



**Canadian Treatment Action Council
HIV/HBV/HCV Co-Infection Research Summit
October 30-31, 2010
Toronto, Ontario**

ROADMAP OF HIV CO-INFECTION RESEARCH

January 2011

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LETTER FROM THE CO-CHAIR...

The 1st Canadian HIV/HBV/HCV Co-infection Research Summit, held in Toronto on October 30th-31st, 2010, was organized by the Canadian Treatment Action Council (CTAC) in partnership with its funders and supporters (Appendix A) including: the Ontario HIV Treatment Network (OHTN), Canadian Institutes of Health Research (CIHR), Canadian Hemophilia Society, Canadian Aboriginal AIDS Network (CAAN), Canadian AIDS Treatment Information Exchange (CATIE), Merck, Gilead Sciences, MAC AIDS Fund, Ontario AIDS Bureau, Public Health Agency of Canada, as well as researchers and community-based organizations.

Summit Co-Chairs Colleen Price, Dr. Marina Klein, Randy Jackson and the Central Planning, Program Planning, Invitation and Scholarship, and Aboriginal Working Group Committees (Appendix B), led this initiative in bringing together an extremely diverse group of stakeholders to identify and respond to the gaps in research, care, treatment and support of co-infected individuals. Their work was made possible with continued support from their partners and stakeholders.

The Summit was a landmark multidisciplinary gathering that invited and ensured equal participation from people living with HIV and HBV/HCV co-infection, general practitioners, hepatologists, gastroenterologists, epidemiologists and others involved with the substantial scientific and therapeutic challenges facing individuals living with co-infection. Participants also included frontline workers, government employees, people working in community organizations and correctional settings, and pharmaceutical industry representatives.

Each and every delegate was highly engaged in reviewing the latest research in a concerted effort to identify and describe gaps in the research that are needed to inform clinical management, policy development and support service delivery.

With the input of 92 delegates from across Canada, CTAC and its partners were able to identify gaps in our existing body of knowledge and generate preliminary research questions in each of the five research tracks: 1) Clinical and Epidemiology Research; 2) Clinical Service Delivery; 3) Socio-Behavioural Research; 4) Support Service Delivery; and 5) Social Policy Research.

The Roadmap that emerged from the Summit clearly delineates 'next steps' for research in Canada.

Overall, the 1st Canadian HIV/HBV/HCV Co-infection Research Summit was deemed a success in meeting its objectives of bringing a diverse group of stakeholders together to focus on the complex issues related to co-infection with HIV and HBV/HCV. Plans are being made for ongoing knowledge transfer and exchange of the information coming out of the Summit. There was general agreement that useful knowledge regarding future research in co-infection was generated as a result of the engagement of community representatives with other stakeholders and experts in the areas of research and policy development.

What follows is the report on the 1st Canadian HIV/HBV/HCV Co-infection Research Summit and the Roadmap that was developed through the combined efforts of each and every participant. We hope you will find it useful and will contribute to keeping it a living document through your work to meet the challenges of caring for people living with co-infection. The report is also available online at <http://www.ctac.ca/en/issues/hivhcv-co-infection>.

Colleen Price
Co-Chair, 1st Canadian HIV/HBV/HCV Co-infection Research Summit
Chair: CTAC HIV and Hepatitis Working Group
CTAC Board Secretary

SECTION 1: INTRODUCTION

The Canadian Treatment Action Council (CTAC), along with key partners, organized the 1st Canadian HIV/HBV/HCV Co-Infection Research Summit in October 2010. The Summit brought together 92 delegates (Appendix C) from across Canada, including researchers, clinicians, people living with HIV co-infections, service providers and government stakeholders. The Summit engaged participants in a highly interactive two-day workshop organized around five tracks:

1. Clinical and epidemiological research
2. Clinical service delivery
3. Socio-behavioural research
4. Support service delivery
5. Social policy research

1.1 SUMMIT GOALS AND OBJECTIVES

The Summit was not designed to simply share current co-infection research; rather it had a much more ambitious and action-oriented goal to develop a Roadmap of HIV Co-Infection Research through broad stakeholder consultations to help guide a co-infection research agenda. The objectives of the Summit were to bring together co-infection researchers and community members from across Canada to:

- Review the most recent information about the epidemiology of HIV/HBV/HCV co-infection
- Review current research in the five tracks covered by the Summit
- Develop short- to mid-term research questions of relevance to each stakeholder group at the Summit in each of the focus areas covered by the Summit with proposals research protocols and process (i.e. the Roadmap of HIV Co-infection Research)

Beyond the Summit and the development of the Roadmap of HIV Co-Infection Research (The Roadmap), CTAC and the Central Planning Committee are committed to a comprehensive knowledge translation and exchange strategy (Appendix D) to ensure ongoing input from all stakeholders, as well as effective dissemination.

