) at a scientific congress, to a professional association, or at a national or an international conference. Among those researchers making an oral presentation, 43% had presented their findings as a keynote address. Overall, a total of 369 oral presentations were made to the associations above – 173 within Canada and 196 outside Canada. In addition, 247 poster presentations were made to the associations above – 133 within Canada and 114 outside Canada.

Table 11 Scientific Presentations 1999-2005

Scientific Presentations 1999-2005	
	N (%)
<i>Number of Researchers Making Oral Presentations †</i>	31 (81.6)
Keynote †	13 (43.3)
Total number of presentations in Canada	173
Median (range)	4.5 (0, 21)
Total number of presentations outside Canada	196
Median (range)	2.5 (0, 82)
<i>Number of Researchers Making Poster presentations †</i>	34 (89.5)
Total number of poster presentations in Canada	133
Median (range)	2 (0, 30)
Total number of poster presentations outside Canada	114
Median (range)	1.5 (0, 20)

† Data missing for one participant.

Knowledge dissemination also took place through the publication of peer-reviewed journal articles. As shown in Table 12, 72 peer-reviewed journal articles, authored by 27 of the researchers surveyed, their students or members of their research team were published during the years of the initiative (1999-2005). In addition, three books and eleven book chapters detailing results from research funded under the initiative and authored by six of the respondents, their students or members of their research team were published during

the years of the initiative as well as 31 reports authored by 13 of the respondents, their students or members of their research team. Between 1999 and 2005, one third of the respondents (32%) applied for and received 23 patents and two licenses associated with their HCV research.

Table 12 Publications, Patents and Licenses Related to HCV Research 1999-2005

Publications, Patents and Licenses		N (%)
<i>Number of researchers with published peer-reviewed articles †</i>		27 (71.1)
	Total number of articles	72
	Median (range)	2 (1, 6)
<i>Number of researchers with published books or book chapters †</i>		6 (15.8)
	Total number of books	3
	Total number chapters	11
<i>Number of researchers with published reports †</i>		13 (34.2)
	Total number of reports	31
	Median (range)	2 (1, 6)
<i>Number of researchers with patents or licenses relevant to HCV re-</i>		12 (31.6)
	Total number of patents	23
	Total number of licenses	2

† Data missing for one participant.

A more detailed and comprehensive assessment of the impact of the research initiative in terms of scientifically sound peer-reviewed research results is revealed through the results of the bibliometric analysis. The impact of the initiative in driving the publication of Canadian-funded and implemented research findings can be seen very clearly through the difference in the number of published peer-reviewed manuscripts in the two years prior to the initiative and the number published in the two years ending in March, 2006.

As shown in Table 13, during the total period of the joint initiative funding, between 2000 and 2005, 187 articles were published by the 64 HCV-funded principal investigators, nearly all in international journals. However, the significance of this total number and the impact of the initiative is clear when the difference in the number of pre-initiative publications (the baseline measure) and the number published in the two years of

the initiative ending in March, 2006 (the follow-up measure) is considered – the baseline measure was 35 published articles and the follow-up measure was 113 published articles. The percentage increase in the number of publications between the two time periods was 223%.

An analysis of the citations data reveals similar results. Scientific journal articles published by the HCV-funded researchers in the pre-initiative evaluation phase from 1997 to 1999 were cited 176 times in other journals. The number of citations rose substantially in the follow up evaluation phase. Articles published by the HCV-funded researchers between 2003 and 2005 were cited 511 times in other journals. The percentage increase in the number of citations between the two time periods was 190%.

Table 13 Publications and Citations

Publications, Patents and Licenses	2000 to 2005	1997 to 1999	2003 to 2005
Total Number of Publications	187	35	113
<i>Total number in international journals</i>	178	33	108
<i>Journal Impact Factor (2004)</i>			
Median	4.816°	6.601°°	4.224°°°
(Range)	(0.153, 38.57)	(0.511, 13.092)	(0.347, 22.355)
Total Number of Citations	1,368*	176**	511***
Median	1	6	4
(Range)	(0, 193)	(1, 30)	(1, 50)
<i>Journal Impact Factor (2004)</i>			
Median	3.975†	3.122††	4.1†††
(Range)	(0.059, 38.57)	(0.171, 38.57)	(0.145, 32.695)

• 80 publications had no citations. ° 3 publications had no JIF. † 75 citations had no JIF.

