

# FINAL REPORT

## **A Coordinated Approach to HIV and Hepatitis C Research in Atlantic Canada: How do we get there?**

*A feasibility workshop for  
an Atlantic Regional  
HIV and Hepatitis C  
Social and Behavioral Studies Unit*

Written and edited by David Fletcher (People Development), Jacqueline Gahagan (Dalhousie University) and Aileen Reynolds (Atlantic Centre of Excellence for Women's Health)

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Sincerely,

Jacqueline Gahagan, Assistant Professor  
School of Health & Human Performance  
Dalhousie University  
Halifax, NS B3H 3J5  
Jacqueline.Gahagan@dal.ca

# EXECUTIVE SUMMARY

On August 27 and 28, 2003, 36 participants from the 4 Atlantic provinces met at a workshop titled “A Coordinated Approach to HIV and Hep C Research in Atlantic Canada: how do we get there?” The workshop was, in part, to investigate the feasibility of an HIV/Hep C Social and Behavioral Studies Unit for the Atlantic Region. The workshop was funded by the Canadian Institutes of Health Research (CIHR) with assistance from Dalhousie Research Services and the Nova Scotia Health Research Foundation. This 2-day workshop was hosted by the Atlantic Centre of Excellence in Women’s Health and the School of Health and Human Performance (Dalhousie University).

The workshop objectives were to provide an opportunity for networking among researchers in the region, to discuss the current gaps in HIV/Hep C research and to promote a coordinated, multidisciplinary & regional response to these research needs. This response was envisioned to include encouraging research teams to apply for funding and to determine the feasibility of a sustainable mechanism to enhance research collaboration around HIV and Hep C in the region.

The workshop was held over two days. Much was accomplished in such a short period of time. This was a result of the experience and commitment of those who gathered for the workshop representing the community, academic and government constituencies. Although coming from different perspectives, experiences and backgrounds, the respect, sharing and collaborative approach participants used to learn from each other was a model of what could be possible in the future.

Significant progress was made in naming the research agenda on HIV and Hep C in the Atlantic Region. Participants named ten major areas where there are research needs and focused on four research gaps that are particularly critically.

- Research with marginalized and vulnerable populations. (e.g. those tattooing in prison populations).
- The complex issue of harm reduction that needs more research done in a way that would show the value and importance of these types of programs.
- Investigating what determines the high-risk behaviors of many Atlantic Canadians that leads to HIV and Hep C infections will assist in developing prevention programs and policies that can make a difference.
- Policy influence and advocacy research including building in a strategy for research translation and uptake from the beginning of all initiatives.

There were also cross cutting issues identified concerning lack of understanding of Hep C by government and the general public, complex and far reaching issues around injection drug use, and broad issues around gay men’s health.

This articulation of a research agenda for the region is a major outcome of the two-day workshop. The fact that a number of participants volunteered to be identified with these issues to “keep the ball rolling” and serve as focal points for follow-up is also very encouraging.

As a result of the 2-day workshop it also became clear that a sustainable mechanism for research collaboration is feasible.

A sustainable collaborating mechanism is definitely relevant and needed, not only because of economic pressures, but also because of the mutually beneficial gain that can be realized. It is essential that a multidimensional collaborating mechanism must also be of high quality and principles.

The workshop participants agreed an overall coordinating structure to enhance HIV and Hep C research in the Atlantic region could get off the ground with a sub-group being established to develop the ideas and to pursue funding from CIHR for “interdisciplinary enhancement funding”. This group was established and is committed to submitting such a proposal in November of this year. In the mean time it was recommended that existing structures should be approached, like ACAP, NSHRF, PPHB to kick-start the process. It was also recommended that lots of work is needed up front and specific timelines and schedules need to be mapped out for planning this “structure”. Participants agreed that whatever the mechanism is called it will realistically need sufficient time and resources to evolve into an effective vehicle for enhancing collaborative research work.

Participants developed a number of tools that would improve collaboration efficiency. This included planning and facilitating productive regular meetings and using technology such as a web site, development of a database, and a list serve to improve networking, communication and information sharing. Involvement in peer review processes and developing graduate programs was also discussed. A logical, strategic process has been put in place for bringing the ideas to reality. Individuals, committees and organizations have taken on the responsibility and shown the commitment to take things forward. The human resources exist and the opportunities for financial resources have been identified. Grant proposals are being developed. In the interim, in-kind contributions may be available from some organizations and some collaboration and coordination can be done with existing resources.

The final, overall workshop evaluation was very positive. Great momentum was built during the workshop. Objectives were achieved and participants were confident the workshop will further research collaboration around HIV and Hep C in the region. Participants left with questions primarily around sustainability, concerned that the enthusiasm developed during the workshop may not be maintained and that people may not stay involved and follow-up consistently.

Clearly, follow-through and continuation of the momentum developed at the workshop is essential. This report can contribute to that in a small way, however, the real impact will come from participants, others interested in these issues, and organizations that will continue to pursue the goal of enhanced research on social and behavioural HIV and Hep C issues in the Atlantic Region.

# TABLE OF CONTENTS

Acknowledgements

Executive Summary

<u>1. Rationale and Overview of the Workshop</u>	
1.1 Background	1
1.2 Overview	1
1.3 Participants and Networking	3
<u>2. Exploring the Terrain - HIV and Hep C Research in the Atlantic Region</u>	
2.1 Provincial Perspectives on Current Research and Research Gaps	4
2.2 Research Gaps and Current Strengths Across the Region	10
2.3 Potential Priority Areas for Research	13
2.3.1 Research with Marginalized Populations	14
2.3.2 Harm Reduction	15
2.3.3 Determinants of Health	17
2.3.4 Policy Advocacy / Influence	18
<u>3. Promoting Collaborative, Multidisciplinary Research</u>	
3.1 Looking at Research Approaches and Finding Complementarities	20
3.2 Dos and Don'ts for Collaborative Research	23
3.3 General Recommendations for Follow-up	24
<u>4. Assessing the Feasibility of A Sustainable Coordinated Mechanism to Enhance Research Collaboration</u>	
4.1 Why Is a Sustainable Mechanism Needed?	25
4.2 What Could a Sustainable Mechanism Look Like?	27
4.3 How Could a Sustainable Mechanism Be Put in Place?	34
4.4 Other Possible Actions for Follow-Up	36
<u>5. Conclusions and Outcomes</u>	
5.1 Naming the Research Agenda	39
5.2 Feasibility of a Regional Collaboration Mechanism	40
5.3 Evaluation and Conclusions	42
<u>Appendices</u>	
A - Workshop Agenda	
B - List of Participants and Coordinates	

# ***Final Report of the Feasibility Workshop on “A Coordinated Approach to HIV and Hep C Research in Atlantic Canada”***

## **1 RATIONALE AND OVERVIEW OF THE WORKSHOP**

### **1.1 Background**

On August 27 and 28, 2003, 36 participants from the 4 Atlantic provinces met in Halifax, Nova Scotia for a workshop titled “A Coordinated Approach to HIV and Hepatitis C (Hep C) Research in Atlantic Canada: how do we get there?” The workshop was, in part, to investigate the feasibility of an HIV/Hep C Social and Behavioral Studies Unit for the Atlantic Region.

The impetus for the workshop arose out of discussions Jacquie Gahagan had with delegates at the Canadian Association for HIV Research (CAHR) Conference, held in Halifax, Nova Scotia in April 2003. Discussions with a variety of groups and individuals at this annual conference led to the identification of the need for a coordinated Atlantic Regional strategy for HIV and Hep C research. During the workshop, participants explored how to augment the response of Atlantic Canada in HIV and Hep C social and behavioral community-based and university-based research.

Six specific objectives were set:

- 1) to bring together a group of HIV and Hep C community- and university-based researchers;
- 2) to discuss the current gaps in HIV and Hep C research in the Atlantic Region;
- 3) to promote a coordinated, multidisciplinary and regional response to HIV and Hep C research;
- 4) to encourage research teams to apply for regional and national funding;
- 5) to determine the feasibility of developing an Atlantic Regional HIV and Hep C Social and Behavioural “Studies Unit” to help facilitate and coordinate the research teams and to determine the scope and parameters of such a proposed “Studies Unit”; and
- 6) to develop a final workshop report that includes the identification of themes and an action plan, to be sent to various HIV and Hep C stakeholders.

### **1.2 Overview**

The workshop was held over 2 days. The first day focused on “checking out the situation”, while the second day looked at “strategizing around complimenting each others work”. Major sessions included introductions, current research/research gaps, research approaches, mechanisms and structures for sustaining research, working out details and bringing it all together. A copy of the workshop agenda is presented in appendix A.

***How can we as an Atlantic Canada unit put together proposals so as not to compete for funding amongst one another?”***

**Jacquie Gahagan**, (Assistant Professor, School of Health and Human Performance, Dalhousie University) the co-initiator of the workshop with Eric Mykhalovskiy (Assistant Professor, Department of Community Health and Epidemiology, Dalhousie University), opened the workshop by welcoming participants. She explained that the feasibility workshop emerged from discussions at the 2003 CAHR conference about the lack of an Atlantic perspective reflected in the so-called

“national” understanding of social and behavioral HIV and Hep C research. Jacquie thanked participants for coming together and asked them, “How can we do our work in a more coordinated, interdisciplinary way and secure funding as an Atlantic regional unit for social and behavioural HIV/Hep C research?” She thanked the Canadian Institutes of Health Research (CIHR) and Nova Scotia Health Research Foundation (NSHRF) for funding the meeting and recognized the support also received from Dalhousie University Research Services. She also thanked Aileen Reynolds from the Atlantic Centre of Excellence for Women’s Health (ACEWH) for her assistance in the overall coordination of this workshop. Jacquie then called on two special guests for words of welcome.

**Krista Connell, Executive Director of the Nova Scotia Health Research Foundation (NSHRF)**, explained that NSHRF is a research capacity building organization that helps with grant writing, collaboration, and capacity building and that they are happy to support gatherings such as this. She reminded participants that NSHRF has an annual competition May 1st, with three categories of grants: 1) individual – within 5 years of an academic appointment or attainment of a PhD, whichever is later; 2) collaboration grants – community groups, university, which are open to all Nova Scotia researchers; and 3) capacity competition. This final category provides Community Research Alliance grants, which provides up to \$20,000 for new teams, and development grants, which involve preparation work before going national and provides up to \$10,000.

**Barbara Clow, Executive Director of the Atlantic Centre of Excellence in Women’s Health (ACEWH)**, explained ACEWH has a gender and HIV/AIDS program area within the Centre with a focus on the impact of gender on HIV-related vulnerabilities. She described how calls for proposals and grants related to HIV/AIDS and Hep C do reach the Atlantic region but that it is a major challenge to secure funding in the region over other parts of the country. She recognized that it was a significant accomplishment to simply getting everyone here for these deliberations and emphasized Atlantic Canada has a great group of people for ongoing research collaborations related to HIV/AIDS.

### **CIHR and Hep C / HIV Research Priorities**

**Bruce Moor, Assistant Director of the Institute of Infection and Immunity (III) from the Canadian Institutes of Health Research (CIHR)** then set the stage for the workshop with a presentation on CIHR’s Hep C and HIV Research Priorities. Bruce pointed out that his Institute has the responsibility for the effective implementation and delivery of the Institute’s strategic research programs, with a particular emphasis on the Institute’s strategic priorities related to HIV/AIDS. In his presentation he provided the background on CIHR, the federal agency that has over \$600 million for health research and a strong interest in HIV and Hep C. He emphasized that CIHR would like to promote the success of researchers in the area of HIV/AIDS and Hep C across the country. He described that Health Canada gave responsibility to CIHR for the administration of Canadian Strategy on HIV/AIDS research funding, and that HIV has become a strong focus of research at CIHR. Similarly, there is a Health Canada/CIHR Research Initiative on Hep C. This funding stream has funded a significant amount of Hep C research and has been directed recently to develop socio-behavioural Hep C research. He explained that funding for HIV/Hep C could be significantly increased, perhaps even doubled in the future. Bruce brought participants’ attention to the Institute’s interdisciplinary capacity enhancement team grant call for proposals that has been released, with registration due on November 1,

***CIHR  
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researchers in HIV  
and Hep C across the  
country.***

2003. He described CIHR's focus on knowledge translation and reminded participants that applications which include a plan for knowledge translation would benefit from this when reviewed. Bruce shared materials and provided his contact information and the CIHR website at [www.cihr-irsc.gc.ca](http://www.cihr-irsc.gc.ca). This was a valuable and informative launch to the workshop as it let people know there is support and encouragement and a policy mandate for research in this area. His full report is available in Appendix B.

The workshop was then turned over to David Fletcher of Holistic Community Pursuits, a Halifax based consulting firm, who acted as facilitator. He explained the approach designed for the workshop was to be invigorating, action oriented, participatory, inspiring, respectful, experience sharing, open, and cutting edge.

This report reflects the outcomes of the workshop organized around the stated objectives. It is not comprehensive of every nuance and discussion that occurred, but hopefully captures the intensity and flavour of the workshop and the wealth of expertise and sharing that took place. The ultimate indicator of the workshop's success will be what happens in HIV and Hep C research in the Atlantic region over the next few months and years. This report is primarily intended for those who attended the workshop and for funders and others interested in collaborative social and behavioral research related to HIV and Hep C, particularly in the Atlantic region.

### **1.3 Participants and Networking**

The first objective of the workshop was "to bring together a group of HIV and Hep C community and university based researchers". Those who attended this workshop far exceeded organizers' initial expectations. It is clear that there is a considerable amount of interest and expertise in the Atlantic region regarding HIV/AIDS and Hep C research and community activism. Thirty-six people participated, representing all four Atlantic provinces (NS-24, NB-3, NL-3 and PEI-4, Others-2). The participants represented community groups (13), academia (18) and government (5). See appendix C for a participants' list with coordinates.

At the end of the first day of the workshop interim evaluation findings demonstrated that meeting with others and networking was proving beneficial. Participants mentioned the sharing of different perspectives, the diversity of individuals working together as a unit, and the simple fact of meeting people face-to-face was useful.

Networking and discussions throughout the day generated great ideas and demonstrated the ongoing dedication people have to this work.

At the end of the workshop almost all the comments on highlights of the workshop were related to the networking and discussions that occurred over the course of the workshop. People commented that the networking and discussions of a diverse group of individuals demonstrated how to work collaboratively. Individuals commented that they have a better understanding of the confines/processes involved with other 'systems' and that they will return home more ready, willing and able to collaborate with others.

The first objective of the workshop was therefore achieved.

*Congratulations for getting people together, helping to make new contacts and preparing the ground work for collaborations.*

## 2 EXPLORING THE TERRAIN - HIV AND HEP C RESEARCH IN THE ATLANTIC REGION

This chapter explores the terrain of HIV and Hep C research in the four Atlantic Provinces: What is happening in each province? What are the strengths? What are the gaps? What are the priorities? What are potential next steps? One of the objectives of the workshop was “to discuss the current gaps in HIV and Hep C research in the Atlantic Region”. This chapter provides evidence that this objective was accomplished. Another objective was “to encourage research teams to apply for regional and national funding”. Section 2.3 below demonstrates that there are a number of teams evolving in the region that are motivated and enthusiastic about pursuing a variety of collaborative community/university research opportunities.

The chapter begins with a synopsis of four provincial perspectives on current research and research gaps, including an aboriginal perspective. The second section reflects conversations that groups of participants had concerning research strengths and gaps. The list of gaps identifies the great breadth of research needs within the region. The third section names some potential priority areas for research and reports on a number of focused discussions participants had on particular research issues such as marginalized populations, harm reduction, determinants of health, and policy advocacy and influence.

This chapter does not comprehensively name the social and behavioral research agenda for HIV and Hep C in the Atlantic region, but it does provide a common place from which workshop participants and other colleagues can continue their work and share their expertise and interests.