1.2 SUMMIT OVERVIEW

The work of CTAC is embedded in a community-based approach, evidenced by their description as a “national non-governmental organization run by and for people living with HIV/AIDS, including those who are co-infected.”¹ Based on this approach, it was important that The Roadmap be developed through input, consultation, and oversight by a broad range of stakeholders.

A highly interactive and engaging workshop was developed with the support of a professional facilitator to fully involve participants at the Summit in reviewing current research, identifying gaps and articulating priority research questions (see Appendix E for a full description of the process).

“[The Summit was] very interactive and participatory, a lot of good work produced in a short time” ~ Summit Participant

For each of the five research tracks, a panel of presenters provided an overview of the current state of HIV co-infection research. All of the participants then worked in small groups to identify gaps and brainstorm important research questions. All of the brainstormed questions were posted in the room and as a whole group the participants went through a process of clustering the questions together based on emergent themes, which were identified on the spot by the participants. The

¹ www.ctac.ca/en/home

participants then returned to their small groups with the themed clusters and narrowed them down into one or two key questions.

In this way, by the end of the Summit a set of 34 key questions (Appendix F) was narrowed down for each of the five research tracks based on nearly 200 questions (Appendix G) initially posed through the brainstorming process. In the final session of the Summit participants then reviewed the 34 key questions to identify priorities and issues of importance.

The process used at the Summit was excellent for engaging multiple stakeholder groups in defining an HIV co-infection research agenda. A key challenge was noted, however, which was discussed in final session of the Summit. That is, in the process of narrowing down the clusters to key research questions, it appeared that specific issues and priorities may have been lost. For example, the clustering sometimes involved grouping together all questions pertaining to specific high risk populations, so that a particular focus on certain communities was lost. Some key issues were discussed in nearly all of the five tracks but were barely present in the final key questions.

“There are some different themes that have just disappeared in making these higher level questions, but they’re there, I think.” ~ Summit Participant

Similarly, in attempting to create one or two overarching questions for each thematic cluster, the questions often became quite general and less specific.

“... in the breakout sessions a large number of specific research questions were generated. The process of distilling these to fewer overarching research questions necessarily resulted in very broad non-specific types of research questions.” ~ Summit Participant

To build on the process, capitalize on the wealth of information gathered and address some of the challenges that were identified in prioritizing the research questions, a secondary analysis was undertaken. Using content analysis, all of the brainstormed questions were reviewed and categorized based on cross-cutting themes. Some of the themes were identified by Summit participants during the discussions in the final session, which was recorded and transcribed, and additional emergent themes were also identified.

Questions were coded into key thematic areas, with some questions being coded in more than one category when necessary. Once all questions were coded they were reviewed again and additional codes and/or sub-codes were identified. Each thematic code was then reviewed and cross-referenced with the other codes to identify commonalities or intersections that may suggest broader categories or groupings.

Based on a post-Summit evaluation, over 80% of Summit participants who completed the evaluation (n=52) rated the Summit as good (12%), very good (39%) or excellent (32%). Participants seemed to find the program and facilitation process to be very engaging and they particularly appreciated the attempt to engage all of the stakeholders in attendance.

“The multidisciplinary and multi-sectoral presence and input [was a strength of the Summit].” ~ Summit Participant

“Lots of useful epidemiological, service, research and policy information and perspectives. [This] gave rise to what I think will be a very useful research agenda.” ~ Summit Participant

SECTION 2: ROADMAP OF HIV CO-INFECTION RESEARCH

The Roadmap of HIV Co-Infection Research has been developed to inform the co-infection research agenda and guide researchers, community members, and other relevant stakeholders engaged in HIV co-infection research and support. The Roadmap was developed based on input gathered over a two-day Summit involving researchers, service providers, clinicians, people living with co-infections, and government representatives.

2.1 GUIDING PRINCIPLES FOR HIV CO-INFECTION RESEARCH

Three overarching themes emerged throughout the Summit that suggest approaches, values or guiding principles for HIV Co-Infection research. The three themes were evident in discussions across all of the five tracks of the Summit. While they are reported separately, they are in fact very inter-related.

The guiding principles are:

1. Meaningful engagement, empowerment, and respect
2. Action/change oriented research
3. Accountability

Meaningful Engagement, Empowerment and Respect

The theme of meaningful engagement was pervasive throughout the Summit discussions and was evident across all five research tracks even in the high-level questions generated through the facilitation process. Participants generated questions such as:

How do we engage clients to find out what services and supports would be meaningful and valuable to them...? How do we improve the inclusion of specific populations in... epidemiological and clinical data collection? How do we ensure... interventions meet the needs of hidden populations? How do we engage... diverse populations and stakeholders (e.g. community, policy makers, researchers, people living with) to broaden the definition of evidence...?