** 16 publications had no citations. °° All publications had a JIF. †† 5 citations had no JIF.

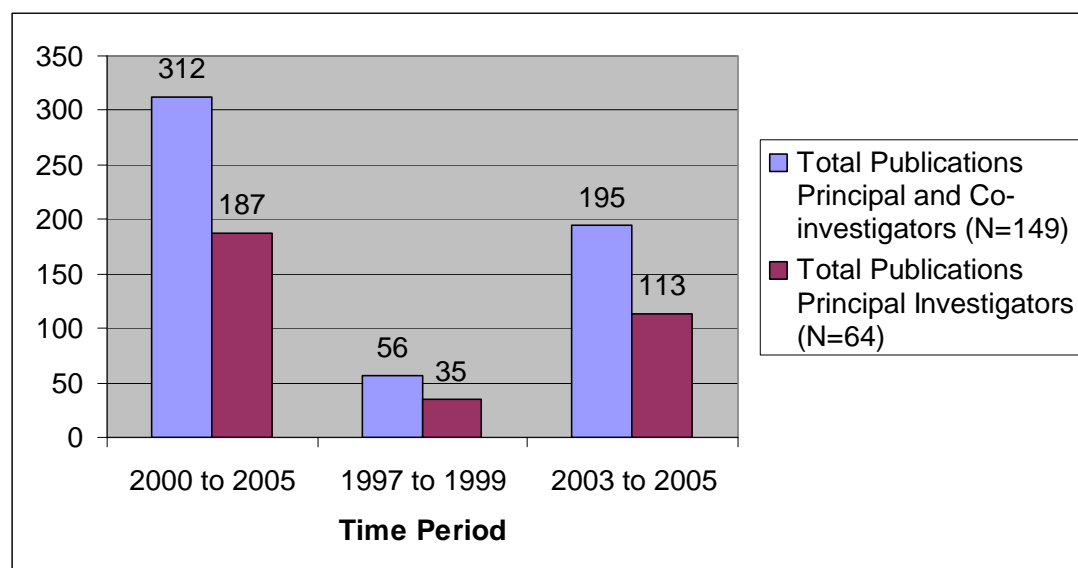
*** 54 publications had no citations. °°° 3 publications had no JIF. ††† 3 citations had no JIF.

Interestingly, while the overall number of citations increased during the final two years of the initiative, a decline in the median number of citations per article was observed. The citation analysis was restricted to citations within two years of the publication date of each article. All citations for articles published pre-initiative would have been identified as the two-year period had elapsed. However, many of the articles identified in the final two year period of the initiative were published in 2004 or later. Hence, the two-year inclusion criteria

would not have been met, resulting in the observed decrease in the median number of citations per article.

The baseline and follow-up publications of principal investigators are shown in the figure below which also shows the results for principal and co-investigators (N=149) receiving grant or award funding through the initiative.

Figure 1 Number of Publications by Principal Investigators and Co-Investigators



Web of Science defines the journal impact factor as “a measure of the frequency with which the ‘average article’ in a journal has been cited in a particular year”⁴. The relative impact factor of the journals in which the scientific papers were published was quite broad, ranging from 0.153 to 38.57. This broad range was also observed for the impact factor of the journals in which the citations were published (range: 0.059 to 38.57). The observed distribution of impact factors is most likely influenced by the high degree of specialization of this research, as the journals in which scientific papers were commonly published target a very specific audience. These journals included: *Hepatology* (JIF=10.416), *Journal of Hepatology* (4.816), *Gastroenterology* (13.092), *AIDS* (5.893), and *Gastroenterologie Clinique et Biologie* (0.816).

In terms of knowledge dissemination beyond the scientific community, respondents were asked about the seminars, workshops and community presentations they may have organized to disseminate their joint initiative-funded HCV research.

As shown in Table 14, nearly three quarters of the researchers interviewed (72%) had organized a seminar to present their HCV research results. Two-hundred and eight seminars were held during the period of the initiative. While the topic of the seminars was aligned closely to the researcher’s line of enquiry, the audiences varied from the university community of scholars to research teams in other disciplines as well as policy makers, frontline workers, public health educators, and HCV support groups.

⁴ ISI, Web of Knowledge, 2005.

Table 14 Seminars, Workshops, Public and Media Presentations on HCV Research Results 1999–2005

Seminars, Workshops, Public and Media Presentations		N (%)
<i>Number of researchers who organized seminars on their HCV research results †</i>		28 (71.8)
	Number of seminars	208
	Median (range)	5 (2, 37)
<i>Number of researchers who organized workshops on their HCV research results †</i>		7 (18.4)
	Number of workshops	26
	Median (range)	2 (1, 8)
<i>Number of researchers who organized public presentations on their HCV research results †</i>		13 (34.2)
	Number of public presentations	100
	Median (range)	3 (1, 60)
<i>Number of researchers interviewed by media about their HCV research†</i>		10 (25.6)
	Number of media interviews	62
	Median (range)	3.5 (1, 30)

† Data missing for one participant.

A much smaller proportion of respondents, 18%, had organized 26 workshops to present their HCV research results with the composition of the audience similar to that for the seminars. In contrast, one-third of respondents (34%) had made 100 non-professional public presentations on the topic of their HCV research to a variety of groups including elementary school students, people living with HCV, Rotary Clubs and law enforcement groups. Approximately one quarter of the researchers, (26%), had been interviewed by the media concerning the results of their initiative-funded HCV research.