### 2.1 Provincial Perspectives on Current Research and Research Gaps

Representatives from the four Atlantic provinces were asked to launch the workshop by sharing, from their own experience, what some of the current research and research needs around HIV and Hep C are within their province. A speaker was also invited to provide an Aboriginal perspective. Below are some highlights paraphrased from each of the presentations.

#### Prince Edward Island

**Barb Gibson**, Executive Director, AIDS Prince Edward Island, who has been working in the field of sexuality education and HIV/AIDS since 1986, provided the first presentation.

The research gaps in PEI are broad. AIDS PEI is a small organization with minimal money, and therefore a minimal amount of research is being done. Unfortunately, there are a significant number of residents and government officials who deny the existence of Hep C and HIV in the PEI community. Injection drug use (IDU) is another issue that seems to be surrounded in denial. AIDS PEI was the first organization in PEI to conduct a needs assessment of IDU in PEI. Currently one individual with previous IDU experience is on the AIDS PEI staff and is looking at the needs of IDU throughout PEI. Due to funding requirements, the organization struggles to keep up with reports required by funders, the services being offered, and the development of new research.

*Injection drug use is another issue that seems to be surrounded in denial in PEI.*

The research that has been completed at AIDS PEI has often been focused on needs assessments or informal research completed between staff and service users. AIDS PEI is finding it difficult to address substance abuse due to the community environment and the denial that surrounds the issue. Currently there are no needle exchange programs within the province, there is resistance to harm reduction initiatives, only abstinence programs exist at rehabilitation centres, and the community is not supportive of methadone use.

AIDS PEI is looking for information regarding what to do next, specifically how they can change policy and attitudes within the province and potentially build an alliance to move the harm reduction agenda forward. Specific things that are believed to be missing in PEI include: the lack of accurate and timely HIV and Hep C surveillance, the lack of co-infection information, and a lack of information to determine if anonymous testing is viable for a province like PEI.

### **Newfoundland and Labrador**

**Bill Downer**, Executive Director of the AIDS Coalition of Newfoundland and Labrador (ACNL), who has been worked in the field of HIV/AIDS for 15 years, gave the second presentation.

In Newfoundland and Labrador there are approximately 110 people living with HIV/AIDS and 77 of those are in contact with ACNL. There are 22 known co-infections and 470 reported Hep C cases (80% male).

ACNL has conducted workshops throughout NL with Hep C, and many of those have been done in remote locations. Workshops were held at both male (5) and female (1) correctional institutions. These workshops included culturally specific training developed in collaboration with an Aboriginal group. It is an exciting action research project and a report is available.

Researchers at Memorial University of Newfoundland (MUN) have done research on HIV and are tracking 22 co-infections. The University of British Columbia (UBC) is also collaborating with ACNL and other partners on a 4-year project looking at the impact of technology on delivering health information to individuals. This project is awaiting a funding decision.

*He explained he felt comfortable coming to the exchange to get needles for his friends because he's a PHA and has gone there before while others are concerned about the stigma.*

Similar to AIDS PEI, ACNL found much research is being done through interaction between staff and service users. This research provides practical information and does not depend on funding. For example, a recent discussion with an IDU about the situation revealed that he knew about 15 people in St. Johns using needles even though the number coming to the centre is much smaller than that. He explained he felt comfortable coming to the exchange to get needles for his friends because he's a PHA and has gone there before while others are concerned about the potential stigma associated with accessing such services.

Minimal information is available on IDUs in Newfoundland and Labrador. A needle exchange is only located in St. John's and it cannot serve the entire population. IDU is not seen as a priority by government and communities. There is a belief by many in health and social services that there are little or no IDU activities going on. It is an issue that must be addressed. A priority is to start gathering information and working with this population.

ACNL works well with both community based researchers and academia, yet there is still a need for more coordinated collaboration.

### New Brunswick

**Margaret Dykeman**, President of AIDS New Brunswick and an Associate Professor at the University of New Brunswick (UNB), provided an overview of the situation in NB.

A number of research studies have taken place in New Brunswick over the past decade or more. These include a seroprevalence study, workplace studies, two needs assessments of PHAs, outcomes of disclosure, and peer education of inmates. Extensive project work has been carried out by ASOs. This work is more community-based than academic and is focused on real, immediate needs such as harm reduction.

Plenty of work has been done around sex education including studies on men having sex with men, attitudinal studies, sex risk behaviours of students, comparisons of safer sex interventions, and attitudes towards female condoms. One researcher is trying to determine what to tell children about sex. The focus is to find out what should be taught in schools and directing curriculum change. Other researchers are focusing on IDU issues. Some of their key questions are “how did users get into drugs in the first place and how did the structure let them down?”

*More Hep C research is needed around rural issues and prison issues.*

Huge gaps still exist, however. The government does not support harm reduction, there are few needle exchanges, and the IDU population is growing rapidly. More Hep C research is needed around rural issues and prison issues. There is also little information about women, despite the fact that women are becoming infected more and more through IDU.

There is no provincial HIV strategy for NB. The argument is there is no money for this. There is no support for methadone programs. Research is required to verify the need. Outcome measures are required to justify the value of the work. Potentially cost-analysis work should also be done because this seems to be the way to speak to government.

Unfortunately, research is being done piece meal. A group is needed with cohesive properties. It is impossible to get good epidemiological statistics in the province. One community clinic has diagnosed 10 new Hep C cases recently so there is obviously a rise in the Hep C problem, but epi stats do not depict this. Research on this and other issues is essential and must be done strategically to lead to policy change.

### Nova Scotia

**Robert Allan**, Executive Director of the AIDS Coalition of Nova Scotia (ACNS) who has been involved in community based AIDS work for 17 years, and **Scott Hemming** a consultant focusing on issues surrounding viral hepatitis and a board member of the Hepatitis C Society of Canada gave a joint presentation on the situation in Nova Scotia.

ACNS has been involved in research over the years, as that is part of their mandate, although there are fewer resources available now than previously. The ACNS website describes some of the current and past research that has been focused on learning about HIV/AIDS. A big project was carried out recently in partnership with Mount Saint Vincent University (MSVU) and the Sharp Advice Needle Exchange. This was a successful example as results were incorporated into a workshop held as part of a skills building Ceilidh. Needs assessments for various projects have been carried out and presently ACNS is developing a community-based research proposal looking at gay/lesbian health needs.

*There is also a need to re-focus on gay men, and to gather more co-infection information.*

The Nova Scotia Strategy on HIV/AIDS will be released in October 2003. It will, among other things, set the strategic direction for research in Nova Scotia. It is an exciting piece of work that will emphasize intersectoral work. Mr. Allan went on to outline the need for more work on mental health issues and PHAs, more work on issues with HIV-positive women, and a prevention focus for gay/lesbian health. There is also a need to re-focus on gay men, and to gather more co-infection information.

Limited resources have gone into Hep C issues. That is true nationally as well as in Nova Scotia. Diagnosis and stigma, routes of infection, community response, symptoms and complications are all things people need to learn more about. There are significant psychosocial reactions, fear, denial, isolation, anger, and lots of inaccurate information that needs to be investigated. There are challenges around stigma and discrimination, labeling, barriers to support, disclosure issues, and occupational concerns. More research is clearly required to address these various health issues. There are organizations such as the Canadian Liver Society working on these issues, but the need is great. The Hep C Society of Canada has no staff. The Hep C Outreach Society in Nova Scotia is the only organization in Canada of its kind to have a staff person, yet 300,000 people are infected across the country. Routes of transmission, such as IDU, transfusions, toothbrushes, drug paraphernalia, occupational risks, tattooing, piercing, as well as symptoms such as fatigue, cognitive impairment, sleep/wake cycles, depression/mood disorders, cirrhosis, liver cancer, and death all need to be researched in more detail. More surveillance is also clearly needed. More collaboration, capacity building and involvement of different sectors is needed for this research to be successful.

### First Nations

**Amanda Feltus**, Acting Executive Director of Healing Our Nations, an organization which provides education and prevention on HIV/AIDS to the 31 First Nations communities in the Atlantic region, completed the panel of presentations by speaking on the situation as it affects aboriginal people.

Healing Our Nations has not done much formal research to date. What they have done, however, has been community-based research. For example, a student has been hired and is teaching others in the community what HIV and Hep C are and is conducting a needs assessment. The focus is on direct services: What do these communities need?

One constraint is that people do not like outsiders coming in to do research. There is mistrust and miscommunication. Even staff from Healing Our Nations are not welcome into some communities, yet there is a definite need for more research. Issues of concern hinge around empowerment and ownership of research.

Researchers have to respect that aboriginal populations are very diverse, and are disproportionately affected by drug issues, poverty, HIV, Hep C, etc. There are many determinants of health issues that impact on the lives of aboriginal populations, including racism, exploitation and increased vulnerability. These issues must be looked into. Community based research is needed around issues such as how to conduct culturally sensitive research.

Aboriginals comprise 2.8% of the Canadian population. Statistics about their health are hard to measure however, partly because few statistics have ethnic identifiers. This makes it hard to track. Nationally, no one has any idea what the actual numbers are and therefore there is a great need for more aboriginal research, specifically epidemiological information.

*Estimates show that one new aboriginal person is infected with HIV or Hep C each day.*

Injection drug use is a big problem. It is the main cause of HIV in this population. It is imperative to recognize that the epidemic in aboriginal populations is not slowing. Estimates show that one new aboriginal person is infected with HIV or Hep C each day.

**DISCUSSION:** Following the provincial presentations, there was a brief question and answer period and discussion.

*REGIONAL RESEARCH:* One of the questions brought forward was whether much research has been done within and among provinces? Panelists responded that some work has been done, such as an Atlantic Canada IDU survey, and some work on HIV/AIDS and palliative care, but for the most part collaborative, interdisciplinary, Atlantic regional work is hard to do. “Collaboration takes time and money”, one panelist responded. Another participant shared that his clinical work is with four provinces, with four different systems and ways of working, and that these provinces need to come together. He said he finds his work at the whim of provinces, and believes the federal government needs to lead the way in promoting Atlantic wide, collaborative research.

*Since Atlantic Deputies and Ministers want to work together more than they did a couple years ago, an opportunity exists to foster more collaborative work.*

Other participants raised the challenges of bilingualism, and the fact that Newfoundland and Labrador often get left out of Maritime initiatives. Essentially, however, all panelists shared that they work with small, resource strapped organizations that are only mandated to look after their own province. There seemed to be some agreement that Atlantic Canada does have it’s own unique lens on the issues and this requires a more strategic process. One participant stated that work needs to be done to identify the barriers that prevent provinces working together. “Since Atlantic Deputies and Ministers want to work together more than they did a couple years ago, an opportunity exists to foster more collaborative work.” Participants also stated that more funding is being put into envelopes for the Atlantic region.

*IMPACT RESEARCH:* Another issue brought forward was that AIDS Service Organization’s are producing research, but often not through their involvement in externally funded research projects. Appreciating needs assessments done internally for project delivery, for example, may be an entry point for organizations to get more involved within funded programs. A participant stated that health service delivery is key, and this orientation may be used to get federal or institutional funding. “What is the impact on health services?”, is the question that is important to funders.

*RESEARCH WITH ABORIGINAL POPULATIONS:* An important issue was raised concerning the lack of capacity building in aboriginal communities. The suggestion was made that projects could help train people in community-based research within the community. Hearing the unique perspectives on issues related to the Atlantic versus provincial concerns, the Aboriginal perspective has added a layer of unique challenges. Participants agreed that training community members is a better approach than bringing outsiders in, however, this approach can be problematic for funders. Funding often starts for people with a completed PhD. The example was given that the Institute of Aboriginal People's Health at CIHR will not likely fund a proposal submitted by a PhD student until after she finishes her studies. This is a problem. Most community-based researchers do not have a completed PhDs. It was felt that the CIHR has an Aboriginal Institute that can't be used to its full potential because of these restrictions. Clearly, these structures need to be investigated.

*MARGINALIZED GROUPS:* Finally, an issue was brought forward concerning some of the epidemiological challenges researchers are experiencing. Much information is not gender disaggregated and this hampers the ability to know the specific needs of males and females in terms of HIV and Hep C. In a similar vein, a participant asked if visible minority groups are using the services represented by the presenters on the panel. She asked, "What are the numbers? What do these groups look like? What about immigrants? What are community-based AIDS Service Organizations seeing in this regard?"

It was reported that Newfoundland is not usually a prime destination for immigrants, although St John's does have an organization for immigrants. Innu and Inuit issues are important in Labrador. Nationally, there is evidence that there are high Hep C rates because of transfusions in the immigrant population so there are concerns, although a strategy is not yet in place. In Nova Scotia, work was done years ago with the African Nova Scotian population, but funding for these projects keeps getting cut and they are not seen as a priority for most funders. In New Brunswick, it was reported that some homeless and addiction work has been done with new immigrants, and a number were found to be infected with Hep C. The issue in this case is whether the people will get full health care coverage. Others stated cultural issues are a concern with new refugees from Africa and elsewhere who have settled in urban centres over the past couple of years. One participant reported that in her clinical work, data are collected on ethnicity for the injection drug community and a report is available.

***Gender is a big problem.***

It was argued that in some places, like St John's, there are not many cultural or ethnic issues, but that gender continues to be a big problem across all provinces.

These brief presentations and discussions provided the starting point for the workshop. Participants were then assigned to mixed groups (participants from different provinces and different backgrounds) and asked to build on the presentations by adding their own experiences, particularly in relation to research issues and priorities. This provided another excellent opportunity for networking. The groups were asked to determine significant research gaps and issues in the region that need to be addressed. In acknowledgement of the experience and strengths that already exist within the region, the groups were also asked to highlight some of the strengths that can be built upon. These two sets of lists are presented in the section below.

## **2.2 Research Gaps and Current Strengths in the Region**

All of the ideas recorded by the working groups were categorized into themes by members of the organizing committee. This was done with the intention of summarizing and clarifying issues to some extent, while still being comprehensive of the wealth of information brought forward.

The issues and gaps are many and cover a broad spectrum. Categorizing the issues helps demonstrate where the priority needs may lay, yet may also downplay some significant issues that are of paramount importance for certain communities or groups of researchers. The strengths articulated may identify particular areas where the region has leverage for doing stellar work. The lists make a contribution by capturing a brief overview of the current status of research in the region. They were used for focusing later discussions in the workshop. In the future, these lists could be used as a starting point within a strategic planning exercise to target particular areas of research to be undertaken.