Meaningfully involving people living with co-infections, as well as those who may be at risk of co-infection, was considered necessary at all steps, reflecting the need for a community-based research approach and more of this type of research in the area of co-infections. Those affected by co-infection need to be involved in defining research priorities and questions, developing research projects, developing and evaluating interventions including clinical, support, and treatment services, and finally in terms of using research findings to raise awareness and create change at both the policy and program levels.

"...we're looking at all the things why people don't get the treatment that we need – they need. So once again, it comes back down to knowing the population that you're working with, the community that you're working with and knowing what their needs are and knowing what the root causes are. And how do you do that? How do you build your programmes around that? So you need to engage the population at risk." ~ Summit Participant

Action/Change Oriented Research

Emerging across all five tracks of the Summit was a clear theme related to the need for change or action as a result of research. While one particular track of the conference – Policy Development Research – was heavily focused on this issue, the theme was evident throughout the questions and discussions generated across each of the other tracks as well.

How can we... get the tools needed to increase public awareness and reduce systemic/internalized stigma? Why has current evidence not been implemented into effective policy? How do we incorporate results from research based on an environmental scan of clients' access to support services?

Many questions were asked about what happens to all the research and why we often do not see anything come from research in terms of real changes to policy or practice. As such, it is clear from the Summit discussions that this is an important guiding principle for co-infection research.

"It's interesting because it's an action idea and that's what we're really keen on... It says to broaden the definition of evidence and move it into action. And the 'move it into action' is very important to a lot of us here." ~ Summit Participant

Research should not be done solely for the sake of inquiry, but rather should be part of a process which includes knowledge translation and mobilization which aims to have an impact on policies and programs that affect the lives of those living with and at-risk of co-infection.

"I would simply like to find a way to identify harmful policies that have perverse effects and need changing and change those policies. To me this is an overriding [theme]... we have evidence coming out of our ears... use the evidence." ~ Summit Participant

Accountability

A third clear theme which emerged throughout the Summit related to ensuring accountability of researchers, policy makers, and service providers. Many questions were posed in this regard:

How do we make all levels of government and all service providers...accountable for lack of effective accessible services? How to create responsive, proactive and efficient policy development... while maintaining accountability? Why has current evidence not been implemented into effective policy?

Research teams should be held accountable in terms of ensuring that their work is relevant and, similarly, that it engages those living with and at-risk of co-infections. They should also be accountable for the utility of their research and ensuring that it is used in some way to support change. Likewise, policy makers and service providers should also be accountable for ensuring that their policy and program decision making is evidence-informed, as well as inclusive through the engagement of those living with and at-risk of co-infections.

2.2 PRIORITY POPULATIONS AND SETTINGS

Several priority populations and settings emerged based on the evidence that exists regarding the dynamics of co-infections and the disproportionate incidence and prevalence among and within certain communities. The specific research questions or priorities for the groups crossed all of the tracks in terms of types of research – they focused on strategies for meaningfully engaging and involving the groups; the need for specific epidemiological data; an understanding of the determinants of co-infection in a cultural and/or population-specific context; the need to address barriers to accessing supports and services and the need for appropriate services and supports. Similarly, the questions raised in relation to priority settings crossed over research tracks.

Priority Populations

- *Aboriginal communities*
- *People who use and/or inject drugs*
- *People with concurrent disorders*
- *People already living with co-infections*
- *Ethno-cultural communities*
- *Trans communities*

- Women
- Young people
- MSM and gay men

“There is an unmet need to focus on specific sub-groups so that we are better able to understand disease progression, target prevention and treatment interventions and engage and deliver clinical services, and that was with respect to diverse populations, including aboriginal people, focusing on gender, ethno-cultural communities, and street youth, for example.” ~ Summit Participant

“There is no future without co-infections, so our approaches to research and its translation to policy, clinical practice and community work must be retooled accordingly. I took with me a message of urgency that we must insert HIV/HCV co-infection into a comprehensive research, education and care plan for gay men’s health.” ~ Summit Participant

Priority Settings

- Prisons
- Rural and remote communities

“There is an acute need for research at all levels in all regions outside of major urban centres, and particularly in the eastern and prairie provinces.” ~Summit Participant

2.3 CLINICAL AND EPIDEMIOLOGICAL RESEARCH

The information gathered through the clinical and epidemiological research track converged with several other themes and issues that emerged. However, four key themes were particularly relevant.