3.6 Impact through Knowledge Translation

The number of presentations to policy makers and fiscal policy makers to attempt to translate research into policy initiatives and funded policy initiatives was much lower and made by fewer researchers in comparison to the number of presentations to the scientific community described above. Between 1999 and 2005, just over a quarter of the researchers (29%) had been invited (or their students or members of their research team) to present their HCV research to federal, provincial/territorial or regional policy makers and 16% had presented their research to fiscal policy makers at one of the three levels (data not shown).

3.7 Respondents' Perception of the Impact of their HCV Research Career

Respondents were asked to rate the impact of their HCV research career in a number of areas.

As shown in Table 15, the area in which the majority of respondents perceived their research had the greatest impact was in the creation of new knowledge that had led to subsequent research. Sixty-four percent of respondents considered that their HCV research had a high (29%) or very high (35%) impact in this area. Interestingly, this was the area in which no researcher felt that they had not made an impact or had made very little impact. Facilitating a return to health through diagnosis or treatment was the area in which the second greatest proportion of researchers (41%) felt that they had made a high (24%) or very high (17%) impact.

Conversely, the areas in which researchers felt that they had made the least impact were in improving the health care system through improvement to health care delivery or health policy. Sixty-one percent of respondents considered that their HCV research had a low (39%) or very low (21%) impact in this area. Perceived impact in the area of helping people stay healthy through health promotion and/or illness prevention was also ranked low; 44% of respondents considered that their HCV research had a low (41%) or very low (4%) impact in this area.

Table 15 Respondents' Perception of Impact of their HCV Research Career

Area of Impact of HCV Research Career ^o		
		N (%)
Creating new knowledge leading to subsequent research.	Very low	0
	Low	0
	Moderate	12 (35.3)
	High	10 (29.4)
	Very high	12 (35.3)
Helping people stay healthy through health promotion, illness prevention.	Very low	1 (3.7)
	Low	11 (40.7)
	Moderate	7 (25.9)
	High	4 (14.8)
	Very high	4 (14.8)
Helping people living with HCV or at risk of acquiring HCV gain a better understanding of the determinants of health.	Very low	2 (7.7)
	Low	7 (26.9)
	Moderate	10 (38.5)
	High	4 (15.4)
	Very high	3 (11.5)
Helping return to health through diagnosis or treatment.	Very low	6 (20.7)
	Low	5 (17.2)
	Moderate	6 (20.7)
	High	7 (24.1)
	Very high	5 (17.2)
Improving the health care system such as improvement to health care delivery or health policy.	Very low	6 (21.4)
	Low	11 (39.3)
	Moderate	3 (10.7)
	High	3 (10.7)
	Very high	5 (17.9)

Data missing for 5 participants (Knowledge), 12 (Healthy), 13 (Determinants), 10 (Diagnosis/treatment), 11 (Delivery/policy).

Given the imbalance of research disciplines among the researchers, the measures of research impact were stratified according to research focus.

Table 16 Respondents' Perception of Impact of HCV Research Career Stratified by Focus of Respondents' Research

Impact of HCV Research Career	Basic science (n=18) N (%)	Clinical re- search (n=3) N (%)	Health sys- tems (n=3) N (%)	Social (n=8) N (%)	Other (n=7) N (%)
Creating new knowledge leading to subsequent research					
Very low	0	0	0	0	0
Low	0	0	0	0	0
Moderate	5 (27.8)	1 (33.3)	0	5 (71.4)	1 (20.0)
High	5 (27.8)	1 (33.3)	1 (100)	2 (28.6)	1 (20.0)
Very high	8 (44.4)	1 (33.3)	0	0	3 (60.0)
Helping people stay healthy through health promotion, illness prevention					
Very low	0	0	0	0	1 (25.0)
Low	9 (64.3)	1 (100)	0	0	1 (25.0)
Moderate	3 (21.4)	0	0	4 (66.7)	0
High	1 (7.1)	0	1 (50.0)	1 (16.7)	1 (25.0)
Very high	1 (7.1)	0	1 (50.0)	1 (16.7)	1 (25.0)
Helping people living with HCV or risk of acquiring HCV gain a better understanding of the determinants of health					
Very low	1 (7.7)	0	0	0	1 (25.0)
Low	4 (30.8)	1 (100)	0	2 (33.3)	0
Moderate	7 (53.8)	0	1 (50.0)	1 (16.7)	1 (25.0)
High	1 (7.7)	0	0	3 (50.0)	0
Very high	0	0	1 (50.0)	0	2 (50.0)
Helping return to health through diagnosis or treatment					
Very low	3 (18.8)	0	0	2 (50.0)	1 (20.0)
Low	4 (25.0)	0	0	1 (25.0)	0
Moderate	4 (25.0)	0	0	1 (25.0)	1 (20.0)
High	3 (18.8)	0	2 (100)	0	2 (40.0)
Very high	2 (12.5)	2 (100)	0	0	1 (20.0)
Improving the health care system such as improvement to health care delivery or health policy					
Very low	3 (23.1)	1 (50.0)	0	1 (14.3)	1 (25.0)
Low	7 (53.8)	1 (50.0)	0	3 (42.9)	0
Moderate	1 (7.7)	0	1 (50.0)	0	1 (25.0)
High	1 (7.7)	0	0	2 (28.6)	0
Very high	1 (7.7)	0	1 (50.0)	1 (14.3)	2 (50.0)