<b>Research Gaps in the Atlantic Region</b>	
<p><b>1 EPIDEMIOLOGICAL INFORMATION</b>            -Epi and Surveillance            -Prevalence information not readily available            -Access to epidemiological strategies            -Epidemiological information to guide research            -Epidemiological data that is up-to-date            -Need to understand the impact of disease and symptoms            -Need for Social and behavioural HIV and Hep C issues to be recognized as a viable/important research area in epi stream            -Need for disaggregated data by sex &amp; ethnicity</p> <p><b>2 RESEARCH WITH MARGINALIZED GROUPS</b>            -Further information from corrections services            -Further Aboriginal information and services            -Further prevention strategies for marginalized populations            -Issues for specific populations e.g. Immigrants, African Nova Scotians            -Aboriginal AIDS strategy            -Gender Based analysis research            -Expertise in gay and lesbian health            -Power/Empowerment issues in CSC context            -Sex workers</p> <p><b>3 HARM REDUCTION RESEARCH / PROGRAMMING</b>            -Consistent harm reduction approaches and a need for support of this method            -Best practice and harm reduction strategies</p> <p><b>4. RESEARCH RE: PROGRAM / SERVICES EFFECTIVENESS</b>            -More evaluation research directed at existing programs and services            -CBO's and mode of delivery in health services            Others:            -Public Awareness – to prevent stigma            -Skill building for community and university collaboration            -Need for anonymous testing E.g. PEI            -Need to understand/respond to use of prescription drugs for IDU</p> <p><b>5. SPECIFIC ISSUES AROUND THE NEED FOR HARM REDUCTION STRATEGIES FOR MEN HAVING SEX WITH MEN IN THE PRISON CONTEXT</b>            -issues of safe sex inside; not only explain risk factors, but educate, provide space for safer sex            -issues of non-consensual sex            -stigma and assault issues (rape)</p> <p><b>6. PRISON PROGRAMS – RESEARCH NEEDED TO JUSTIFY ISSUES SUCH AS:</b>            -safe sites for tattooing in prisons            -needle exchange programs in prisons            -condoms – and security issues/accessibility            -screening of inmates on admission versus x years later</p>	<p><b>7. FUNDING RESOURCES</b>            -Lack of Hep C resources            -No operational funding for Hep C            -Lack of social science funding in HIV &amp; Hep C research            -Lack of funding for pilot projects, team capacity and large research projects            -Cut backs in the transportation of service users            -Further regional funding            -Funding mechanism that are applicable to non-traditional research and research agencies            -More recognition of CBR from funding agencies            -More money for region – often cost more to do same research in this region due to travel etc.            -Funding mechanism (can be small) to support non-traditional non-established researchers</p> <p><b>8. POLICY ADVOCACY RESEARCH AND / OR STRATEGIES</b>            -Lack of research turning into gov't policy            -Political opinions within the region need to be encouraged to change            -Strategy to take findings to decision makers so they will change            -Need for Social and behavioural HIV and Hep C issues to be recognized as a viable/important research area in epi stream            -Locally we need to take what we know to change policy            -Atlantic provinces economic burden of blood borne pathogens</p> <p><b>9. DISSEMINATION OF RESEARCH STRATEGIES</b>            -Need for more project follow up            -Dissemination and implementation of findings            -Need for next steps with research            -Gathering together what has been done – within region and elsewhere            -Sharing research Direction 180 and Mainline have already done            -Methadone issues; stakeholders need to know impacts            -Knowledge translation and uptake – recognize allies who support this work (CIHR) and find champions to take it forward with others; specifically around harm reduction strategies</p> <p><b>10 DETERMINANTS OF HEALTH RESEARCH</b>            -Exploration of the impact of determinants of health of HIV and Hep C            -Incorporation of the determinants of health into research initiatives            -Specific work in Atlantic Canada to study determinants that lead people to IDU            -Evaluation of culturally specific strategies            -Need to understand the impact of religion on issues related to HIV and Hep C            -Gender Based analysis research and disaggregated data</p>

## **Research *Strengths* in the Atlantic Region**

### Interest, Dedication and Commitment

- High interest level within the region to do research
- More than one group of individuals with a high interest to initiate research in HIV&HCV
- Dedicated individuals and a relatively small group of people who work efficiently together
- Proposal in Halifax for community-based HCV clinic with methadone

### Community Experience

- Strong community-based movement which reflects our creativity and resourcefulness
- Nova Scotia: needle exchange & methadone programs
- Every province has one or more ASOs
- Experience in needs assessments

### Academic Experience

- We have the academic and human resources to get the work done
- Academics in all four provinces interested in or already doing research
- Addictions Research Centre in PEI with full time researcher associated with Harm Reduction
- Academic community connections exist

### Networking and Partnerships

- Good mix of academic and non-academic individuals
- Strong regional networks of various types exist
- Resources in the room; knowledge & experience
- CBAO's have partnerships that are well established
- Partnerships have been developed between CBO's and universities
- Forged strong partnerships
- Small community means easier networking
- Familiarity with one another within the region
- There is a real mix of gender and orientation for those working in Newfoundland

### Policy Development

- HIV Provincial strategy in PEI and NL
- NS has almost completed their AIDS strategy

### Struggle

- Increased knowledge / creativity / resourcefulness because we have to work harder as compared to rest of country

### Shared Context

- Cultural issues we share
- Dealing with similar issues within the region

### Resources

- HIV groups have access to resources
- CIHR willing to fund research for all Atlantic provinces
- CAAN funds students to do community based research in aboriginal communities
- Healing our Nations has financial support from chiefs

**DISCUSSION:** In highlighting the key points from these lists, participants spoke out on five issues.

1) *ADVOCATING WITH GOVERNMENT AND THE PUBLIC:* The federal government has it in their mandate and mission that they have to do disease prevention. We should be able to make them accountable to support more. The public also needs to support these issues. Everything does not need to be framed in regards to saving money, but it is one strategy to sell new ideas to many audiences. Harm reduction, for example, can be promoted from an economic angle to capture the public's attention.

2) *HARM REDUCTION:* Extensive work is needed on harm reduction because policy makers don't want to understand the issue. Investigating how has harm reduction been staged in different provinces will be valuable. Clarifying that provincial funding is responsible for harm reduction efforts is also necessary. In

***Harm reduction  
needs an image  
makeover!***

regards to this, many participants were surprised that methadone isn't available everywhere and that some people have to pay for it.

3) *FUNDING*: There were some differences of opinion among the group concerning levels of funding in different provinces and jurisdiction over certain areas of work. Clarity on these kinds of issues would obviously be valuable and perhaps a regional “mechanism” could help to develop that clarity. What was clear, however, was that funding for programming and research in each province is limited and more resources for community-based studies are needed. More operational funding is also needed across the board. When programs get pulled, clients feel let down and trust is broken.

4) *DETERMINANTS OF HEALTH AND POLICY CHANGE*: There was agreement that it is necessary to study the determinants of health in Atlantic Canada that lead to drug use and high risk behaviours that lead eventually to Hep C and HIV cases. It was suggested that framing of research projects must include policy change and dissemination in their design. More generally, it was agreed that we all need to study mechanisms of change and look at how we can influence policy with our research. “How can we ensure knowledge transfer and uptake?”, was a phrase that was repeated over and over again. CIHR places emphasis on this.

5) *RESEARCHER RELATIONSHIPS*: Finally, it was agreed that there is a need to lobby for funding opportunities for non-PhDs, and non-traditional researchers. There needs to be a recognition that some university-based researchers may intimidate CBAO workers, and that university-based researchers might be intimidated by the community at the same time. Team building for collaborative, interdisciplinary research is necessary.

*How can we ensure knowledge transfer and uptake?*

### 2.3 Potential Priority Areas for Research

During the second day of the workshop, participants were asked to vote for the four “research issues” that they thought deserved some more focused discussion. All possible areas of research were considered important, but as an activity to effectively use the time available, a “dotmocracy” was used as a method to identify and prioritize issues for more in-depth discussion.

Results of the voting activity were:

	7	Epidemiological Information
Chosen for further discussion	17	Research with Marginalized groups
Chosen for further discussion	18	Harm reduction research / programming
	8	Research re: Program / Service Effectiveness
	1	Specific Issues around the need for harm Reduction Strategies for Men having Sex with Men in the Prison Context
	7	Prison Programs – research needed to justify issues such as safe sites for tattooing and needle exchange
	8	Funding resources
Chosen for further discussion	13	Policy Advocacy Research and / or Strategies
	4	Dissemination of Research Strategies
Chosen for further discussion	11	Determinants of Health Research

Each of the 4 priority research areas that were identified were assigned to a table for further discussion. Participants were asked to choose a particular discussion table based on their own research interests. Groups of 4 to 7 participants then had the opportunity to discuss for 90 minutes about these potential priority areas for research. Progress was made in sketching out some potential research proposals for possible follow-up. Groups presented their ideas back to plenary and received important feedback and suggestions.

Presented below is a synopsis of the ideas that emerged from each group. Extensive development is still necessary, yet now there is a starting point that people can build upon. There is also a contact person, someone to “keep the ball rolling”, for each issue. Other people from across the region, in both community and academic environments, who are interested in supporting and contributing to the development of collaborative, multidisciplinary research on these issues need to make their interest known.

### **2.3.1 Research with Marginalized Populations – Group 1** ***Safe Tattooing Space in Prisons***

*THE ISSUE:* It was identified that research with marginalized and vulnerable populations is urgently needed in the region and that there are many important issues. A wide range of research topics and questions could be developed for First Nations, African Nova Scotians, heterosexual women, incarcerated populations, IDUs or other populations. For the purpose of this exercise, the marginalized populations group chose to discuss the idea of “safe tattoo space within prisons” as the key researchable issue.

*RESEARCH QUESTIONS:* What are the social, cultural, political, historical and economic constructions of tattooing among inmates in federal corrections facilities in Atlantic Canada? Why do people get tattoos? Is there an issue around tolerance to pain, belonging? What is significant about tattooing as a gay issue, an HIV or hepatitis issue? Another set of questions for investigation were: What is the injection drug user culture in rural and urban communities – differences? similarities?

*IMPORTANCE:* The group agreed that these issues are of critical importance because the public and Corrections Services Canada (CSC) need to be educated about the importance of harm reduction and access to treatment so that effective programs can be put in place for vulnerable, incarcerated populations. The issue is particularly important for health promotion among marginalized groups within the prison setting (e.g., heterosexual women, IDU, Aboriginal, and African Canadians)

*RESOURCES:* The group asserted that Community-based AIDS Service Organizations (CBASOs), researchers, academia, and CSC staff locally and in Ottawa are all resources that are needed. It was made clear that links to Corrections Canada in Ottawa would need to be made as they have ultimate jurisdiction over what research can go on in CSC facilities. It was decided that it would be important to “go to the top” to make this work a reality. Contacting Ottawa directly to lobby and network with other groups doing similar work would be imperative. Working with the halfway house system would also be important. There would be a need for a physical space, confidentiality, and safe space for both the interviewing and any subsequent programming.

*PARTICIPATION:* The most essential input for this research would be insider knowledge from inmates. To secure this involvement, the biggest challenge would be developing trust. It was made clear that prisoners tend to trust CBASO's rather than academics. Other key informants such as health professionals in prisons would be valuable, but they may be concerned about liability and therefore not want to talk. Peer led training initiatives could be a key component, involving interviews of inmates establishing trust with other inmates. Creating a citizens advisory committee would be valuable.

*FEEDBACK QUESTIONS / COMMENTS / SUGGESTIONS:*

- An addition to the research could be looking at the burden on the health care system as a result of unsafe tattooing.
- Exploring the issue in relation to the reintegration into society of inmates would also be valuable. It is clear that many inmates want safe tattoo spaces. Some inmates are artists and could set themselves up for jobs as tattoo artists outside of prison. The "Hope deck of cards" that has been produced was given as an example.
- Local projects could be layered. One participant explained, "when you apply for large funding, they want proof that you have done other studies. Therefore, map out where you want to go over time. Develop small projects going towards a big one. Test out methods, and test out conceptual models to ultimately lead to a bigger project. This process is important to build in order to be competitive."
- It will be important to have good surveillance information to start. The Northern AIDS Connection in Truro is willing to do some work on this, but they are not operationally funded and do not have researchers, and simply survive on project funding. Therefore they may need to call on other researchers to help.

*I have been  
becoming cynical.  
It is a long time  
since I have been  
excited about a  
research project.  
This is great!*

**KEEP THE BALL ROLLING:**

- ❖ Al McNutt (t\_o\_p2000@hotmail.com) agreed to be the point person for follow up on this issue.

**2.3.2 Harm Reduction – Group 2**

*THE ISSUE:* This group reported they had a hard time coming up with a researchable question because it was important to talk a lot about the methodology, and different interpretations people have of the methodology.

*RESEARCH QUESTION:* Why isn't harm reduction available in all provinces?

*IMPORTANCE:* The issue is important because access is not equal, it affects the health of the general public and there is evidence to support the use of these programs. Drug users, community based organizations and health care providers all have a stake in understanding the methodology better. Findings can be used to improve programs, develop new programs and influence public policy.

*RESOURCES:* A list of needed resources was developed: stakeholders, travel, space, computer, community based organizations, universities, computer expertise, regional health boards, drug users, people in recovery, money, representation from all four provinces. Health grants, and support from community partners were identified as possible sources for what is needed.

*PARTICIPATION:* It was considered essential to clearly identify what exactly is expected from different players involved. Involving universities and setting deadlines was considered valuable, yet the most important issue was to develop trust. One way to begin doing this was to establish a comfortable meeting space (equipment, computers, etc), and fund travel and support for meetings. In addition the group encouraged HIV and Hep C groups, and regional Health Boards to be involved.

*FEEDBACK QUESTIONS / COMMENTS / SUGGESTIONS:*

- A discussion centred on the definition of harm reduction. There appeared to be much agreement that, broad as it is, there is a need to define harm reduction. This is important so a definition can go into grant proposals. People currently use the term differently and that leads to lack of commitment and support. Participants agreed that cohesion on this definition would help solidify support for the concept.
- One current definition brought forward from PEI is:  
*“A continuum of strategies that aim to decrease the harm associated with high risk behaviours, such as injection drug use, and improve the physical, mental, spiritual and social health of individuals, families and communities. Harm reduction strategies may include prevention education, needle exchange programs, safer needle use, methadone maintenance therapy, and abstinence.”*
- Most participants felt that this definition could be used as a starting point, yet the definition still needs a lot of work. For example, in the above definition one suggestion was to not use the example of injection drug use because it might make people think this is the only focus. One person commented that there may be a national definition we are “supposed” to use and if we make up our own it might cause problems. Another person commented that the blood borne pathogens strategy defines harm reduction. Someone else suggested the use of the term ‘risk reduction’ instead of ‘harm reduction’ should be considered. An agreed definition couldn’t be resolved immediately, but it was obvious that this is an important and critical issue.
- Participants were then challenged to decide on one small step that can be taken to work on this important element? It was agreed that people would share definitions and try to come up with one definition to then propose to others. Definitions would be circulated among the group on a list serve for discussion.

September 10, 2003  
*A MSN Chat Group has  
been set up to discuss and  
define harm reduction.  
Get involved at  
eHepatology@hotmail.com*

**KEEP THE BALL ROLLING:**

- ❖ **Christine Porter ([chrisporter@acsb.ns.ca](mailto:chrisporter@acsb.ns.ca)) will be a focal point for this. Gerry Mugford ([gmugford@mun.ca](mailto:gmugford@mun.ca)), Cindy MacIssac ([cynthmacissac@aol.com](mailto:cynthmacissac@aol.com)) and Jacquie Gahagan ([jacqueline.gahagan@dal.ca](mailto:jacqueline.gahagan@dal.ca)) are also interested. Definitions and contacts can be sent through Aideen Reynolds ([Aideen.Reynolds@dal.ca](mailto:Aideen.Reynolds@dal.ca)) who will distribute them to others who are interested.**

### **2.3.3 Determinants of Health - Group 3**

*THE ISSUE:* This issue was considered very broad and complex.

*RESEARCH QUESTION:* What are the determinants of health that lead Atlantic Canadians to engage in high risk behaviors, such as IDU and unprotected sex?

*IMPORTANCE:* This issue was considered of critical importance because understanding it will inform future research and service delivery. The group argued, “Until we understand why people do what they do, we can’t try to stop it”. Such a project would include many stakeholders such as service providers, education, decision and policy makers, health care, treatment and support services. Findings from a study on this issue will be useful to access funding, develop policy and help identify more specific issues for follow-up.

*RESOURCES:* Human resources needed include: academics, community members, and target populations. Skills required include: interviewing, focus groups, survey, proposal writing, asset mapping, facilitation, capacity building, evaluation, advocacy, and technical skills.

*PARTICIPATION:* All participants agreed that a sharing of expertise and an agreement to collaborate will be important to move this research agenda forward. Specific guidelines will need to be defined, expertise will need to be shared, capacity building and qualitative research will need to be carried out. All those involved will be co-owners of the research. Resources can be secured through collaboration, contacts, sharing, acknowledging contributors, teaming up with universities and creating sustainable linkages. The process of actually conducting this research will strengthen the regional response to HIV and Hep C and will support all other work being done.