Surveillance

How can surveillance data be improved? How can reporting be improved to ensure accuracy and identify population-specific data? What impact would automatic ‘co-testing’ have in terms of reporting and prevention of co-infection?

Several questions were articulated which spoke to a need for improved surveillance not only of HCV but also HBV co-infection. This would help ensure that data is consistent and comparable across provinces and nationally. It could also help ensure more accurate reporting for different demographics and sub-populations and co-infection-related deaths. Some discussions considered automatic co-testing for HIV and hepatitis, given some of the overlap in risk factors, as a means to improve surveillance and reporting of co-infection and as an opportunity for prevention of co-infection.

Disease Progression

What is the short and long term impact of co-infection on the liver? How can liver disease progression be slowed? What are the genetic and cultural determinants of disease progression?

Understanding liver disease progression emerged as a key area of inquiry. Questions focused on how co-infections affect the liver in the short and long term and what interventions can slow liver disease progression. There was also particular emphasis on examining the genetic and cultural determinants of disease progression and understanding different demographic, genetic and environmental variables that influence liver disease progression.

Sexual Transmission of HCV

How does sexual transmission actually occur? How much sexual transmission occurs and how many HIV+ MSM were co-infected this way?

Although HCV is often not considered a sexually transmitted infection, there was considerable discussion on this topic. There appears to be a need to gain a better understanding of the issue, particularly as it relates to those who are already HIV positive. This begins with surveillance and reporting.

Treatment

What are the most up-to-date treatment guidelines? How can we improve uptake and adherence to treatment? What drug interactions need to be considered?

The need for up-to-date treatment guidelines was very prominent in the discussions. Many questions were raised which focused on uptake of and adherence to treatment. Understanding drug interactions between both pharmacological treatments and street drugs was also an identified need, given the risk factors for co-infection. Research is needed related to treating people that are on Methadone and those who are concurrently disordered, effective strategies for treatment uptake, maintenance of treatment, relapse prevention and strategies for people not on treatment.

2.4 MODELS OF CARE AND SERVICE DELIVERY

The Summit presented clinical service delivery and support services research in two separate tracks, however service delivery issues were prominent throughout the Summit. A clear theme emerged around the need for integrated service delivery and innovative models of care.

"...but why is our clinical service delivery research and our social behavioural research and our support services research... why are they all separate? It's all about one person and there are all these bits." ~ Summit Participant

As a result, rather than separating out research priorities related to certain types of services and supports, they have been integrated into this one section on research examining models of care and service delivery.

Integrated Models of Care

How do we better integrate all support services to mitigate social determinants of health? What is the impact of a holistic approach – mental, physical, emotional and spiritual? How do we develop models of care that incorporate the integration of mental health, addictions, concurrent disorders to support those with co-infection? How do we marry medical modeled care with community care to create one-stop shopping?

Many of the discussions related to clinical and support service delivery focused on identifying and determining effective models of care. As indicated, integration emerged as a key theme – that is, how could different levels and types of care, treatment and support be integrated to better serve all the needs of people living with co-infection.

There was a particular focus on multi-disciplinary, holistic models of care that also include care, treatment and/or support for underlying issues and root causes, namely mental health and addictions. As well, holistic models of care that address existing basic needs or the determinants of health.

"There are important co-morbidities, particularly mental health and addictions, that are obstacles to effective HCV care and service delivery. Novel models... need to be

developed and evaluated that address the co-morbidities, concurrently – and I think that’s an important word with hepatitis treatment and care.” ~ Summit Participant

Improving Access

Included in the dialogue related to service delivery and integrated models of care was the theme of access – specifically, how to improve access and reduce barriers to care, treatment, and support.

“So anything that is a removal of barriers, it cuts across all of these [tracks of research]. Any research that talks about a removal of barriers could be key for any of these then.” ~ Summit Participant

Consistent with the emergent guiding principles and priority populations, many of the questions and discussions related to engaging people living with co-infections in the development of appropriate supports and services, particularly in terms of reaching underserved populations. Similarly, discussions also focused on examining models of care, treatment, and support that would increase access in rural and remote areas and help to create a seamless transition between prisons and communities.

2.5 SOCIO-BEHAVIOURAL RESEARCH

While many of the discussions in the socio-behavioural research track were inter-related with those in the clinical and support services delivery tracks, several other key themes emerged here and throughout the Summit which should be highlighted as priority issues. There was a recognized need for more intervention research – research about what is working, what is not working and best practices for interventions throughout the HIV and hepatitis lifespan.

Understanding Contexts of Risk

Rather than focusing on individual risk and how to change certain behaviours, some Summit discussions attempted to move the focus toward understanding the contexts of risk. That is, how do certain environments and conditions contribute to risk-taking? Through gaining an understanding at this level, risk taking can also be addressed.