2 participants indicated 'basic science & clinical research', 1 participant indicated 'basic science, clinical research & social', 1 participant indicated 'clinical research & health systems', 1 participant indicated 'clinical research & social', 1 participant indicated 'health systems & social' as their primary research focus.

As shown in Table 16, among basic scientists, the pattern of research impact reflected that of the overall pattern among all respondents. This is not surprising given that the majority of respondents were basic scientists. Among clinical researchers, facilitating a return to health through diagnosis or treatment was the area in which they considered their research to have a high impact. In contrast, improving the health care system through improvement to health care delivery or health policy was the area in which they considered their research had made the least impact.

Health systems researchers identified helping people stay healthy through health promotion or illness prevention as the area in which they considered their research had made the greatest impact. Helping people living with HCV infection or at risk of acquiring HCV infection gain a better understanding of the determinants of health and improving the health care system through improvement to health care delivery or health policy were the two areas in which they considered their research had made the least impact.

Social and population health researchers identified two areas in which their research had had the greatest impact. Unique among the other researchers, social and population health researchers identified helping people living with HCV infection or at risk of acquiring HCV infection gain a better understanding of the determinants of health, and improving the health care system through improvement to health care delivery or health policy as the two areas in which they considered their research had made the greatest impact.

3.8 Major Challenges in Conducting HCV-related Research in Canada

The researchers surveyed identified four main areas of challenge in conducting HCV-related research in Canada: fiscal constraints, onerous ethical and clinical trials guidelines, an over-emphasis on bio-medical and clinical research, and the perception of a lack of focus by the public (including decision makers) on the newly emerging groups with the highest rates of hepatitis C infection.

Irrespective of scientific discipline or research focus, the major challenge identified was a fiscal challenge - the lack of adequate, sustainable funding with which to conduct HCV research, “*the quality suffers if funding is not there.*” For example, cuts to requested budgets in CIHR proposals frequently necessitated changes to the research methodology resulting in less than optimal research designs and reduced outcomes. Additionally, in some cases the lack of research funds resulted in the abandonment of some research designs. For example, lack of funding to support a cohort study was seen as a significant challenge for clinical researchers. The consequence of budget cuts for other researchers resulted in a lack of infrastructure to conduct their research. For example, researchers commented on the removal of research assistants’ salaries from their budgets.

In addition to individual consequences of a lack of funding, researchers identified the overall level of Canadian funding available for HCV research as a significant and long standing challenge. For example, one researcher commented that the amount of grants awarded for HCV research was below the CIHR average ⁵, others compared the low level and then cessation of HCV research funds with that available on a continuing basis for HIV research, and another commented that Canadian funding for HCV was insufficient when compared with other G7 countries.

For some researchers, overall inadequate funding for HCV research has played out in a lack of personnel to undertake needed research:

insufficient resources in universities and hospitals to do the research that is required

For others, insufficient dedicated HCV research funds to attract and subsequently keep students, doctoral fellows and postdoctoral trainees in the HCV field was seen as a current and future challenge to conducting HCV research in Canada.

The perceived limited scope, and the experience of the delayed renewal in the final years of the PHAC/CIHR Research Initiative on Hepatitis C were considered particularly problematic:

PHAC/CIHR created some capacity, and having created it, then stopped funding it. Therefore, capacity was lost.

I have to reapply to CIHR for renewal of my grant and since the PHAC initiative is no longer there it will be very difficult to fund many Canadian labs. Before PHAC there were no Canadian labs working in the hep C area. It should be continued since 4%⁶ of the population is affected.

Among basic science researchers, limited access to an animal model⁷ and therefore reliance on human material was seen as a considerable challenge. In the absence of easy access to an animal model, some researchers were of the opinion that the ethical guidelines for obtaining human blood samples were too restrictive:

One of the major challenges was access to adequate resources of blood to study the effects of hepatitis C on human immune cells. This issue delayed the research but has now been solved.