#### *FEEDBACK QUESTIONS / COMMENTS / SUGGESTIONS:*

- It will be important in this work to be reflective of different stakeholder group’s realities. Also different geographic areas have different population characteristics, so it will be important to get fair representation amongst / between different areas since all provinces are so different. One participant suggested that balance in a regional study could be designed on a per capita basis.
- Determinants of health is very broad. Quantitative studies can work to a point, but qualitative research would potentially be more appropriate for determinants of health research. It was agreed that more qualitative work is needed, but looking at all the determinants of health is huge, and they are all interconnected. One participant asked, “Where could we possibly begin? It may turn out that the research will just depend on individual’s interest”. One participant suggested perhaps a way to start would be to get ASOs to prioritize which issues / statistics are important for their area and build on that.
- A suggestion was then made that for the purpose of an application it would be important to state, “here are the determinants of health identified by this group that have been targeted for further research”. Alternately, statistics could help identify the priority determinants most likely to influence at risk behaviours. This second approach would give credibility to the decisions made about what determinants of health would be researched in more detail.

*What are the determinants of health that lead Atlantic Canadians to engage in high risk behaviors, such as IDU and unprotected sex?*

- The conclusion was that this is a big topic that needs a lot more attention!

**KEEP THE BALL ROLLING:**

- ❖ **All participants should think about how best to forge or augment contacts across the Atlantic region.**

**2.3.4 Policy Advocacy / Influence – Group 4**

*THE ISSUE:* Policy research is a complex issue and the group agreed that research is needed at two levels. First, the program and project level which can be looked at both locally and provincially. Second, the strategy level, both provincially and regionally. The research will need to be evidence-based and inclusive of economics, science and public opinion to determine, “what information will move the government?”. The group argued that policy makers should be involved as stakeholders from the beginning of the process.

*RESEARCH QUESTION:* What has worked in the past? What structures, processes and principles were used? How can policies between groups inform best practice? What are the motivations and what is the information needed by policy makers?

*IMPORTANCE:* This issue was considered important because all of our work is vulnerable to political powers and trends. It would be valuable to study the trickle down of national policies to provinces and to community action and the trickle up from grassroots back to provinces and the national level to determine where we can have the most influence. An essential element of this will be to determine the motivations of policy makers and the policy making process.

*RESOURCES:* In order to determine resources needed, it will be essential to use others’ “templates” for strategies. For example, what language, structure and process has been designed and used previously to explore and determine what works with government. It will also be important to investigate how this research fits within government structures such as health services administration.

*PARTICIPATION:* Involvement of Health Canada and provincial governments is necessary. Confidentiality will be key. Researchers will need to be sensitive not to upset the government by giving out information that may be counterproductive. Similarly, strategic involvement of the media, as well as bureaucrats will be necessary. This research should be done as an inter-provincial comparison. The research could be carried out by an investigation of best practices through a literature review, or a full project or a pilot study with the policy component built on. One suggestion was that internships could be established for thesis topics for students across several provinces.

*FEEDBACK QUESTIONS / COMMENTS / SUGGESTIONS:*

- A participant asked, “In what capacity will stakeholders be involved?”, and this launched an interesting discussion on government involvement. One participant suggested that the government needs to be fully integrated as, for example, those listed on research team. There might be some disadvantages of having government involved as it could skew the research. “It is a catch 22”, one person argued. Policy makers are decision makers, so it is good to have them engaged. However, experience has shown they often state that they can’t do it; they have no time and will always send staff members who actually have no power. Front line people know what’s needed, but

unfortunately the top level is out of the loop, but they won't come to the table. A suggestion was then made that perhaps this organizational issue could be part of the research question. "Has this decision making group ever been convinced to come to the table before?" This kind of research is only in the grey literature, if documented at all. It requires key informant interviews with a wide audience of stakeholders. There are researchers that are doing this sort of thing and should be engaged in the process. They might be in economics, political science, and drawing on their expertise could be very valuable. The government has employees with research background as well. It was agreed that it will be important to find these individuals and get them involved in the process to "champion" these concerns.

- A participant then asked if Nova Scotia is the only province that has a government strategy for HIV. It was discovered that PEI has had a strategy since 1993, but it is ineffective and doesn't have any action items. NB has nothing, and NFLD is just developing one. It was noted that it will be difficult to get the provinces to work together on this. Where's the buy in? The research will need to look at how to be influential and recognize that although some things will work in one province, they may not in others. At the same time, if Deputy Ministers are going to be talking to each other more, researchers should try to influence this group. Lots of inter-provincial committees should be targeted.
- From an economic point of view, who might need to be engaged in strategic collaboration?  
CBAOs should press the determinants of health to influence policy across the board, not just health policies. We have to make this interconnectedness explicit. Policy influence shouldn't be limited to health.

*UNB and Dalhousie have researchers who specialize in policy development. Maybe they can get involved?*

**KEEP THE BALL ROLLING:**

- ❖ **Larry Baxter ([larrybaxter@ns.sympatico.ca](mailto:larrybaxter@ns.sympatico.ca)), Scott Hemming ([asconsulting@eastlink.ca](mailto:asconsulting@eastlink.ca)), Aideen Reynolds ([aideen.reynolds@dal.ca](mailto:aideen.reynolds@dal.ca)) and Jacquie Gahagan ([Jacqueline.gahagan@dal.ca](mailto:Jacqueline.gahagan@dal.ca)) are interested in following up on this. There is the possibility of grant funding to look at some of these issues and a deadline for submission coming up. Those interested should get in touch as soon as possible.**

### 3 PROMOTING COLLABORATIVE, MULTIDISCIPLINARY RESEARCH

This chapter provides an overview of the discussions workshop participants had concerning different research approaches and their complementarities. One objective of the workshop was to promote a coordinated, multidisciplinary and regional response to HIV and Hep C research. This chapter describes some of the successes and challenges in doing research across different disciplines and between universities, research institutes and communities. A list of “Dos and Don’ts” for collaborative research, as developed by the participants, is shared and a number of suggestions and action points for enhancing collaborative work in the future are articulated.

#### 3.1 Looking at Research Approaches and Finding Complementarities

Four presenters were invited to share their perspective on research and research approaches and some lessons learned from their successes and challenges. The panel of presenters looked at research from a university perspective, a community perspective, a clinical perspective and the perspective of Corrections Canada. Summaries of these presentations are captured below, followed by the questions and discussion that ensued. The full presentations are included in Appendix D.

##### A University Perspective

**Grace Getty**, Director of the School of Graduate Studies and Faculty of Nursing at UNB and **Lois Jackson**, Associate Professor at the School of Health and Human Performance, Dalhousie University, gave the first presentation.

Their presentation focused on university-based academics working with partners outside of academia, with a particular emphasis on working with community-based organizations. The presenters provided a university perspective on conducting social and behavioural studies with individuals and organizations outside of the university setting. It was argued that more and more academics recognize that one has to be cognizant of community-based issues to really understand relevant and pressing research questions. Good research questions come out of the realities of practice and we should not think about academic research versus the research by ASOs, but rather we should work to improve models of collaborative research.

Using examples from their own research, they described what they have learned about working together:

- Trust and respect are key.
- A team approach that is equitable is necessary.
- A division of labour can be established without creating hierarchy.
- Experience with funders not wanting CBAO workers as co-investigators can be overcome.
- Accountability, transparency of decisions, openness, time, humour, and confidentiality are all needed.

They also described some of the challenges experienced:

**For Academics** - they must “publish or perish”, they have a huge workload, their differing responsibilities are like a juggling act, and their research must be reviewed

*Good  
research questions  
come out of the realities  
of practice.*

by university ethics boards as per the Tri-Council guidelines, and that in some cases the individuals reviewing proposals are not acquainted with, and do not have a solid understanding of community-based research.

**For ASOs** - it is a very long process, it is labour intensive and “must seem like a lifetime” before a research project may be fully carried out.

Several of their examples touched on the benefits of ethics committee approvals, the importance of being flexible and sensitive to people’s schedules, and the advocacy work that is sometimes necessary to convince ethics committees about issues such as honoraria for key informant interviewees.

One piece of advice offered was to double the time you think you will need for a proposal if you are doing collaborative work. For example, often people from inside the community are required to conduct interviews and training takes time.

### **A Community Perspective**

**Cynthia MacIsaac**, Program Director of Direction 180, a low threshold methadone program in Halifax, NS offered the second presentation.

Cindy described how research and evaluation played a critical role in transitioning Direction 180 from a pilot project to a sustainable, ongoing program. This process evaluation helped to develop outcome measures. The interim report demonstrated Direction 180 as a ‘best practice’ in harm reduction and addiction treatment model. This is significant in terms of the continuation of the program. Direction 180 and Mainline Needle Exchange participated in a project last year to examine the gaps in services IDUs encounter throughout their lives in institutions, community agencies, and social services. This study identified that many users went ‘off track’ just before or during the transition from grade 6 into junior high. This kind of finding has major implications for the education system and prevention programming for youth.

She reiterated the importance of evaluation in proving accountability, building capacity, securing funding, and forging relationships. Although evaluation is costly and time-consuming for a small organization, it is vital for sustainability. She challenged participants to help her “prove to policy makers that my program is working”. Cindy described how she can see a change in clients’ health, but it doesn’t always translate into documents that funders and decision makers accept. Although research and evaluation activities often diffuse our focus, she said, the process enables us to redefine and clarify our vision. She concluded that successes have been based on access, rapport, and trust: there is a real “art” to CBAO work.

### **Corrections Canada Research Perspective**

**Odette Pellerin**, Regional Chief of Clinical Services for Correction Services of Canada (CSC) has been a member of HIV/AIDS and Hepatitis C associations and groups for years.

CSC works in five federal institutions in Atlantic Canada providing harm reduction and surveillance with a large emphasis on addictions. They publish the *Forum Journal* on research briefs being done within CSC which can be accessed through their website. Much of their research is on offender needs in order to develop effective treatment programs. Odette explained how a program was developed to introduce methadone for offenders coming in that were already on it. Initially the government did not support this practice, but once it was shown to reduce violence they were able to establish “buy in” from decision makers. The fact that inmates’

*Research and evaluation played a critical role in transitioning from a pilot project to a sustainable program.*

*Research on offenders’ needs helps to develop effective treatment programs.*

health was improved was not important. She described that in CSC facilities, IDU is a major problem, particularly in relation to HIV and Hep C. The number of people who use drugs in prison is increasing every year.

A passionate argument was made to recognize that offenders have many social issues – many factors which determine their health – that need to be explored. Offenders come from vulnerable populations - many are victims of sexism, racism, classism, – which leads to a vicious cycle. Many inmates return to the streets and then return to prison numerous times and therefore research to deal with the issues of the determinants of health is essential. She stated that offenders have very high HIV rates (more women than men), and that Hep C is a catastrophe from a health care perspective.

The biggest challenge she sees for the research community is how community researchers can use the knowledge gained from Corrections to develop a regional response to HIV and Hep C research? Specifically she asked participants, “How do we ensure that progress made with inmates inside is maintained on the outside?”

### **A Clinical Research Approach**

**Kevorg Peltikian** is with Hepatology Services at QE II in Halifax. He presented jointly with **Michael Vallis**, a Psychologist with the QE II and Dalhousie University.

*Hep C research is very rooted in Atlantic Canada.*

**Kevorg** began the presentation by stating that there is enough Hep C in Atlantic Canada to do research based on experience. He explained that Hepatitis impacts more Canadians than we can imagine and is a major burden on the health care system. He also explained how Hep C research is very rooted in Atlantic Canada. He provided a general overview of the disease as a lifelong disease that can be accelerated depending on certain variables. He stated that there are approximately 4,000 people known to be living with Hep C in Atlantic Canada and that more surveillance is definitely needed. He restated the key fact that the burden of Hep C on health care is enormous. **Michael** supplemented these comments by talking about the psychological impact of the illness. He described that there is a widely held bias in health care that ‘Hep C is no big deal’. This is false, however, because although fatigue is the primary initial symptom and health care professionals don’t treat fatigue, the psychological impact of this is much more telling. There is a need to prioritize quality of life, study impact of treatment, emotional impact/cognitive impact/social impact. One approach being taken is re-defining fatigue and calling it *lassitude*, something that will require additional social and behavioural research efforts in the future.

### **DISCUSSION:**

A number of questions and comments came forward following the presentations.

*Perhaps CSC believes if they don’t identify the problem, they don’t have to deal with it.*

*INFECTIONS AND HARM REDUCTION IN PRISONS.* An initial question concerned the percentage of people who develop infections during incarceration. It was explained that testing is optional. CSC may not want to know because they may be liable. Research proposals have been submitted on this very issue, but have been stalled. One study from Springhill showed that people were getting infected inside, but for legal reasons it was silenced. Clearly this is a politically charged issue in need of additional research.

A participant said that prison workers are very harm reduction positive, but their hands are tied because politicians do not support harm reduction due to concerns about popular opinion. “Eventually there will be a needle exchange program in the

jails”, one participant stated, “but it could be too late”. IDU is the big issue in jails and even condom distribution is problematic because of stigmas attached to it and the concern of using condoms for suitcasing drugs. Research work on harm reduction methods is of paramount importance.

*SEX IN PRISONS.* A question was raised about sex related research done in jails. It was described that explicit pamphlets and brochures are given concerning safe sex are distributed, but that the law does not talk about sex in prisons and that officers turn a blind eye. This may lead to rape. There is a major stigma around men having sex with men. Protection and empowerment of vulnerable populations within the prison setting is desperately needed.

*ETHICS.* A comment was made about the bias in some ethics work. An example was given of a poster to recruit gay males for a study. People in hospital were upset by the poster on ethical grounds. It caused a political problem. The hospital did not have any ethical policy for what research recruitment posters should look like. Another participant related how the only way they got through an ethics committee on a sensitive issue of community participation was by threatening to send money back to funders. At that point the ethics committee approved the work. A suggestion was made that one way to deal with this might be to become more actively involved with ethics committees so that they can be challenged from within.

*Become more actively involved with ethics committees so you can challenge them from within.*

### **3.2 “Dos and Don’ts” for Collaborative Research**

Groups of participants were asked to reflect on the presentations and their own experience and discuss what factors promote successful research and research teams and to name some of the challenges – and what can be done to prevent the challenges and to work through them if they do arise. To summarize the discussions they were then asked to make concise and clear statements about “Dos and Don’ts” for collaborative research.

Useful discussions were held in each table group and many experiences were shared. Participants then came up with lists of Do’s and Don’ts that were synthesized into the following lists. These can be used as a reminder for anyone pursuing collaborative research in the future.

#### “Dos” FOR COLLABORATIVE RESEARCH

1. Communicate
2. Keep the project manageable
3. Take time to truly involve partners – build in skill transfer if necessary
4. Build teams – work on this specifically early in the process (e.g., a workshop)
5. Use lay person language that is appropriate to background of community team members
6. Negotiate barriers – recognize they are there and are real and but don’t accept them
7. Know your ethics board
8. Network locally regionally nationally and globally to complete a thorough analysis of past work to avoid reinventing the wheel
9. Focus research on local specific information when needed
10. Be transparent re: authorship, ownership of data etcetera
11. Strategize for uptake and dissemination from the beginning
12. Plan for how the research will impact on policy

#### “DON’T’S” FOR COLLABORATIVE RESEARCH

1. Don’t force partnerships that don’t make sense

2. Don't continue collaborating if it is obviously not working – sometimes you can agree to disagree
3. Don't duplicate existing research ( e.g., can use questionnaire from elsewhere)
4. Don't assume anything (e.g., don't assume university people are isolated off in ivory towers and don't care or know about community and vice versa)
5. Don't patronize target population – don't involve them as tokens
6. Don't loose yourself in the research (e.g., take a vacation from it occasionally)

### 3.3 Recommendations for Follow-up on Collaborative Work

It was generally agreed that collaborative work is necessary to deal with the multidimensional nature of HIV and Hep C and that developing trust and respect between team members coming from different contexts is the essential first step.

A number of other issues were highlighted in the “parking lot” discussion at the conclusion of the workshop that also deserve attention for making collaboration as effective and efficient as possible.