“In the socio-behavioural research stream or that particular area a lot of it does focus on , you know, why do we as individuals not do the right thing? Go to the doctor, brush our teeth... eat an apple. You know, for me the question is really about context of risk. So the example that we used at our table was it’s not the prisoner per se that is the risky thing, it’s the prisoner going to jail not having access to the things they need to keep themselves negative and healthy... The reality is that constitutes a risk context that transcends a sort of micro-cognitive behavioural decision making process.” ~ Summit Participant

As is evident, prisons emerged as a specific context of risk during the Summit and were singled out as an overarching priority setting because of its pervasiveness, as a theme, across all of the tracks. Prisons were not discussed just in relation to risk but also with regards to service delivery, treatment, improved surveillance and epidemiology and knowledge mobilization and policy change.

Another context of risk identified from the Summit discussions was drug use. While there is more known about risk in the context of injection drug use, other drug using environments were indicated. This included drug use and its impact on sexual behaviour, recreational drug use, crack use and its impact on oral health and intra-muscular injection of steroids and other enhancement drugs.

Stigma and Discrimination

Stigma was a clear theme that emerged throughout the Summit and has implications for all tracks of research. It can affect willingness to get tested, therefore impacting on reporting and

surveillance. It creates barriers to accessing care, treatment and support, contributes to adherence issues and has implications for the mobilization of research.

“The last theme that we noticed was that stigma and discrimination really are driving sort of the ideological barriers that occur at the policy level.” ~ Summit Participant

There was a clear distinction in the discussions about examining and addressing both internalized stigma – that is the experiences of people who are co-infected – and general or systemic stigma.

Aging with Co-Infection

Finally, aging in the context of living with co-infection was also evident in the Summit discussions. It appears to be an emerging priority issue given the growing numbers of HIV long-term survivors and an area requiring research development. Generally, a better understanding of the implications of aging with co-infection is needed in terms of treatment, as well as care and support.

2.6 MOVING RESEARCH TO ACTION

Although social policy research was an explicit track within the Summit, the issue of translating research into changes in policy and practice was raised across all five tracks. The theme was so pervasive that it also clearly emerged as a key principle to guide research in this area – that is that research should be action-oriented and should be carried beyond reporting of findings to an actual focus on impacting policy and/or practice. However, while it emerged as an overarching guiding principle, several issues were also raised as specific areas of inquiry.

Identifying Effective Strategies

What are the most effective strategies for using research to impact on policy and practice? What are the barriers to effectively influencing policy and practice and how we can address them?

A clear priority appears to be in identifying effective models of knowledge translation and exchange to move research evidence into action. Related to this was also an identified need to determine and address barriers to effectively influencing change.

Different Types of Evidence

Several strategies were identified for further exploration in terms of the type and level of impact they could have. These include cost-benefit analyses, real and human stories and international case studies. Another approach that emerged involved broadening the definition of what is considered ‘evidence’.

Working with Different Stakeholders

Finally, there are many questions and discussions raised related to engaging different stakeholders or ‘change agents’ to improve the reach and impact co-infection research. At one level, there appears a need to identify who the best change agents are, while also examining the best methods of engagement.

A considerable amount of discussion revolved around the media and the general public as important agents of change. The media can help to better inform the public and address stigma and discrimination, and both the media and the public could work together to influence good public policy and decision-making.

2.7 CONCLUSION

The HIV/HBV/HCV Co-Infection Research Summit was the first meeting in Canada to bring together national stakeholders on the issue. The outcome of the two-day Summit is The Roadmap of HIV Co-Infection Research, developed using an innovative consultation approach that allowed input from researchers, clinicians, government representatives, service providers and people living with HIV co-infection. The Roadmap is intended to be used to inform the co-infection research agenda and guide researchers, community members and other relevant stakeholders engaged in HIV co-infection research, programs, support services and policy.

APPENDIX A

1st Canadian HIV/HBV/HCV Co-Infection Research Summit

Public Health Agency of Canada	PHAC HCV Division, PHAC HIV Division
Ministry of Health and Long-Term Care (Ontario)	
Canadian Institutes of Health Research	 CIHR IRSC <small>Canadian Institutes of Health Research / Instituts de recherche en santé du Canada</small>
Ontario HIV Treatment Network	 Ontario HIV Treatment Network
* Gilead	 GILEAD
* Merck	 MERCK
MAC AIDS Fund	 MAC AIDS FUND
Canadian Hemophilia Society	 Canadian Hemophilia Society Help Stop the Bleeding
Canadian Aboriginal AIDS Network	