Restrictive guidelines for clinical trials were also cited as a major challenge in conducting HCV-related research in Canada. While conducting clinical trials in Canada was considered less expensive than in the United States, the requirement for separate agreements for each clinical trial rendered the Canadian clinical trials system slow and onerous. These restrictions caused one Canadian researcher funded under the joint initiative to run these trials in the United States. Thirty sites were opened in the United States; no sites were opened in Canada.

Social science researchers in particular perceived a biomedical and clinical focus on HCV research rather than engagement of people living with HCV in the research process as a major challenge in conducting HCV-related research in Canada. Low political significance and a lack of knowledge and awareness by the public (including the decision makers) of the group most adversely affected by hepatitis C infection, injection drug users, was cited as one of the challenges in conducting HCV-related research,

The HCV-affected community is within a vulnerable population. A population that has no political voice. Therefore, policy makers have no impetus to support HCV research.

⁵ CIHR staff reviewed the results of the four most recent CIHR HCV and corresponding open competitions. In three of the four competitions, the HCV funding average was actually higher. However, it needs to be made clear that this statement reflects the perception of the researcher.

⁶ This population estimate of the prevalence of HCV infection at 4% is most likely referring to HCV global prevalence. The population estimate for the prevalence of HCV among Canadians is 0.8%.

⁷ A mouse model for HCV research does in fact exist. Canadian researchers, funded under the joint initiative, developed this mouse model for HCV research. However, the high cost of this model (\$600 per mouse) has resulted in limited accessibility.

3.9 Suggested Responses to the Implementation Challenges Identified

In framing a response to the identified implementation challenges, the researchers' perspectives converged on two main themes: "*more money, more people.*"

Researchers were overwhelmingly in favour of a reinstatement of the PHAC/CIHR Research Initiative on Hepatitis C to encourage and sustain Canadian HCV research:

Continue strategic funding, more specifically this initiative.

Reinstatement of program. (The program) got a lot of new researchers involved – 20 to 30 involved – and they have made amazing progress for Canadian HCV research.

Many researchers alluded to the amount of money that continues to be invested in HIV research and would like to see similar levels for protected HCV research:

HCV needs to be more of a funding priority.

HCV needs to be re-emphasised.

Must keep the funding in the program in the same way as HIV has kept funding.

Distribute money evenly between the viruses.

Depending on their area of HCV expertise, researchers made specific funding suggestions to further the development of HCV research in Canada and to reverse some of the identified problems in conducting HCV research in Canada:

Funding needs to be invested in treatment as a good investment (to promote a) return to health.

Better management and treatment needed – need to transfer funds into this area.

More money into prevention research.

Allow sufficient funds to cover cohort initiative – need a national cohort covering many different populations.

Researchers also made suggestions as to how the lack of Canadian HCV researchers could be addressed:

Flexibility in research funding with an emphasis on career awards to enable protected research time for established researchers.

More money, more initiatives to sustain career opportunities for those who want to do clinical and research work.

More incentives for clinicians who are treating people living with HCV to be involved in research.

Scientists who had identified restrictive guidelines in accessing human blood samples as a challenge suggested a compromise solution:

If the use of research material from a patient is not adversely affecting that patient, then there should be more freedom in obtaining and using this material.

Similarly, scientists who experienced difficulties running clinical trials in Canada suggested a specific solution:

Health Canada needs to revise method of operation for clinical trials.

Social scientists concerned about an over-emphasis on funding basic and clinical science research, suggested funding decisions should not only be made in the context of a bio-medical perspective, but should also include the psychosocial aspect. It was suggested that experts in this particular domain should evaluate psychosocial projects. Many researchers suggested a greater emphasis on the social aspects of HCV:

Address research that looks at the social-cultural determinants of HCV transmission.

CIHR should support more research on the determinants of health, harm reduction and co-infection.

A greater emphasis on the public health aspects of the impacts of HCV infection and greater engagement of the community in research.

3.10 Major Challenges in Disseminating HCV-related Research in Canada

The researchers surveyed identified three main areas of challenge in disseminating HCV-related research in Canada: lack of support for dissemination activities; lack of perceived severity and therefore visibility of HCV in comparison with HIV; and again, the lack of interest in the health of injection drug users, the population most affected by HCV.

Many researchers spoke to the need for support in disseminating their research. Some identified the need at the individual level:

Basic scientists need help in disseminating. This is a specialist role. Specialists should be available to basic scientists.

Other researchers saw a lack of national support for dissemination as a big challenge:

Lack of national infrastructure for dissemination.

No national institute, national initiative to assist with dissemination.

For other researchers, the lack of interest in HCV infection was identified as the dissemination challenge:

Other issues have a higher profile e.g., cancer, breast cancer – HCV not on radar.

Whereas for others it was the characteristics of the population that posed dissemination challenges:

Dissemination not important as population not important.

Lack of interest in and marginalisation of IDUs.