One issue was around the translation of this workshop report into French. It was pointed out by one participant that this is a very expensive process, but that when built into grant proposals from the beginning federal funders sometimes give a special allocation for translation. The grant for this project will not allow full translation to be done (the cost is approximately 20 cents per word), but efforts should definitely be made to translate a summary document. Similarly, for the Aboriginal population in NL, it was suggested that translation into Inuit and Innu would be valuable (Bill Downer has contacts to get this done). The lesson learned here was for successful collaborative work in the Atlantic, a greater sensitivity to different languages is needed and this needs to be considered from the outset of new initiatives.

Another issue raised was around the fact that statistics and data clarification are needed in a number of instances and that as an Atlantic region, we could try and put a collaborative system in place to deal with this. For example, looking at the number of co-infections and how accurate they are, what geographic areas they include and do not include, keeping ethnic identifiers in statistics to determine whether we are working with a multicultural community, ensuring gender disaggregated data reporting, collating numbers on funding issues in the Atlantic provinces to come up with accurate comparative information. Doing these fairly simple tasks and posting the information in one place would avoid energy wasted over people arguing whether numbers are correct.

The issue of working sensitively with Aboriginal groups also came up. It was decided that Health Canada's regional office should be contacted for advice on this issue concerning report distribution. Participants recognized that in order to be inclusive of the aboriginal community from a regional perspective we need aboriginal representation on grant applications in addition to provincial representation. Pursuing this will require consideration of both financial and policy issues (federal and provincial health jurisdictions). This also includes sensitivity to the need for academic credentials in developing teams and the unique systemic challenges experienced for aboriginals in securing these credentials.

These issues and the “Do and Don't” reminders, developed by participants of this workshop, are all important in promoting collaborative research with groups coming from different backgrounds.

## **4. ASSESSING THE FEASIBILITY OF A SUSTAINABLE COORDINATING MECHANISM TO ENHANCE RESEARCH COLLABORATION**

This chapter outlines the evolution of discussions that took place during the workshop concerning the development of a sustainable coordinated mechanism to enhance research collaboration on HIV and Hep C in the Atlantic Region. It outlines what was achieved with regard to the specific objective: “to determine the feasibility of developing an Atlantic Regional HIV and Hep C Social & Behavioural “Studies Unit” to help facilitate and coordinate research teams and to determine the scope & parameters of such a proposed “Studies Unit”. It also shows the efforts that were made “to promote a coordinated, multidisciplinary and regional response to HIV and Hep C research in Atlantic Canada”.

This chapter is based exclusively on input from participants during the second day of the workshop. The first section captures why a mechanism is needed. The importance of a mechanism was generally agreed to, yet certain cautions were also expressed. The second section describes some possible mechanisms that could enhance research collaboration, states some advantages and disadvantages for each, and concludes with possible recommendations for follow-up. The third section describes two proposals being developed to secure funding to build a sustainable mechanism for promoting research in the Atlantic region. If these proposals are funded the aspirations of the participants and workshop organizers will be fulfilled. The final section lists some other actions that individuals and/or their organizations committed to at the end of the workshop.

### **4.1 Why is a Sustainable Mechanism Needed?**

A mind map activity was utilized to facilitate this discussion. The proposition was put forward that “a sustainable mechanism is needed for enhancing research collaboration on HIV and Hep C in the region”. Participants were then asked to offer reasons why this was true. If participants disagreed with the proposition their views were also recorded. At the end of a lively one hour discussion it was agreed that a mechanism is important, yet certain cautions must also be recognized. Highlights of the discussion are recorded below.

Twelve factors were brought forward to support the proposition that “a sustainable mechanism is needed for enhancing research collaboration on HIV and Hep C in the region”. These have been grouped together in five thematic areas. Ultimately, economics seemed to be the reason most people brought immediately to mind. However, upon reflection there appeared to be general consensus that coordination and collaboration is mutually beneficial and this has already been demonstrated with some work in the field. Participants also argued that the debate on harm reduction and understanding the needs of injection drug users could be furthered by collaborative work. Finally, people recognized that working together could provide an opportunity to develop improved and augmented service to those living with HIV and Hep C.

**A SUSTAINABLE MECHANISM IS NEEDED FOR ENHANCING RESEARCH COLLABORATION ON HIV AND HEP C IN THE REGION BECAUSE:**

**COORDINATION AND COLLABORATION IS MUTUALLY BENEFICIAL**

- ❖ Coordinating efforts will have greater impact, particularly around policy uptake and harm reduction.
- ❖ Groups will be able to learn from each other. For example, Hep C groups will be able to learn about working on issues of stigma from HIV groups that have lots of experience with this issue. Networking will happen which can have numerous unexpected benefits.
- ❖ Critical research issues can be linked with a broader definition than just HIV and Hep C. Collaborative, multidisciplinary research approaches are essential to get at the “real issues” in social and behavioral research.

**ELEMENTS OF COLLABORATION ALREADY EXIST**

- ❖ The literature supports collaboration in these areas. For example, there are data that point to the fact that those with HIV are more likely to become infected with Hep C.
- ❖ There are people with co-infections. Estimates range from 5% to 20%.
- ❖ Many researchers and community groups do not work exclusively in HIV or Hep C. Collaboration of researchers from this part of the country is better than competition amongst ourselves. CIHR links the issues on their website and provides a rationale for doing so.

**HARM REDUCTION AND IDU ISSUES ARE COMMON**

- ❖ There are commonalities around harm reduction. There is experience to build upon concerning this issue, but it is a struggle against many decision makers. Working cooperatively on a common harm reduction orientation will be valuable.
- ❖ There are some similarities concerning prevention issues and the impact on people’s lives. There are also differences concerning symptoms and educational approaches that can be better articulated by clearly identifying what those differences are.
- ❖ Injection drug users are both at high risk for HIV and Hep C. They are probably the largest vulnerable group for both infections. Needle exchange programs deal with both infections.
- ❖ More work still needs to be done on education and advocacy for Hep C and HIV.

**ENHANCED SUPPORT IS NEEDED FOR PEOPLE WHO ARE INFECTED**

- ❖ If people infected with either HIV or Hep C want to work together on these issues that would be an excellent reason for collaborative work. Whether or not they do is the first issue that needs to be explored.
- ❖ There is a stigma and labeling of people infected with both HIV and Hep C and for different reasons. If researchers, programmers and policy advocates work together it could help overcome these stigmas.

**ECONOMICS SAY SO**

- ❖ Funders are requesting researchers, community groups and programmers to work on HIV and Hep C issues jointly. HIV and Hep C is considered a funding category. There may be political reasons for linking these issues as well, but it is unclear how that could be tackled. Funding is limited and people need to support each other. Money for Hep C work has been very low, but it is growing and money for HIV work is shrinking. Both sectors can be served if joint research is carried out. As one participant stated, “the writing is on the wall, we have to work together”. This doesn’t mean that

some particular work cannot be targeted at one infection or the other once a collaborative mechanism is established that appreciates both.

The last is a convincing argument, however, it is important to recognize that serious concerns were brought forward about the “shot gun marriage” of HIV and Hep C induced by economic pressures.

One major issue is to recognize that HIV groups had to fight to get the services they have today. HIV groups are not only part of a health support group, but part of a political movement that had to struggle and overcome huge obstacles to get the level of respect and support they receive today. Labeling and stereotyping is still an issue, and they should not be blamed for being resistant to being forced together with Hep C issues that arise from a different context. Similarly, Hep C is unique in many ways and deserves significantly more attention and concern than it has received to date.

Compared to Hep C, overall health, mental health, etc. are more pressing issues for the HIV community. Forcing HIV and Hep C issues into the same pot could lead to missing out on more pressing health needs that individuals in both groups are experiencing. Ensuring any kind of a research collaborating structure focuses on the needs of those infected with either of the viruses first – and not the infections themselves will be essential. Research work should be driven by the membership of the women and men who are infected.

Another issue centred around the potential exclusivity of defining the mechanism as focusing on “HIV and Hep C”. Participants argued that perhaps hepatitis generally should be included, or perhaps even TB issues as well. People even questioned how useful the title “blood borne pathogens” is, and some voices were raised about keeping the viruses separate. However, it was recognized that the biomedical model has put them together and social and behavioral researchers will have to work collaboratively to show the commonalities and the instances when specific work must be done for each individual virus.

Participants also raised the issue that collaboration around research is not the only thing to consider, but collaboration is also needed in the areas of policy and programming as well. Finally, the argument can be made that “Atlantic statistics” are needed to demonstrate the needs in this area as compared to the rest of Canada, but we must also remain aware that individual provinces and communities are unique and that fact of our lives must not be lost.

There was general agreement that although this may be a marriage of convenience (or an arranged marriage), if the concerns above can be considered, an attempt should be made to work things out – a sustainable mechanism is needed for enhancing research collaboration on HIV and Hep C in the region.

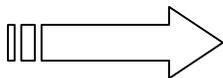
## **4.2 What Could a Sustainable Mechanism Look Like? Recommendations for Follow-up**

Continuing with the mind mapping activity participants brainstormed the following mechanisms that could enhance regional research collaboration.

- Developing an Emerging Teams grant and implementing it.

- Holding regular meetings. These could be face-to-face or virtual meetings of community and researchers in the region. Traditional conferences or video conferencing were proposed.
- Establishing a studies unit. This could potential be a formal unit initially evolving into a virtual unit or vice versa.
- Carrying out specific research projects and thereby indirectly developing better ways of collaborating together.
- Building a data base – research policy and NGO
- Organizing a clearinghouse of research and other information.
- Creating a web site and linking it to existing sites such as the Community Based Research net [www.hiv.cbr.net](http://www.hiv.cbr.net). A monitored list serve could be part of this. Connecting with researchers in central Canada would also be facilitated.
- Setting up a loose structure to coordinate initiatives. Potentially a research coordination structure using and linking with the university research centres.
- Developing peer review groups. E.g. groups and buddies.
- Developing graduate programs concerning research collaboration for the future. This could include student placements in ASOs.

Participants were then put into trios and asked to elaborate on each of these ideas on “idea sheets”. Using a carousel activity each trio had a chance to add to each set of ideas. This enabled significant information to be developed on each idea. Recommendations for next step actions are also included in relation to each idea. If only some of the enthusiasm and momentum built during these discussions is continued, many of these ideas could see reality in the near future.



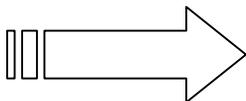
Three of the “idea sheets” were concerned with an overall coordinating structure, whether it is called an emerging team, a research coordination structure or a studies unit. Much experience was shared around these issues and it was decided that by combining and taking the best of the different approaches, important progress could be made. Definite follow-up must be made in this area.

<b>EMERGING TEAMS</b>	
<u>What does this look like?</u> -regular representatives work together -multisectoral (public, private, community, academics, infected/affected, ASOs) -ideally the research starts in the community/ASO -need a topic, how do we choose, who chooses? -multi-disciplinary	
<u>Advantages</u> -resources for coordination when funded -Atlantic Canada on the map -dissemination, capacity building, bonding between community and university -coordination equals better research -improved program development	<u>Disadvantages</u> -sustainability, what will keep it moving? -burnout of few people -control issues -may create opportunities for funders to dilute money -division of labour missed
<u>Suggestions / Comments:</u> -need a coordinator (built into proposal) -requires follow-up with deliverables -use technology – email, virtual, network -research question should emerge from community	

<ul style="list-style-type: none"> <li>-accountability mechanism to stakeholders</li> <li>-inclusive of government personnel (provincial)</li> <li>-will have to be grouped: i.e. 1) policy research; 2) community service research; 3) clinical research; 4) theory research; 5) government research</li> <li>-separate overriding agendas of disciplines/groups</li> </ul>
<p><u>Recommendation for Action:</u></p> <ul style="list-style-type: none"> <li>➤ <b>Establish a sub-group to follow up on CIHR new emerging team funding (must go for this!) and the Interdisciplinary Capacity Enhancement (ICE) funding as well.</b></li> </ul>

<p><b>RESEARCH COORDINATION ‘STRUCTURE’ – TIED TO UNIVERSITY RESEARCH CENTRE</b></p>	
<p><u>What does this look like?</u></p> <ul style="list-style-type: none"> <li>-project/team manager and secretary to coordinate communication, data, feedback, input and output for research team and interested partners/persons</li> <li>-sub-teams with specific topic interests and research agendas. They will meet occasionally with everyone.</li> <li>-better if research emerges from community</li> </ul>	
<p><u>Advantages</u></p> <ul style="list-style-type: none"> <li>-data collected leads to improved programming/health of those infected</li> <li>-communication</li> <li>-tapping into expertise</li> <li>-everything up front and available to all</li> <li>-coordination</li> <li>-promotes cooperation and development of research skills</li> <li>-multi-site access</li> <li>-success in obtaining funding</li> <li>-increased sample size</li> <li>-capacity building among community groups and university researchers involved</li> </ul>	<p><u>Disadvantages</u></p> <ul style="list-style-type: none"> <li>-salary of project manager and secretary</li> <li>-workload of coordinator</li> <li>-need funding</li> <li>-possible disparity in viability of sub-team</li> <li>-territoriality could develop</li> <li>-topic selection/division of labour/who chooses? Or maybe volunteer program based on known skills</li> <li>-difficult for ASOs to participate</li> </ul>
<p><u>Suggestions / Comments:</u></p> <ul style="list-style-type: none"> <li>-educational sessions to get everyone on the same wave length (egalitarian relationships)</li> <li>-terms of reference (develop and have vetted through stakeholders)</li> <li>-need to avoid territoriality</li> <li>-share ownership of findings/results</li> <li>-tap into research offices at universities</li> <li>-look for existing organizations who have already don’t this work (e.g. – cancer society)</li> <li>-ensure accountable to all stakeholders</li> </ul>	
<p><u>Recommendation for Action:</u></p> <ul style="list-style-type: none"> <li>➤ <b>Approach existing structures to help start this (ACAP, NSHRF, PPHB)</b></li> </ul>	

<b>STUDIES UNIT</b>	
<p><u>What does this look like?</u></p> <ul style="list-style-type: none"> <li>-collaboration of disciplines</li> <li>-emerging team and research structure (those are all too similar to be different)</li> <li>-‘studies’ broad enough to encompass research, community, sharing, programming, networking, etc.</li> <li>-depository for information sharing</li> <li>-inclusive of populations/communities</li> <li>-who is going to ‘own’ it?</li> <li>-board or something to oversee?</li> </ul>	
<p><u>Advantages</u></p> <ul style="list-style-type: none"> <li>-structure, coordination</li> <li>-accessing research/program dollars</li> <li>-sharing resources</li> </ul>	<p><u>Disadvantages</u></p> <ul style="list-style-type: none"> <li>-very difficult to sustain</li> <li>-who will be responsible?</li> <li>-accountability</li> <li>-must be multi-lingual</li> <li>-need A LOT of \$</li> <li>-need to be up front to all provinces</li> <li>-potential to become province specific; must maintain regional focus and avoid becoming province specific</li> <li>-brick and mortar or even cedar shingled unit means ½ your time is spent administering and sustaining the unit</li> <li>-location would influence support and participation</li> </ul>
<p><u>Suggestions / Comments:</u></p> <ul style="list-style-type: none"> <li>-be truly realistic, don’t set up for failure</li> <li>-individuals who agree to take on the task must be committed/consistent</li> <li>-schedules and timelines to be coordinated</li> <li>-ACEWH could be part of it or possibly house it</li> <li>-sustainability needs to be built in from day one</li> <li>-needs designated space, not everyone can go virtual</li> <li>-go virtual – more inclusive, less costly, you can be involved from any location</li> </ul>	
<p><u>Recommendation for Action:</u></p> <ul style="list-style-type: none"> <li>➤ <b>Merge this idea into the emerging team proposal and research coordination discussions.</b></li> <li>➤ <b>Develop a focus for any kind of a “mechanism” with specified timelines and schedules.</b></li> <li>➤ <b>Recognize a lot of work has to be done upfront.</b></li> </ul>	



Four of the idea sheets were tools that could be used to improve collaboration. Three of these were technology based that ultimately could be combined if the appropriate resources were secured. All four of these tools could be integrated within the framework of the overall coordination structure that is developed out of the first three approaches.