* Funding provided through an unrestricted educational grant

APPENDIX B

1st Canadian HIV/HBV/HCV Co-Infection Research Summit

Central Planning Committee

Claudia Medina	Margaret Akan
Colleen Price (Co-Chair)	Marina Klein (Co-Chair)
Curtis Cooper	Mark Ragan
Ed Jackson	Michel Long
Frank McGee	Randy Jackson (Co-Chair)
Jack Haight	Richard Baker
Jeff Potts	Ron Rosenes
John Plater	Samantha Earl
Lisa Mortell	Sean Rourke
Louise Binder	Sheldon Joseph

Program Planning Committee

Claudia Medina	Mark Ragan
Colleen Price (Co-Chair)	Margaret Akan
Curtis Cooper	Marina Klein (Co-Chair)
Gerald Morin	Randy Jackson (Co-Chair)
John Plater	Ron Rosenes
Sean Rourke	

Invitation and Scholarship Committee

Colleen Price (Co-Chair)	Richard Baker
Ed Jackson	Ron Rosenes
Lisa Mortell	Sean Rourke
Michel Long	Sheldon Joseph

Aboriginal Working Group

Colleen Price (Co-Chair)	Lisa Mortell
Gerald Morin	Margaret Akan
Jack Haight	Randy Jackson (Co-Chair)
Sheldon Joseph	

APPENDIX C

Summit Participation

PARTICIPANTS

A total of 92 participants attended the Summit, with 52 respondents for the online evaluation, or a 57% survey participation rate. The percentile breakdown, by demographic, was as follows:

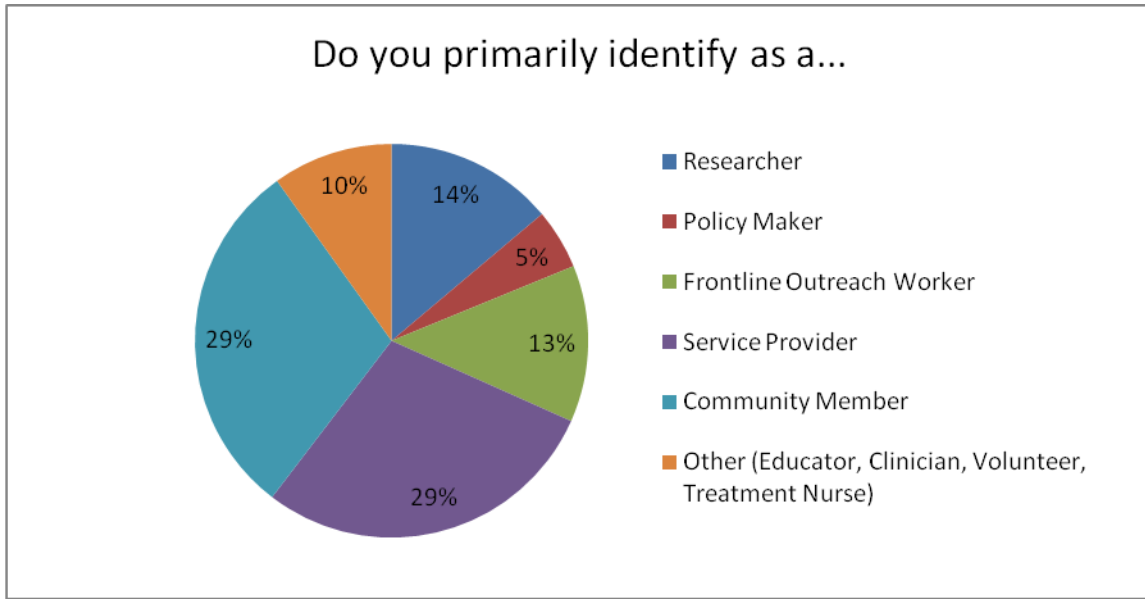


Figure 1 - Total 63 responses (some respondents identified with more than one demographic)