3.11 Suggested Responses to the Dissemination Challenges Identified

Some researchers, as previously, identified enhanced funding to facilitate dissemination activities as the solution to the dissemination challenges experienced. These researchers placed the responsibility for responding to the challenge at the feet of the funders:

If CIHR and other organisations want appropriate dissemination, (they) need to take this into consideration when reviewing proposals and when cutting budgets as it is always dissemination that is cut.

For research for which there are likely to be recommendations for policy makers, these proposals need consideration for more funding and more time for dissemination of these results. This takes time.

In terms of individual-level responses, protected time for dissemination activities was identified by some researchers:

Necessary funding to free up time for dissemination – an important task.

Protected research time to publish.

Other researchers suggested more population-level responses:

Media relations department – encourage researchers to disseminate their findings through media or scientific publishing.

However, the intervention that was identified by most of the respondents was some form of networking, perhaps in the form of a national annual meeting. Researchers held varying views as to the composition of the audience:

National annual meeting of researchers, health care providers and people living with HCV.

Annual meeting or workshop for HCV researchers.

National body to bring these groups together.

Involvement with other researchers, scientists, public and professional groups.

We need to provide opportunities for collaboration with Public Health and Health Canada so that they are aware of the data that are available. Enable recommendations from research to be available to the policy makers.

3.12 Key Interventions for Translating Research into Action

The researchers' perspectives on the action required to translate research into action converged on three themes: revisions to research funding opportunities and procedures, the creation of national networking initiatives, and a consistent and sustainable long-term program of research emphasizing collaboration between researchers from all disciplines engaged in HCV research and enriched by a long-term funding program of resource allocation, training and resource development.

In this section of the report, the researchers' perspectives on the key actions to be undertaken by federal research funding agencies and Health Canada are considered in the context of the information that was retrieved concerning other HCV initiatives in the United States, Australia and the UK.

Research funding opportunities and procedures

Respondents had several recommendations for amendments to CIHR and PHAC's current funding strategy in general and the granting of salary support in particular.

The lack of protected research time was a theme cited by many researchers as one of the challenges in conducting and disseminating HCV research in Canada. Increasing the number of salary awards available and the time period of each one was suggested by many researchers. In terms of removing some of the challenges associated with dissemination of research results, the issue of salary awards was again raised. Granting established researchers salary awards that are not tied to further research grants was a suggested strategy to ensure that the results of one grant are effectively and efficiently disseminated before commencement of another project.

Support for professional researchers in terms of salary awards to enable protected research time. Research awards from CIHR and PHAC should not be tied to a research project.

Respondents also considered that PHAC and CIHR had a key part to play in the knowledge transfer domain, suggesting that issues of knowledge transfer and exchange should be an integral part of the review process:

Studies that have implications for policy should be flagged at the beginning of the review process and given consideration for increased timelines and increased funding.

National networking initiatives

A recommendation to improve the transfer of research into action cited by many researchers was to institute an annual national workshop or conference, similar to the ones in the HIV domain:

A national networking meeting is needed. There are 30 scientists in the area. Put these together with educators to increase knowledge transfer and exchange.

Annual HCV Scientific Symposium.

National networking group essential to support researchers across disciplines.

Sustainable funding

Researchers' responses to the question of what federal action needed to be taken to translate research into action were consistent with those to many other questions requesting responses to challenges in conducting HCV research in Canada. Researchers consistently attested to the need for sustainable long-term funding for HCV research in Canada, the need for a mechanism to bring together researchers in the basic, clinical, prevention and treatment disciplines involved in HCV research, and the need to develop a secure HCV research infrastructure through long-term investment in training and medical microbiology infrastructure. Analysis of comprehensive research strategies accomplishing these goals in other developed countries, suggests a Canadian HCV research strategy may well contribute to addressing some of the issues identified by Canadian researchers.

In the United States for example, a number of national institutes undertake HCV research. The Liver Disease Research Branch in the Division of Digestive Diseases and Nutrition, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is the institute that has major responsibility for hepatitis C research at the National Institutes of Health (NIH). However, at the NIH, hepatitis C is a shared research focus of the NIDDK, the National Institute of Allergy and Infectious Diseases, the National Cancer Institute, the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Drug Abuse, and the National Heart, Lung, and Blood Institute.

Not unlike CIHR, the NIH conducts, supports, plans, and coordinates hepatitis C research in a number of ways: investigator-initiated hepatitis C research grants, solicited research proposals, scientific conferences, workshops, and public education. While hepatitis C research is pursued by multiple institutes, there are mechanisms in place to assure coordination among the institutes and centres in the funding of research grants, research centres, and clinical trials. The institutes and centres work together under the auspices of a trans-NIH Hepatitis C Working Group to develop new initiatives, requests for applications, and ideas for workshops and symposia. For fiscal year 2004, hepatitis C research was funded at a level of \$118 million.