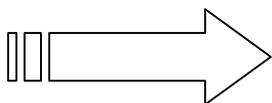
<b>REGULAR MEETINGS</b>
<p><u>What does this look like?</u></p> <ul style="list-style-type: none"> <li>- one annual face to face meeting of this group and / or regional meetings</li> <li>- provincial counterparts could meet as they decide</li> <li>- teleconference/video</li> </ul>

- who are provincial counterparts? Who will organize?	
<u>Advantages</u> -maintains momentum -allows for networking -permits exchanges -increases efficiency thru face to face	<u>Disadvantages</u> -cost -scheduling -is once a year enough? -distance -logistics in coordination (need leadership role and follow through) -potential forming of 'cliques'
<u>Suggestions / Comments:</u> -share resources and technology -tap into existing meetings (e.g. ACHIVE, Atlantic CBAOs, CAHR, ACAP); possibly tag on an extra day to these -recognize this needs a lot of pre-meeting preparation -face to face opportunity may be more effective and sustainable than virtual methods	
<u>Recommendation for Action:</u> ➤ <b>Assign key people to carry activities/ideas forward.</b> ➤ <b>Apply for financial support including support to hire coordinator/organizing person.</b>	

<b>LIST SERVE / WEB SITE</b>	
<u>What does this look like?</u> -create an Atlantic website listing all organizations, universities, interested parties in HIV and HCV research and links to other existing sites -newsletter -linked to the database and clearinghouse -secure website	
<u>Advantages</u> -no travel -reach numerous stakeholders -share information	<u>Disadvantages</u> -computer illiteracy necessary -not having a computer -knowledge of the site outside of those on list serve -huge amount of work to oversee, it can't be done by one person -\$ to maintain
<u>Suggestions / Comments:</u> -link to <a href="http://www.accb.ns.ca">www.accb.ns.ca</a> , <a href="http://www.acns.ns.ca">www.acns.ns.ca</a> , <a href="http://www.csc-scc-gc.ca">www.csc-scc-gc.ca</a> , <a href="http://www.micmacnativefriendshipcentre.ca">www.micmacnativefriendshipcentre.ca</a> , -link to existing list of sites – CIHR, HIV/HCV sites, NS gov't -one representative from each province to take the lead -Atlantic Hep C Network – Dr. Peltekian's website / chat room "the ignored epidemic" is a good example -try to link up with HIV-CBR.net; there is no HCV content there, but great site and no cost to link up -link, link, link -lots of advertising needed -a list serve needs to be maintained and edited -investigate possibility of list serve rather than website -link with DB text for literature database	
<u>Recommendation for Action:</u> ➤ <b>Pay someone to do this. Creating a list serve / website is huge. Write a proposal for a project to do this.</b> ➤ <b>Include list serve as part of an emerging team grant from CIHR; build in \$ required to maintain it (as only part of grant).</b>	

<b>DATABASE</b>	
<p><u>What does this look like?</u></p> <ul style="list-style-type: none"> <li>-could be on website or hard copies</li> <li>-all organizations' names, contact information, expertise, skills, past and current research and materials produced, stats on HIV, HCV, IDU in that city/province, research contacts, providers/practitioners, funding sources and amounts available (links to sites), links to list serve, government</li> <li>-will have to be maintained regularly</li> </ul>	
<p><u>Advantages</u></p> <ul style="list-style-type: none"> <li>-cost effective</li> <li>-everyone has access to it</li> <li>-up to date</li> <li>-CSHA has plans to do this as well</li> </ul>	<p><u>Disadvantages</u></p> <ul style="list-style-type: none"> <li>-may not be up to date/lack of funds to maintain</li> <li>-not always accessible</li> <li>-human resources</li> <li>-computer illiterate will alienate some</li> <li>-people might not want to give out their personal contact information</li> </ul>
<p><u>Suggestions / Comments:</u></p> <ul style="list-style-type: none"> <li>-link to national work in this area through CSHA</li> <li>-access electronically</li> <li>-this could be joined with the website development</li> <li>-who will be responsible for updating this?</li> <li>-build on what already exists – CIHR Atlantic, ACEWH, AHPRC</li> <li>-focus on a list serve instead please!!!</li> <li>-could be used as a tool for another initiative</li> </ul>	
<p><u>Recommendation for Action:</u></p> <ul style="list-style-type: none"> <li>➤ <b>Integrate this aspect with other activities, particularly the list serve and web site.</b></li> </ul>	

<b>CLEARING HOUSE</b>	
<p><u>What does this look like?</u></p> <ul style="list-style-type: none"> <li>-CPHA Clearinghouse; connect with this one. They already do HIV/HCV.</li> <li>-www.hiv-cbr.net (HCV has a clearinghouse as well)</li> <li>-Canadian Women's Health Network</li> <li>-encompass diverse communities interests</li> </ul>	
<p><u>Advantages</u></p> <ul style="list-style-type: none"> <li>-cost effective</li> <li>-Atlantic specific focus</li> <li>-exists already at a national level, just needs to be linked</li> </ul>	<p><u>Disadvantages</u></p> <ul style="list-style-type: none"> <li>-cost of ordering material</li> <li>-accuracy of information</li> <li>-government should pay for all costs (mailing costs for multiple copies add up especially for Atlantic region)</li> </ul>
<p><u>Suggestions / Comments:</u></p> <ul style="list-style-type: none"> <li>-promote use in Atlantic – CPHA Clearinghouse</li> <li>-not to be used in isolation</li> <li>-promote Atlantic region to post work/activities</li> <li>- make sure it has an Atlantic focus</li> <li>-ensure equal access for both CBOs and universities/academia</li> <li>-link to CPHA Clearinghouse</li> <li>-get government to fund</li> <li>-not just publications, could include research projects, 'grey literature', funding opportunities, contacts, data</li> </ul>	
<p><u>Recommendation for Action:</u></p> <ul style="list-style-type: none"> <li>➤ <b>Don't re-invent the wheel, this is not the first priority.</b></li> </ul>	



The final two idea sheets described stand alone activities that could have a major influence on sustaining research collaboration into the future. Separate groups could take these on, or, once again they could fall within the mandate of the overall emerging team or coordinating structure.

<b>PEER REVIEW GROUP INVOLVEMENT</b>	
<u>What does this look like?</u> -recognize there is an opportunity for people to become team members -nominations to sit on peer-review committees are possible (e.g. CIHR's vulnerable pops, HIV/HCV) -could be made a mentorship group -have our own peer review group before proposal is sent out	
<u>Advantages</u> -improve understanding of issues in Atlantic Canada at a national level -get to know what's being funded -great way to learn how to write a proposal -can contribute to tenure and promotion - would require an official designation -chances of getting funded would improve	<u>Disadvantages</u> -time commitment is huge -no results guaranteed -1 or 2 people may become overloaded -how are ASOs involved here? Need to advocate to build a mechanism for community involvement -CAHR, CIHR should be targeted -confidentiality and conflict of interest issues?
<u>Suggestions / Comments:</u> -local groups should not be too big -groups should include university/community members -mechanism in place to bring in new people to mentorship group -recommend to CIHR and SSHRC to have members on review committee -train people how to be peer reviewers -should be based on proposal content – need to have expertise in subject matter -reviewers need to understand methodologies and realities of Atlantic Canada -capacity building around research with CBOs needed.	
<u>Recommendation for Action:</u> ➤ <b>Make multiple nominations from Atlantic Canada. Bill Downer will take the lead and Margaret Dykeman, Cindy MacIssac and Diane Bailey will also be involved.</b>	

<b>DEVELOP GRADUATE PROGRAMS</b>	
<u>What does this look like?</u> -CIHR/SSHRC student grants (MA, MSc, PhD, Post Doc) related to psychosocial behavioural, social determinants of health related to HIV/HCV, biopsychosocial, etc -cross disciplinary course development – open to students at MUN/UNB/DAL/SMU/UCCB/UPEI -look at existing cross disciplinary courses offered in Atlantic region -one has started, this could be a site; students from different universities could enroll in the course as an elective -practice-based internship as a component	
<u>Advantages</u> -could be a source of funding for students -stimulates different disciplines to work together -source of learning for students and community workers	<u>Disadvantages</u> -university-based -time is a factor -decrease in # of CRCs available -infrastructure capacity needs to be in place -beyond us to do this

-broadens what can get accomplished -increased knowledge -CBR scholarship in CSHA -increased visibility/credibility in the field to have MA/PhD students studying topic	
<u>Suggestions / Comments:</u> -build capacity within CBAOs – allow PT study for existing folk -more CRCs in area of HIV/HCV/vulnerable pops needed to provide funding and programs for students -involve professors and educate the educators	
<u>Recommendation for Action:</u> ➤ <b>Identify representatives from each institution to push this agenda and ensure there is community input into the process.</b>	

This activity was a very useful one. No one was made accountable for the recommendations put forward, but momentum was certainly built and any of the players involved could take the initiative to move these ideas forward to the next step. There was a desire to go into more depth immediately on one or two of the most important issues and begin some concrete action planning. That was done in the next activity described below.

### 4.3 How Could a Sustainable Mechanism be Put in Place?

Following the discussions of each of the possible mechanism a “dotmocracy” voting activity was used to determine which of the two mechanisms deserved further attention by a sub-group at the workshop. Again, all mechanisms were considered valuable and worthy of further work, but some decisions needed to be made about what further work could be done within the workshop setting. The table below shows the outcome of the voting.

Mechanisms for Sustaining Research Collaboration		
	7	Regular Meetings
Chosen for further discussion	9 ½	Emerging Teams
Chosen for further discussion	10 ½	Research Coordination Structure
	5	Develop Grad Programs
	3	Peer Review Groups
	6	List Serve / Web Site
	5	Studies Unit
	0	Clearing House
	4	Data Base

Eight participants gathered to discuss the top two issues above and decided to merge into one discussion group focused on the emerging teams grant proposal. Following lengthy discussion the group came up with a number of key points and action items for follow-up. This team also agreed to remain in contact. They have committed to submit two proposals for funding: a CIHR Operating grant on September 15, 2003 and a CIHR ICE grant on November 1, 2003. They welcome others in the region interested to join them in the proposal development.

Contact people are: Margaret Dykeman, Gerry Mugford, Cindy MacIssac and Jacquie Gahagan.

The points below reflect their preliminary ideas supplemented by other participants during the plenary session.

### Pursuing Funding for Emerging Team Grants

#### Description of First Proposal:

Submit a 1-year \$100,000 grant proposal for an “emerging team” by Sept 15<sup>th</sup>. The application would go to the Canadian Institutes of Health Research, Operating Grant for a proposal with preliminary title “Developing a Multidisciplinary Team to Investigate the Determinants of Health that Effect the Transmission and Illness Trajectory of HEP C and HIV in Atlantic Canada”. This will be an Atlantic based multidisciplinary team. Groups included will be those infected with HIV and/or HEP C, or at risk for HIV and/or HCV. Part of the rationale is that males and females infected are at risk for longer-term health consequences. The heart and stroke foundation, for example, should be approached to get involved. From the beginning, a focus will be placed on the dissemination and utilization of findings. Central to the success of the team will be the inclusion of community partners.

*From the beginning a focus will be built in on the dissemination and utilization of findings. Central to the success of the team will be how to include community partners.*

The grant proposal will focus on team building. Funds will be available for a skill development component to develop common CVs and to build people’s skills in writing grant proposals. This will help to involve community members. The Addictions Centre will be invited to be part of the team. Since the grant application deadline is so soon involvement seems to be limited right now. Involvement will be widened to a large degree once the project funding is secure. Upon receiving this grant, it is assumed that this group will help assist what other individual groups have presented. The grant would be good for many projects and would help to put together a team and define research questions further for the future. It potentially incorporates all stakeholders, addresses lack of resources, and is multidisciplinary.

#### Action Steps for First Proposal:

- Get further information from CIHR on the application process, specifically investigate whether funding is available for a team coordinator, and submit an application if appropriate. (NB: As of the time of writing this report CIHR had been contacted and it was deemed the proposal did not fit this particular call. Work is being done on identifying alternate sources of funding.)
- Communicate results of progress through e-mail and phone conferencing.

#### Description of Second Proposal:

Submit a 3-year \$600,000 grant proposal (Nov 1<sup>st</sup> Registration, full proposal by January 15<sup>th</sup>) for an emerging team. The application would go to the Canadian Institutes of Health Research, Social and Behavioral Research Issues in HIV / AIDS and Hepatitis C, Institute of Infection and Immunity (III) Interdisciplinary Capacity Enhancement (ICE) Teams Grant Program.

This proposal will focus on “Access to liver treatment, care, and support across the Atlantic Region”. This will be a qualitative, exploratory approach with a specifically outlined dissemination plan that will include the following four components:

- 1) provincial policy analysis (documents)
- 2) cost-benefit analysis of ‘modalities’ (community-based vs. hospital / institution)
- 3) qualitative, exploratory (to develop questions for survey / in-depth interviews)
- 4) policy uptake / dissemination

*Users must also have a voice.*

The team to successfully implement this work will include people with expertise in epidemiology, medicine and community. Both community and university people will be needed in each province. Users must also have a voice. The Canadian Liver Society should be involved and policy groups should be brought on board. A regional coordinator, a policy analyst, a statistician and administrative support will be essential to this process.

The focus on liver treatment is just one idea to push forward. A team funded to do this kind of work could also help support everything we've talked about at this meeting.

The group will have to think about sustainability. A two or three year project is a good starting point, but what about after that time period has elapsed. One grant often leads to another, but that kind of continuity needs to be planned. Advice from CIHR is that a proposal needs to be large like this to make anything happen and it should have two full time employees. It will also be important to use the outcomes of this particular meeting whenever possible as building blocks since it has been funded in part by CIHR.

Action Steps for Second Proposal:

- Consult with CIHR to enhance the preliminary ideas to make them stronger.
- Identify other potential pools of money that exist.
- Ensure the core team is in communication to get the registration in by November 1<sup>st</sup>.

#### **4.4 Other Possible Actions for Follow-up**

Participants were pleased with the steps made towards the development of two grant proposals that will contribute immensely to establishing a sustainable mechanism for HIV and Hep C research in the Atlantic region. As a final activity around the issue of “mechanisms for sustainability”, however, participants were challenged with the question, “what if the grants are not funded? What can we do while we wait for funding?”

The following issues were brainstormed:

- Industry funding could be pursued to back certain initiatives. For example “the Buddy Study was able to get Pharma to pay for our website. Perhaps they could be approached for a website for this.”
- Conferencing calls could be set up around particular issues
- HRDC grants could be looked into
- Linking with ACEWH
- AHPRC could be tapped for some support
- NSHRF team building application may be able to provide support
- Canadian Trials Network could act as funding source
- Corrections Canada Funding (however there are challenges to be aware of when working with this agency) CSC gets portion of Canadian HIV Strategy funding. They need to be held accountable with regard to what they're doing with this money for prevention if it is not being spent appropriately it should go to others.
- Two-way information sharing with the Atlantic Canada HIV Education group (ACHIVE) a clinical group focusing on education and sharing of

clinical experience, may also lead to some benefits. Contact [Yvonne.Lynch-hill@cdha.nshealth.ca](mailto:Yvonne.Lynch-hill@cdha.nshealth.ca)

- Post the final report of these meetings on ACAP website, Hep C government Website or potentially setting up another website for the report by itself. The information may motivate others.
- A link with ACAP will also be important to keep them current. A link with them will be valuable and it can start with a request to put this report on their website as PDF. That will be good for dissemination. This would be a helpful in-kind donation. There is a separate Health Canada section for Hep C and they should be contacted for support as well.
- Ensure that federal, provincial and territorial people get a copy of the final report.
- Research around methadone could come through different pockets of funding; even just sharing this information is valuable.
- Better use of the clearinghouse. Ensure in your individual reports that certain things are highlighted so that information can be more readily accessed and shared.
- Send Aileen other contacts that should be involved in this group and in further communication.