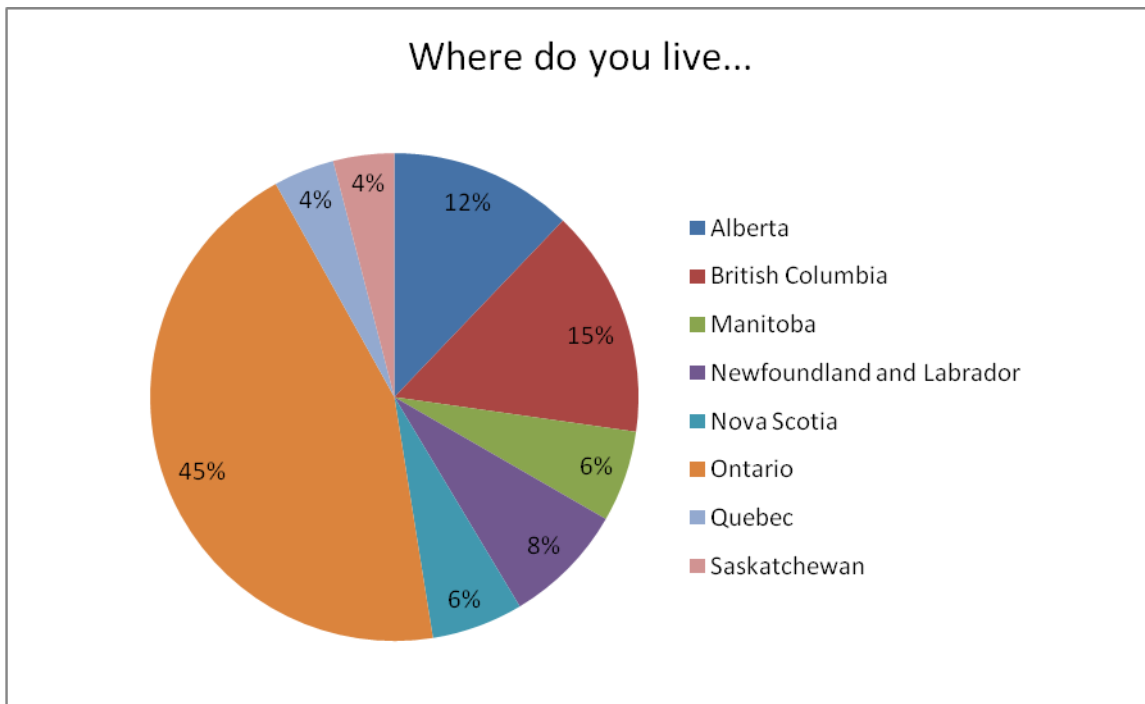


Figure 2 - Total 52 responses

APPENDIX D

Roadmap of HIV Co-Infection Research KTE Strategy

The development of the Roadmap of HIV Co-Infection Research used an integrated KTE approach in that key stakeholders were identified in advance and involved through the process. This report describes how stakeholders were involved in shaping The Roadmap. Once The Roadmap is complete, the following end-point strategies will also be used to support the dissemination and utilization of The Roadmap.

- Develop a plan to communicate The Roadmap report through all stakeholder channels to assist in ongoing knowledge transfer and capacity building as required
- Submit a paper outlining the results of the Summit to an accredited journal with a senior researcher as principal author
- Establish dedicated co-infection tracks at key Canadian conferences such as the Canadian Association of HIV Researchers, Ontario HIV Treatment Network, and key non-governmental community organizations working in HIV
- Establish HIV Co-infection Provincial Working Groups to support the implementation and monitoring of the HIV/HBV/HCV Co-Infection Roadmap
- Evaluate the process and the outcomes of the Summit

APPENDIX E

Summit Facilitation Process

The Central Planning Committee engaged a professional facilitator to assist in developing a process for the Summit. The facilitation process was designed to allow for all Summit participants to be involved in identifying key questions and priorities for research in each of the five tracks. The process involved five steps: 1) Presentations on the current state of research in each track; 2) Brainstorming key research questions; 3) Cluster analysis; 4) Defining key research questions; and 5) Prioritizing key research questions.

Step 1: Presentations on the Current State of HIV Co-Infection Research – whole group

The first step involved several presentations that provided an overview of the current state of research and understanding by researchers and clinicians in each of the five tracks..

Step 2: Brainstorming Key Research Question – small group

Following the presentations, Summit participants broke up into small groups of 5 to 10 people. The facilitators worked to ensure each table had a diverse group of participants (e.g. clinician, researcher, service provider, community member). The groups were provided with discussion questions to guide them through a process of reflecting on the presentations, identifying gaps in the current research and articulating key research questions that should be addressed. Facilitators roamed the room during this phase to help guide the discussions and keep the groups on task. Each participant had an opportunity to write down at least one question on a piece of paper and then post this on a wall in the room.

Step 3: Cluster Analysis – whole group

Once all of the small groups had posted all of their questions on the wall, two primary facilitators brought the whole group together to review all of the questions. Summit participants were literally invited to pull-up their chairs and stand or sit in front of the wall. The facilitator read through all of the questions and then with guidance from the group sorted the questions into thematic clusters. The clusters were defined organically in the moment by the participants and grouped according to questions that were perceived to be related. Each of the individual questions was reviewed and classified into one of the existing clusters or a new cluster, until all of the questions were clustered. The resulting clusters contained as few as 2 or 3 questions and as many as 9 or 10 questions. The clusters were not named or defined in any way during this process.