An NIH Action Plan will guide future American HCV research directions for liver disease research driven by a multi-stakeholder research planning process which involved external scientific and lay experts.⁸

A similar course of a directed national program of HCV research driven by stakeholder consultations is proposed for the UK. In the process of developing the country's *Hepatitis C Strategy for England (2002)*,

⁸ Hepatitis C Research at the National Institutes of Health. Accessed 20 February 2006

<http://www.hhs.gov/asl/testify/t041214a.html>

the Department of Health (DH) was made aware of knowledge gaps and the need for research to help reduce the impact of these gaps. The DH recommended several areas of research – research on the survival of hepatitis C virus in used injecting equipment, internationally coordinated research to reduce the risk of mother to baby transmission of HCV, mathematical modeling to determine where to target prevention resources to have maximum effect, research into prevention of initiation into injection, and research evidence from large studies to determine the effectiveness of complimentary and alternative medicine in the management of hepatitis C⁹.

Australia's national HCV research program similarly encourages collaboration, dissemination and translation. In 1999, Australia introduced its plan to combat the increasing burden of hepatitis C, *the National Hepatitis C Strategy 1999-2000 to 2003-2004*. Several priorities were identified in this strategy, including *research*¹⁰. At the beginning of this period (1999-2000), the Australian government contributed AU\$ 12.4 million over four years to *The Hepatitis C Education and Prevention Initiative*, and contributed an additional AU\$ 15.9 million over four years in 2003/04. The funding was allocated to State and Territory Governments for the development and implementation of hepatitis C programs, and towards national activities¹¹. Since 1999, approximately AU\$ 8 million of this funding has contributed to the funding of hepatitis C research through research grants given out by the National Health and Medical Research Council¹¹. Furthermore, through the National HIV Centres, AU\$ 8 million per year has been allocated to combined research into HIV and HCV¹¹. Examples of titles of projects funded in 2004, included: 'Choice or chance: contraceptive use by women with Hep C', 'Hepatitis C culture and control for vaccine development', and 'Factors influencing Hepatitis C virus infection in injecting drug users'¹². In order to continue the momentum that was gained through the first strategy, *The National Hepatitis C Strategy 2005-2008* was implemented. In terms of research, the strategy detailed specific priority action areas, encouraging collaboration, dissemination and translation¹⁰.

Additionally, in 1998, the *Strategic Research Development Committee (SRDC)* of Australia announced that it would allocate AU\$ 1 million of funding towards a program for social and behavioural research into hepatitis C. Under this program, 12 project grants received funding¹³. After a two-year period, a report of preliminary findings for each project was completed and the SRDC convened a workshop bringing together the researchers with other key stakeholders.

⁹ Hepatitis C Strategy for England. Accessed 20 February 2006

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT_ID=4103274&chk=c2RL0X

¹⁰ National Hepatitis C Strategy 2005-2008. Commonwealth of Australia 2005. Accessed 7 January 2006

<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/phd-hepc-strategy-0508-cnt.htm>

¹¹ Hepatitis C funding and initiatives. Accessed 7 January 2006

http://www.health.gov.au/internet/wcms/publishing.nsf/Content/health-pubhlth-strateg-hiv_hepc-hepc-funding.htm

¹² Research Snapshot – Hepatitis C. Accessed 7 January 2006 www.nhmrc.gov.au/news/snapshots/hepatitisc.htm

¹³ Report on the SRDC's of Social and Behavioral Research into Hepatitis C. Accessed 7 January 2006

<http://www.nhmrc.gov.au/publications/files/hepc.pdf>

4.0 CONCLUSIONS

In concluding this report, there are certain limitations to be considered. The data in this report relate only to the perspectives of those researchers who responded to the email request to participate in the telephone survey. These respondents comprise two-thirds of those researchers who received funding through the joint initiative. These data cannot therefore be considered to represent the perspectives of all researchers funded through the joint initiative.

However, the research domains, as assigned by CIHR, of the 13 researchers who did not respond to either of two email requests or two phone requests to participate, of the three researchers who declined to participate, and of the four researchers who were not available at the time of the survey were very similar to those of the researchers who did participate. For example, the greatest proportion had been assigned “biology” as their research focus by CIHR and no researcher had been assigned “prevention”, mirroring the balance of the domains of those researchers who did respond.

Through the auspices of the PHAC/CIHR Research Initiative on Hepatitis C over its seven-year history, more than 18 million dollars Canadian has been committed to research operating grants, over one and three-quarters of a million dollars to salary awards and over three-quarters of a million dollars to training awards. These funding dollars compare reasonably favourably with those dollars made available by the Australian government through its National Hepatitis C Strategy but, not surprisingly, are much lower than those available for HCV research in the United States.