*Participants were very appreciative of the in-kind support that ACEWH and Aileen Reynolds personally are willing to give in the interim.*

A significant comment was made that, “Everyone will continue the work they are doing now.” This is significant because there was a general feeling that the dedication and extent of the work and expertise that already exists will contribute to sustainability.

Participants were very appreciative of the in-kind support that ACEWH and Aileen Reynolds personally are willing to give in the interim. This will include establishing an email list and disseminating information to the group, updating the list and generally keeping people in the loop. A fax back form can be included with the final report to enable people who want to join the list to do so. This will be the beginning of a database. Aileen can be contacted at [Aileen.Reynolds@dal.ca](mailto:Aileen.Reynolds@dal.ca).

In the final workshop evaluation participants were asked what they will do, and what their organizations will do to help further collaborative work on HIV and Hep C research in the Atlantic Provinces.

In regards to sustainable mechanisms for change one participant related that she has “a better understanding of the confines and processes involved with other ‘systems’” and another stated that she “will go back to my office with a greater understanding of the resources or lack thereof available in other Atlantic provinces”. This awareness is probably an excellent first step in sustaining an effective collaborative structure for the future. Other participants stated that they “will volunteer my time in any way possible” and “form partnerships to develop proposals”. All participants stated some form of commitment to “follow up” on the workshop, demonstrating that some momentum was obviously built at an individual level.

From an organizational perspective there were not specific commitments articulated by any institution other than ACEWH, however, participants made comments such as, “my organization will stay involved and active with this initiative in whatever direction it takes”, and “I can offer my organization’s infrastructure as support”. More generally, participants articulated their organizational commitment to provide research expertise and support with virtual services, to become a collaborative partner, to share information (i.e. a CBR training manual for community members),

*My organization will stay involved and active with this initiative in whatever direction it takes.*

to share research/evaluation re: various projects, and to participate in future planning. One participant articulated an organizational commitment that seemed to sum up the enthusiasm and dedication that everyone showed: “my organization will be consistent in following through on all issues discussed”.

A specific action plan for follow-up (other than the two grant proposals pending) was not constructed. However, if the individual and organizations continue what they have been doing and follow up on the commitments made over the two days of this workshop, great strides will have been made towards a “sustainable mechanism for HIV and Hep C research in the Atlantic region”.

## 5. CONCLUSIONS AND OUTCOMES

What was accomplished at the workshop?

### 5.1 Naming the Research Agenda

Significant progress was made at this workshop in naming the research agenda on HIV and Hep C in the Atlantic Region. Participants named ten major areas where there are research needs (see page 11 above for details).

<b>RESEARCH ISSUES RELATED TO HIV AND HEP C IN THE ATLANTIC REGION</b>
Epidemiological Information
Research with Marginalized groups
Harm reduction research / programming
Research re: Program / Service Effectiveness
Specific Issues around the need for harm Reduction Strategies for Men having Sex with Men in the Prison Context
Prison Programs – research needed to justify issues such as safe sites for tattooing and needle exchange
Funding resources, access and comparisons
Policy Advocacy Research and / or Strategies
Dissemination of Research Strategies
Determinants of Health Research

Participants focused on four research gaps that are particularly critical.

First, research is needed that focuses specifically on marginalized and vulnerable populations. An example of this was the idea for a research initiative on safe tattooing sites in prisons – prison populations being a particularly vulnerable group.

Second, the complex issue of harm reduction needs more research done in a way that would illustrate the value and importance of these types of programs. Needs assessment and evaluation work is particularly useful. There is not a lot of support for harm reduction by decision makers and the public. More research is essential to demonstrate the positive impact of harm reduction programs in order to justify their continuation and expansion.

Third, extensive work needs to be done from a determinants of health perspective. Investigating what determines the high risk behaviors of many Atlantic Canadians that leads to HIV and Hep C infections will assist in developing prevention programs and policies that can make a difference in terms of prevention, care, treatment and support.

Fourth, research that has a specific policy development and advocacy component needs to be carried out. For example, “determining what the barriers are to prevent Atlantic provincial governments working together on these issues” would be a starting point. Building in a strategy for research translation and policy uptake from the beginning of all initiatives should become the norm. Ensuring that research shows how new learnings will have an impact on health services directly is what policy makers want to see. This may mean more work on cost effectiveness studies, since that seems to be the language decision makers most easily understand, and regional research can also be an important advocacy tool to influence the government to assume their responsibilities for protecting and promoting the health of the population.

There were cross cutting issues that came up again and again in the context of the above four gaps. One is the lack of understanding of Hep C by government and the general public (including the potential burden of this disease on the health system in the future). Others are the complex and far reaching issues around injection drug use, and broad issues around gay men's health that go beyond HIV or any other specific infection.

This articulation of a research agenda for the region is a major outcome of the two day workshop. The fact that a number of participants volunteered to be identified with these issues to "keep the ball rolling" and serve as focal points for follow-up is very encouraging. Names and coordinates of these volunteers are in section 2.3 (page 14 – 19 above).

*Those infected and affected should take the lead in choosing research priorities.*

Concerning how the research agenda should be taken forward there was much support for the idea that those infected and affected should take the lead and be directly involved in choosing research priorities, carrying out studies, and strategizing how results will be utilized. The nature and quality of all research will be enhanced by the kind of anecdotal and in-depth information that can be gathered by working with community people who work with these issues on a daily basis. In this regard the relationship between researchers coming from different perspectives was talked about as being very important and therefore there is a great need for cultural sensitivity. Team building is necessary for research teams. This applies when working across disciplines and also with specific vulnerable and marginalized groups. Sensitivity for working with the aboriginal community, for example, is an area where the needs are great. This may necessitate the inclusion of capacity building of researchers within the aboriginal community and generally with non-traditional and non-PhD researchers.

## **5.2 Feasibility of a Regional Collaborative Mechanism for HIV and Hep C Research**

As a result of the two day workshop it became clear that a sustainable mechanism for research collaboration is feasible.

In order for a mechanism to be feasible it must first of all be relevant. A sustainable Atlantic regional mechanism to support HIV and Hep C research is needed. There is a unique Atlantic Canadian lens on HIV and Hep C. There are unique needs and capacities. There are exceptional strengths in the research community. There are specific research gaps that must be investigated. Coordinating research and collaborating between groups that traditionally work on HIV or Hep C can be mutually beneficial. Coordinating research and collaborating across disciplines and between provinces is mutually beneficial. Conducting research that works inter-sectorally with academia, service providers and people infected and affected is also mutually beneficial. Elements of this kind of collaboration already exist and provide a foundation that we can build upon. Major issues such as harm reduction and injection drug use are common throughout the region and for people working in the different sectors. It is essential to remember that enhanced support is needed for people who are infected with HIV and Hep C and research can support this. All of this collaboration takes time and money, however, and most organizations working in this field are cash strapped. Economic pressures encourage a meeting of HIV and Hep C issues. This may be seen as an opportunity to access the resources needed for this important work. Coordinating a strategy to access these resources would

enhance the region's competitiveness when competing against the rest of the nation for research funds. Coordinating a strategy to access these resources is more beneficial than competing amongst ourselves within the region for limited funds. A sustainable collaborating mechanism is definitely relevant.

It is essential that a multidimensional collaborating mechanism must also be of high quality and principles. The collaboration that is encouraged must be based on the utmost trust and respect for all parties involved. For the research work to be effective working through ethics committees will be essential. This means that collaborating partners will need to recognize and value different perspectives on ethics. Partners will need to be willing to engage in the ethics process to ensure quality standards are met and unique perspectives and concerns of diverse groups are valued. Regional work for the Atlantic needs to take the task of French language translation seriously. The inclusion of the aboriginal community, of women, and of all marginalized and vulnerable groups is critical. Incarcerated populations in the region need to be viewed as part of the population of the region and learnings from work with them on the inside about treatment and prevention needs to be used on the outside. Data and statistics need to be clarified and referenced consistently to provide a common foundation from where to begin the important and challenging work of social and behavioral studies. The feasible mechanism envisioned will ensure these quality standards and principles are met.

A feasible mechanism will be realistic and effective. The workshop participants agreed that an overall coordinating structure to enhance HIV and Hep C research in the Atlantic region could get off the ground with a sub-group being established to develop the ideas and to pursue funding from CIHR for "interdisciplinary enhancement funding". In the mean time, it was recommended that existing structures should be approached, like ACAP, NSHRF, PPHB to kick start the process. It was also recommended that a lot of work is needed up front with specific timelines and schedules for planning this "structure". Participants agreed that whatever the mechanism is called, an "emerging team", "a research coordination structure" or "a studies unit", it will realistically need sufficient time and resources to evolve into an effective vehicle for enhancing collaborative research work. This is realistic.

While ensuring that the mechanism is effective, it will also need to be efficient. Participants developed a number of tools that would improve collaboration efficiency. This included planning and facilitating productive regular meetings. Assigning someone to this responsibility and paying and supporting them for this important task of coordination was agreed. Using technology was also considered important and was recommended to be integrated into any grant proposals. Efficiency is enhanced by clear and timely communication. The web site, development of a database, and the list serve planned were all considered essential communication elements. These avenues of communication and information sharing can build on clearinghouses and networks that already exist.

Sub-groups taking on tasks such as getting involved in the peer review process and developing graduate programs can also enhance effectiveness and efficiency. Volunteers have already stepped forward for the former and representatives from each institution will be solicited for the later. These independent sub-groups can efficiently focus on tasks where they have the desire and expertise to make significant contributions.

*A sustainable mechanism for enhancing HIV and Hep C research in the Atlantic region is feasible. The human resources exist and the opportunities for financial resources have been identified.*

A feasible mechanism needs to be put in place in a logical sequence with sufficient resources. Action recommendations by a sub group of participants to get further information from CIHR on funding possibilities, communicating results through email, identifying other pools of money that exist and setting deadlines for their grant registrations are a clear and logical framework for progress. The fact that individual participants and organizations also made commitments to follow up on specific issues and shared ideas about what can be accomplished in continuing to build rapport and sharing information and resources demonstrates that the human resources to take the idea of a sustainable mechanism forward definitely exist. Various potential funding sources exist from the “usual suspects” of CIHR and NSHRF to industry, HRDC, AHPRC, CTN, CSC and many others. In-kind contributions may be available from some organizations and much will be done simply by the individual people and committed groups in the region continuing to do what they do. Significant collaboration and coordination can be done with existing resources. The money is not in the bank to launch the realistic coordinating structure yet, but the enthusiasm and the research, management and technical expertise exists.

A sustainable mechanism for enhancing HIV and Hep C research in the Atlantic region is feasible. It is something that is relevant and that has been envisioned as a qualitative, effective and efficient device for promoting research collaboration. A logical, strategic process has been put in place for bringing the ideas to reality. Individuals, committees and organizations have taken on the responsibility and shown the commitment to take things forward. The human resources exist and the opportunities for financial resources have been identified.

### **5.3 Evaluations and Conclusion**

The end of the workshop evaluation was very positive. Great momentum was built during the workshop. Nineteen people took the time to complete the final evaluation forms.

Participants commented that:

- “This workshop was an excellent environment for both community and academic individuals.”
- “A great energizer for the fall. Lets keep it going.”
- “I was not initially enthusiastic when I heard about the meeting. What was accomplished here made the trip worthwhile. Many deliverables will come from this”.

One participant stated that she came with trepidation and was worried from past workshops about wonderful ideas that develop and then momentum gets lost. She said she was glad interaction was encouraged and action pieces were articulated and she left very pleased. “We recognized lots of assets in this region and realized the kind of collaboration mechanism we want is more than a pipe dream”, she said.

Many people stated they have a better understanding of the confines/processes involved with other ‘systems’ and are willing to go ahead and form partnerships to develop proposals. Each individual committed to doing what they can to help forward all issues discussed at the workshop, to share information, and to work with the team to further this initiative.

A community person mentioned she had some fears of academia that have been broken down. She stated she now sees we're all human, and is happy action pieces are coming out.

Participants overwhelmingly stated they agreed or strongly agreed that the workshop was well organized (4.3 out of 5) and that the facilitation (4.4 out of 5) and small group activities were effective (3.8 out of 5).

Participants strongly agreed that their awareness of the need and importance of collaborative research was increased (4.1 out of 5) and agreed that the presentations provided useful information (3.8 out of 5).

Participants stated they agreed that the objectives of the workshop had been achieved. Ratings (out of a possible 5) for individual objectives are provided below.

*I was not initially enthusiastic when I heard about the meeting. What was accomplished here made the trip worth while. Many deliverables will come from this.*

1) to bring together a group of HIV/Hep C community- & university-based researchers: **rating of 4.5**. This networking objective was well achieved.

2) to discuss the current gaps in HIV/Hep C research in the Atlantic Region: **rating of 4.3**. This objective of identify gaps was well achieved.

3) to promote a coordinated, multidisciplinary & regional response to HIV/Hep C research: **rating of 3.6**. Ten out of seventeen respondents stated this was achieved and three thought it was strongly achieved. However one person disagreed and three were unsure. More work will need to be done in this area.

4) to encourage research teams to apply for regional & national funding: **rating of 3.8**. Eight agreed this was achieved and five strongly agreed. However, 3 disagreed and 2 were unsure. This is an area where those responsible for follow-up should take on the responsibility of sharing information about research funding opportunities and encourage people to work together and apply for funding.

5) to determine the feasibility of developing an Atlantic Regional HIV/Hep C Social & Behavioural "Studies Unit" to help facilitate & coordinate the research teams and to determine the scope & parameters of such a proposed "Studies Unit": **rating of 3.7**. Six people agreed and four strongly agreed with this statement. Six were not sure, however, and one strongly disagreed. Hopefully this report pulls some ideas together that may have been unclear in the workshop about the feasibility issue and again the responsibility lies here for specific follow-up on this critical component.

Participants were asked if they thought this workshop will further research collaboration around HIV and Hep C in the region. Seven participants agreed with this statement and five strongly agreed, clearly demonstrating the momentum that was built (overall rating 4 out of 5). Unfortunately it was not so clear whether they were able to identify how to apply what they have learned directly to the work they do: one participant disagreed, five participants were not sure, four agreed and three strongly agreed (overall rating 3.7 out of 5).

Participants left with questions primarily around sustainability: "How will we ensure follow up will be done?, what is the ownership going to look like?, what are the

concrete next steps? How are we going to keep the agenda going?” These are definite concerns. As one person stated, “now that the workshop is done, sustainability is a big question; is everyone involved going to stay involved and be consistent?”.

There was advice for the future to get appropriate groups to the table (e.g. GLB groups, women’s groups, prisoner groups) and to consider the delivery of CBR skills building opportunities for CBOs and their local partners. Participants suggested maintaining a healthy mix of academics and community-based organizations in future sessions such as this.

Overall the workshop was a success. However, the follow through and continuation of the momentum developed at the workshop is essential. This report can contribute to that in a small way (that is the 6<sup>th</sup> workshop objective) and the continued support of the ACEWH as an interim focal point for this initiative provides great hope.

To truly have any impact, however, participants and others interested in these issues and reading this report must take the responsibility and hold themselves accountable for the follow-up that is necessary.

*We worked well together, there was good communication between the groups. I’m proud of what we accomplished.*

*Thanks for believing in this idea! A few months ago we didn’t know what we could do. We worked something out, just to get people together and the group has achieved much. Thank you!*

## **A Coordinated Approach to HIV & Hepatitis C Research in Atlantic Canada: How do we get there?**

*A Feasibility Workshop for an Atlantic Regional  
HIV and Hepatitis C Social and Behavioral Studies Unit  
Future Inns, Halifax, Nova Scotia - August 27 & 28, 2003*

### **Workshop Objectives:**

- 1) to bring together a group of HIV & Hepatitis C community- and university-based researchers;
- 2) to discuss the current gaps in HIV & Hepatitis C research in the Atlantic Region;
- 3) to promote a coordinated, multidisciplinary and regional response to HIV & Hepatitis C research;
- 4) to encourage research teams to apply for regional and national funding;
- 5) to determine the feasibility of developing an Atlantic Regional HIV & Hepatitis C Social & Behavioural "Studies Unit" to help facilitate and coordinate the research teams and to determine the scope and parameters of such a proposed "Studies Unit"; and
- 6) to develop a final workshop report that includes the identification of themes and an action plan, to be sent to various HIV & Hepatitis C stakeholders.

## Workshop Overview for August 27<sup>th</sup> and 28<sup>th</sup>, 2003

### **Day 1 – Checking Out The Situation**

7:30 – 8:00	Registration
8:00 – 10:00	Welcome, Objectives and Introductions <ul style="list-style-type: none"><li>• Jacqueline Gahagan, Assistant Professor, School of Health and Human Performance, Dalhousie, Nova Scotia</li><li>• Krista Connell, Executive Director, Nova Scotia Health Research Foundation</li><li>• Barbara Clow, Atlantic Centre of Excellence for Women’s Health</li></ul>
	CIHR III: Hepatitis C & HIV Research Priorities <ul style="list-style-type: none"><li>• Bruce Moor, Canadian Institute for Health Research</li></ul>
10:00 – 10:15	Stretch and Nutrition Break
10:15 – 11:15 Perspectives	Current Research and Research Gaps – Provincial <ul style="list-style-type: none"><li>• Barb Gibson, AIDS PEI</li><li>• Bill Downer, AIDS Committee of Nfld and Labrador</li><li>• Robert Allen, AIDS Coalition of Nova Scotia</li><li>• Scott Hemming, ASR Consulting, NS</li><li>• Margaret Dykeman, University of New Brunswick</li><li>• Amanda Feltus, Healing Our Nations, NS</li></ul>
11:15 – 12:00	Identifying Commonalities and Unique Aspects of the Research Environment – <i>small group activity</i>
12:00 – 1:00	Lunch (provided)
1:00 – 3:00	Looking at Research Approaches and Finding the Complimentarities <ul style="list-style-type: none"><li>• University-Based Research Approaches – Successes and Challenges: Grace Getty and Lois Jackson</li><li>• Community-Based Research Approaches – Successes and Challenges: Cindy MacIssac</li><li>• How to go about research in Correctional Service of Canada? – Successes and Challenges: Odette Pellerin</li><li>• Hep C Research – A Clinical Perspective: Kevork Peltekian, Hepatology Services,</li></ul>

QEII and Michael Vallis, QEII and  
Dalhousie University

- Finding the Complimentarities – *small group activity*

3:00 – 3:15

Stretch and Nutrition Break

3:15 – 5:00

*collective activity*

Exploring the Terrain / Naming the Research Agenda -

5:00-5:30

Evaluations

How far have we come? What happens tomorrow?

6:30-8:00

Dinner at the Future Inn

*Workshop Overview for August 27<sup>th</sup> and 28<sup>th</sup>, 2003*

**Day 2 – Strategizing Around Complimenting Each Other’s Work**

8:00 – 8:30	Welcome back – Group check-in
8:30 – 10:00	Sustainable Research Collaboration: Mechanisms and Structures – Are they needed? How do we do it? - <i>group discussions</i>
10:00 – 10:15	Stretch and Nutrition Break
10:15 – 12:00	Working Out Some Details - <i>focused small group work on chosen priorities in research issues and ways of collaborating</i>
12:00 – 1:00	Lunch (provided)
1:00 – 3:00	Bringing it All Together / Planning for the Future - <i>report back from small groups and discussing commitments needed from individual, organizational and/or regional levels</i>
3:00 – 3:30	Conclusions, Evaluations and Appreciations

**Thank you!**

# **A Coordinated Approach to HIV & Hepatitis C Research in Atlantic Canada: How do we get there?**

*A Feasibility Workshop for an Atlantic Regional  
HIV and Hepatitis C Social and Behavioral Studies Unit  
August 27<sup>th</sup>-28<sup>th</sup> Future Inns Halifax*

## **Nova Scotia**

Robert Allen  
Executive Director  
AIDS Coalition of Nova Scotia  
1657 Barrington Street, Suite 321  
Halifax, NS B3J 2A1  
Phone: 902-429-7922  
Fax: 902-422-6200  
E-mail: [ed@acns.ns.ca](mailto:ed@acns.ns.ca)

Diane Bailey  
Program Director  
Mainline Needle Exchange  
2158 Gottingen Street  
P.O. Box 47012  
Halifax, NS B3K 3B4  
Phone: 902-423-9991  
Fax: 902-423-1619  
E-mail: [mainline92@hotmail.com](mailto:mainline92@hotmail.com)

Larry Baxter  
Chair  
NS Advisory Commission on AIDS  
6th Floor, Dennis Building  
1740 Granville Street  
Halifax NS B3J 1X5  
Phone: 902-454-5158  
Fax: 902-424-4727  
E-mail: [larrybaxter@ns.sympatico.ca](mailto:larrybaxter@ns.sympatico.ca)

Janet Braunstein-Moody  
Senior Director  
Nova Scotia Department of Health/Office of Health Promotion  
1690 Hollis Street, 11<sup>th</sup> Floor  
Box 488  
Halifax, NS B3J 2R8  
Phone: 902-424-5187  
Fax: 902-424-0663  
E-mail: [moodyjb@gov.ns.ca](mailto:moodyjb@gov.ns.ca)

Barbara Clow  
Executive Director  
Atlantic Centre of Excellence for Women's Health  
305 – 5475 Spring Garden Rd.

Halifax, NS B3J 3T2  
Phone: 902-494-7850  
Fax: 902-494-7852  
Email: [barbara.clow@dal.ca](mailto:barbara.clow@dal.ca)

Cindy Coles  
Coordinator  
Hepatitis Outreach Society  
1994 Main-a-dieu Rd.  
Main-a-dieu, NS B1C 1W4  
Phone: 902-733-2214  
Fax: 902-733-2043  
E-mail: [hosc@ns.sympatico.ca](mailto:hosc@ns.sympatico.ca)

Krista Connell  
Executive Director  
Nova Scotia Health Research Foundation  
P. O. Box 488  
Halifax, NS B3J 2R8  
Phone: 902-424-4043  
Fax: 902-424-7753  
Email: [connellke@gov.ns.ca](mailto:connellke@gov.ns.ca)

Amanda Feltus  
Acting Executive Director  
Healing Our Nations (Atlantic First Nations AIDS Network)  
45 Alderney Drive, Suite 607  
Dartmouth, NS B3Y 2N6  
Phone: 902-492-4255 / 492-2833  
Fax: 902-492-0500  
E-mail: [director@accesswave.ca](mailto:director@accesswave.ca)

David Fletcher  
Principal Consultant  
Holistic Community Pursuits  
2528 Sherwood Street  
Halifax, NS B3L 3G8  
Phone: 902-454-5906  
Fax: 902-423-7214  
E-mail: [davidfletcher@yaho.ca](mailto:davidfletcher@yaho.ca)

Jacqueline Gahagan  
Assistant Professor  
School of Health & Human Performance  
Dalhousie University  
6230 South St.  
Halifax, NS B3H 3J5  
Phone: 902-494-1155  
Fax: 902-494-5120  
E-mail: [Jacqueline.Gahagan@dal.ca](mailto:Jacqueline.Gahagan@dal.ca)

Scott Hemming  
Project Consultant  
ASR Consulting  
105 Dickey Dr.  
Lower Sackville, NS B4C 3E2  
Phone: 902-865-2946  
Fax: 902-865-2948  
E-mail: [asconsulting@eastlink.ca](mailto:asconsulting@eastlink.ca)

Lois Jackson  
Associate Professor  
School of Health & Human Performance  
Dalhousie University  
6230 South St.  
Halifax, NS B3H 3J5  
Phone: 902-494-1341  
Fax: 902-494-5120  
E-mail: [lois.Jackson@dal.ca](mailto:lois.Jackson@dal.ca)

Susan Kirkland  
Associate Professor  
Community Health and Epidemiology  
Dalhousie University  
5790 University Rm. 432  
Halifax NS  
Phone: 902-494-1235  
Fax: 902-494-1597  
E-mail: [susan.kirkland@dal.ca](mailto:susan.kirkland@dal.ca)

Yvonne Lynch-Hill  
Clinical Nurse Specialist  
Infectious Disease Centre  
Capital Health  
5820 University Ave  
Rm 5079 Dickson Bld  
Halifax, NS  
Phone: 902-473-7794  
Fax: 902-473-7394  
E-mail: [Yvonne.lynch-hill@cdha.nshealth.ca](mailto:Yvonne.lynch-hill@cdha.nshealth.ca)

Cindy MacIsaac  
Program Director  
Direction 180  
2158 Gottingen Street  
Halifax, NS B3K 3B4  
Phone: 902-420-0566  
Fax: 902-420-1549  
E-mail: [cynthmacisaac@aol.com](mailto:cynthmacisaac@aol.com)

Jeannine McNeil  
Executive Director  
Stepping Stone Association  
2224 Maitland Street  
Halifax, Nova Scotia B3K 2Z9  
Phone: 902-420-0103  
Fax: 902-422-9665  
E-mail: [steppingstone@navnet.net](mailto:steppingstone@navnet.net)

Albert McNutt  
Northern AIDS Connection  
Board Member/PHA Resource  
Northern AIDS/Canadian AIDS Society  
33 Pleasant Street  
Truro, NS B2N 3R5  
Phone: 902-895-0931  
Fax: 902-895-1533  
E-mail: [t\\_o\\_p2000@hotmail.com](mailto:t_o_p2000@hotmail.com)

Susan McWilliam  
Graduate Student  
School of Health & Human Performance  
Dalhousie University  
6230 South Street  
Halifax, NS B3H 2J5  
Phone: 902-494-1237  
Fax: 902-494-5120  
E-mail: [smcwilli@dal.ca](mailto:smcwilli@dal.ca)

Eric Mykhalovskiy  
Assistant Professor  
Community Health & Epidemiology  
Clinical Research Centre  
Dalhousie University  
5849 University Ave.  
Halifax, NS B3H 4H7  
Phone: 902-494-2789  
Fax: 902-494-1597  
E-mail: [eric.mykhalovskiy@dal.ca](mailto:eric.mykhalovskiy@dal.ca)

Kevork Peltekian  
Hepatology Services, QEII  
1278 Tower Rd. VG Site 911  
Halifax, NS B3H 2Y9  
Phone: 902-473-2898  
Fax: 902-473-2894  
Email: [kevork.peltekian@dal.ca](mailto:kevork.peltekian@dal.ca)

Christine Porter  
Project Coordinator  
Sharp Advice Needle Exchange  
150 Bentinck St.  
Sydney, NS B1P 6H1  
Phone: 902-539-5556  
Fax: 902-539-0290  
E-mail: [chrisporter@accb.ns.ca](mailto:chrisporter@accb.ns.ca)

Aideen Reynolds  
Research Officer  
Atlantic Centre of Excellence for Women's Health  
305 – 5475 Spring Garden Rd.  
Halifax, NS B3J 3T2  
Phone: 902-494-7850  
Fax: 902-494-7852  
E-mail: [Aideen.Reynolds@dal.ca](mailto:Aideen.Reynolds@dal.ca)

Nicholas Robinson  
Graduate Student  
School of Health & Human Performance  
Dalhousie University  
6230 South Street  
Halifax, NS B3H 2J5  
Phone: 902-470-7706  
Fax: 902-494-5120  
E-mail: [narobins@dal.ca](mailto:narobins@dal.ca)

Christine Saulnier  
Senior Research Officer  
Atlantic Centre of Excellence for Women's Health  
305 – 5475 Spring Garden Rd.  
Halifax, NS B3J 3T2  
Phone: 902-494-7877  
Fax: 902-494-7852  
Email: [christine.saulnier@dal.ca](mailto:christine.saulnier@dal.ca)

Michael Vallis  
Psychologist  
QEII and Dalhousie University  
1278 Tower Road  
Room 332, Bethune Building VG site  
Halifax NS B3H 2Y9  
Phone: 902-473-8635  
Fax: 902-473-2148  
E-mail: [tvallis@dal.ca](mailto:tvallis@dal.ca)

## **New Brunswick**

Margaret Dykeman  
School of Nursing  
University of New Brunswick  
PO Box 4400  
Fredericton, NB E3B 5A3  
Phone: 506-451-6895  
Fax: 506-447-3347  
E-mail: [margdyk@unb.ca](mailto:margdyk@unb.ca)

Grace Getty  
Faculty of Nursing  
Director Graduate Studies, UNB  
PO Box 4400  
Fredericton, NB E3B 5A3  
Phone: 506-458-7644  
Fax: 506-447-3374  
E-mail [getty@unb.ca](mailto:getty@unb.ca)

Odette LeBlanc Pellerin  
Regional Chief Clinical Services  
Correctional Services of Canada  
4902 Main Street  
Dorchester, NB E4K 2Y9  
Phone: 506-379-4128  
Fax: 506-379-4272  
E-mail: [pellerinom@csc-scc.gc.ca](mailto:pellerinom@csc-scc.gc.ca)

Deborah Warren  
Executive Director  
SIDA-AIDS Moncton  
165A Gordon Street  
Moncton, NB E1C 1N1  
Phone: 506-859-6916  
Fax: 506-855-4726  
E-mail: [sidaidsm@nbnet.nb.ca](mailto:sidaidsm@nbnet.nb.ca)

## Prince Edward Island

Diane Birt  
Project Coordinator  
AIDS Prince Edward Island  
P.O. Box 2762  
Charlottetown, PEI C1A 8C4  
Phone: 902-566-2437  
Fax: 902-626-3400  
E-mail: [info@aidspei.com](mailto:info@aidspei.com)  
Internet Site: [www.aidspei.com](http://www.aidspei.com)

Barbara Gibson  
Executive Director  
AIDS Prince Edward Island  
P.O. Box 2762  
Charlottetown, PEI C1A 8C4  
Phone: 902-566-2437  
Fax: 902-626-3400  
E-mail: [bgibson@aidspei.com](mailto:bgibson@aidspei.com)

Jo-Ann MacDonald  
Assistant Professor  
University of PEI  
550 University Ave.  
Charlottetown, PEI C1A 4P3  
Phone: 902-566-0771  
Fax: 902-566-0777  
E-mail: [jammacdonald@upei.ca](mailto:jammacdonald@upei.ca)

## Newfoundland & Labrador

Natalie Beausoleil  
Assistant Professor  
Community Health & Epidemiology  
Memorial University  
Faculty of Medicine, The Health Sciences Centre  
300 Prince Philip Drive  
St. John's, NL A1B 3V6  
Phone: 709-777-8483  
Fax: 709-777-7382  
E-mail [nbeausol@mun.ca](mailto:nbeausol@mun.ca)

Bill Downer  
Executive Director  
AIDS Committee of Newfoundland & Labrador  
P.O. Box 626, Station C  
St. John's, NF A1C 5K8  
Phone: 709-579-8656  
Fax: 709-579-0559  
E-mail: [bdowner@acnl.net](mailto:bdowner@acnl.net)

Gerry Mugford  
Clinical Epidemiologist  
Faculty of Medicine, The Health Sciences Centre  
C/o H-2701  
Memorial University  
300 Prince Philip Drive  
St. John's NF A1B 3V6  
Phone: 709-777-7390  
Fax: 709-777-6603  
E-mail [gmugford@mun.ca](mailto:gmugford@mun.ca)

### **Other Provinces**

Bruce Moor  
Assistant Director  
CIHR Institute of Infection and Immunity  
SDRI 214, 1400 Western Road  
University of Western Ontario  
London, ON N6G 2V4  
Phone: 519-661-3228  
Fax: 519-661-4226  
E-mail: [bmoor@uwo.ca](mailto:bmoor@uwo.ca)

Barbara Paterson  
Physician  
UBC & BCCDC  
T201 - 2211 Wesbrook Mall  
Vancouver, BC B6T 2B5  
Phone: 604-822-7505  
Fax: 604-822-7466  
E-mail: [paterson@nursing.ubc.ca](mailto:paterson@nursing.ubc.ca)