However, one of the objectives of the joint initiative was to *effectively and efficiently select and fund a broad spectrum of scientifically meritorious and relevant research*. The fact that nearly half of the researchers participating in this review identified themselves as basic science researchers suggests that the initiative may not have been particularly successful in this regard. Indeed, the fact that social science researchers lamented the lack of funding directed towards social behavioral research in general, and research on the social determinants of health associated with HCV infection in particular, lends credence to this contention. This imbalance in research focus also plays out in the data on the research domains of respondents. Biology, either as a single research domain (26%) or in combination with other domains (10%), predominated; whereas no respondent researchers stated prevention was their main research domain and only 13% combined prevention with other research domains. This situation has prevailed despite the recognition of the problem by CIHR which launched the Social and Behavioral Research Issues in HIV and Hepatitis C targeted call for research proposals specifically to respond to this issue; four projects were funded under this initiative.

The impact of this funded research has been notable in a number of areas. One of the most compelling outcomes of the joint initiative has been the extent of collaboration among researchers and a wide range of diverse groups in both the design of research and in the implementation of the research. Researchers attested that this collaboration would not have been possible without the impetus and funding provided through the initiative.

The extent of knowledge dissemination and knowledge transfer and exchange activities has also been impressive. Results of the researchers' HCV-funded research have been disseminated through a comprehensive range of activities including the traditional methods of presentations at national and international conferences to a largely professional scientific audience as well as at more community-based venues to non-professional audiences including people living with, or at risk of infection with HCV. The increase in HCV-related peer-reviewed journal articles by Canadian researchers in international journals deserves particular mention. The two-hundred-fold increase in publications in the scientific literature domain between the period prior to the commencement of the joint initiative (1997-1999) and the years following its establishment (2003-2005) attests to the utility of the initiative in this particular aspect of knowledge dissemination.

Capacity-building through supervision of graduate and post-doctoral students was considerable throughout the period of the initiative as nearly all researchers had supervised at least one graduate student in the HCV domain. The number of graduate students and, notably, post-doctoral students supported through joint initiative funds or training awards is another indicator of the success of the initiative in the capacity building domain. In this regard, the initiative can be considered to have successfully met another of the established objectives, that of increasing research capacity and productivity in HCV through training programs.

Achieving these significant outcomes has not been without some challenges from the researchers' perspectives. Whether related to the implementation of the research itself, or to the essential dissemination of emerging research findings, the lack of sufficient, sustainable strategic funding was seen by nearly all respondents as the major obstacle in conducting HCV research in Canada. The anticipated demise of the joint initiative with its protected funds for HCV research was a major concern. Researchers commented on the potential loss of research capacity in terms of new researchers entering the field, the loss of research infrastructure in terms of loss of the extensive funding required to equip labs to study HCV, and the overall loss of momentum and interest in HCV research initially engendered by the joint initiative.

Specifically, in terms of research knowledge transfer and exchange, further identified challenges lay in the lack of a national structure dedicated to facilitating and supporting dissemination of research findings among researchers from different disciplines, within the same discipline, to policy makers and to people living with, or at risk of, hepatitis C. This area clearly requires further development for the joint initiative to be considered to have met its objective of *encouraging the dissemination and uptake of research findings through the funding of special initiatives, workshops, colloquia, or other events designed to promote the synthesis of findings or to facilitate the uptake of research results by clients.*

Having achieved substantial progress in stimulating productive, informative, highly relevant and essential HCV research in Canada, further work is required to maintain this level of success and to respond to some of the obstacles to conducting and disseminating HCV research in Canada identified by the respondents participating in this review.

Sustainable, protected long-term funding in the context of collaborative planning and support was overwhelmingly considered the means to enhanced HCV research in Canada.

The results of such specific financial and resource allocation was considered necessary to achieve an increased pool of highly qualified researchers at all levels of experience and in all the multi-faceted areas of research to meaningfully respond to the socially important health issue of HCV prevention for those at risk of acquiring the virus; advanced treatment for those living with the virus; and care and support for those living with the long-term sequelae of the disease.

The sentiments of two researchers summarize the features described by many other researchers as essential to transfer research into action – “*An adequately funded research structure with an emphasis on dissemination*” which, the second researcher argues, can be achieved through a renewal of the PHAC/CIHR Research Initiative on Hepatitis C:

*It has been difficult to maintain a stable financing base to continue our research effort in HCV research. Ironically, this comes as our research program finally gets off the ground and real exciting research results are coming out. I believe this is a situation that is experienced by many Canadian investigators who were initially funded by the PHAC/CIHR Initiative in Hepatitis C. This type of situation should be taken into account when designing and launching strategic initiatives (the initiative on SARS is also a telling example). Not only does biomedical research take a lot of time, but it also represents an important investment in terms of an investigator’s career: when a researcher (and his/her team) choose to take on a novel scientific challenge and in so doing strays from his/her basic specialty, he/she should be offered more than temporary funding. **Otherwise, the long-term benefits for the research community, the patients, the population at large, and the country as a whole are compromised.***

5.0 Appendices

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