Step 4: Defining Key Research Questions – small group

With all of the questions clustered thematically, each small group was then given one or more clusters to work on. Together, the small groups would review the questions in their clusters and attempt to articulate one key question which captured the primary theme or issue within the cluster. By the end of the five Summit tracks there were a set of key research questions for each track.

Step 5: Prioritizing Key Research Questions – whole group

The final session of the Summit brought all of the participants together to review key questions defined in Step 4, in each of the five tracks (Appendix C). The aim of the final session was to prioritize the questions using hand-held voting devices. One of the facilitators first asked the participants to identify a research question in each track for which they had the most 'ownership'. This was defined as "the question that you live with all the time." Then participants were asked to identify a research question that was the most urgent to be addressed, the most important, the one that would have the most impact if addressed and the one that would be easiest to address.

APPENDIX F

Key Questions Defined in Step 4 of the Summit by Research Track

Clinical and Epidemiological Research	Clinical Service Delivery Research	Socio-Behavioural Research	Support Services Research	Policy Development Research
<ol style="list-style-type: none"> 1. What are the health and social implications of aging/long term survivors and what are the best practices for testing? 2. How do we create a model of rural/urban collaboration? 3. How can HIV/HBV/HCV clinical services act as an effective gateway to additional services? 4. How can we better research treatment guidelines for liver transplants, expanded HAART, Interferon-based treatment for all affected populations? 5. What are methodological approaches to obtain better epidemiological data? 6. How do we improve the inclusion of specific populations, in all aspects of epidemiological and clinical data collection? 7. What are the relationships between different specific populations and treatment outcomes and disease progression? 8. What is the impact of funding on programming, knowledge transfer and exchange? 9. How do you identify and address barriers? 	<ol style="list-style-type: none"> 1. What models of care would increase access for underserved and remote/rural people? 2. What benefits /advantages come with client-centred multidisciplinary care teams? 3. How can we advocate to get the tools needed to increase public awareness and reduce systemic / internalized stigma? 4. How can we provide multidisciplinary teams within the prison system?. 5. What is the most effective role of the community in providing care, treatment, prevention, support, and education? 6. How do we address barriers to treatment access? 	<ol style="list-style-type: none"> 1. Using KTE what strategies improve health policy to influence public opinion and affect positive health policy change? 2. How do we ensure prevention and treatment interventions meet the needs of hidden populations? 3. How effective are existing prevention and support interventions at addressing root causes of at risk behaviours? 4. What evidence-based research might demonstrate that harm reduction can protect both prisoners and security staff? 5. Why has current evidence not been implemented into effective policy? 6. Will cost benefit analysis improve use of resources and impact client outcomes? 7. What is the impact of a wholistic approach on prevention treatment and support? 	<ol style="list-style-type: none"> 1. How can we better integrate all support services to mitigate social deterrents of health? 2. How do you implement best practices with community care for all? 3. How do we incorporate results from research based on an environmental scan of client’s access to support services? 4. How do we as stakeholders engage our at-risk community to create effective support programs? 5. How do we engage clients to find out what services and supports would be meaningful and valuable to them...and who should be the service deliverer? 6. How do we make all levels of government and all service providers, both community and clinical, accountable for lack of effective accessible services? 7. How can we get research on: accountability, peer to peer, clinical provision, mental health and addictions, hardship of third party payment (FNIB) and lack of consistent service on and off reserve? 	<ol style="list-style-type: none"> 1. What are the most effective models of KTE and how can we ensure that research knowledge reaches beyond government to private actors, the media and the general public to mobilize for public (and private) policy development? 2. How do we identify and engage “change agents” within and between systems, institutions and governments who can drive evidence-informed social policy? 3. How do we engage diverse populations and stakeholders (e.g. community policy makers, researchers, people living with) to broaden the definition of evidence and move it into action? 4. How do we identify, meaningfully engage and sustain the appropriate diverse influencers in “all phases” of effective policy? 5. How to create responsive, proactive and efficient policy development (which includes implementation, evaluation, monitoring etc) while maintaining accountability?

APPENDIX G

Brainstormed Research Questions

Clinical Research and Epidemiology

- 1. How do we design effective prevention interventions targeted to specific ethno-cultural demographic diverse at-risk populations?**
 - Clinical studies showing drug interactions (medical vs. street)
 - What are the social factors that impact or impede adherence?
 - How do we/can we assure a cohesive link between broad social determinants and co-infection/IDs?
 - What can we do to create a bridge between low income and lower income regarding treatment?
 - Research on peer driven interventions for HIV/HCV
 - How do we improve or prevent our mono-infected individuals from becoming co-infected? What strategies would be most effective for the at-risk population?
 - Are harm reduction programs working or not? More epidemiological research is needed to determine why prevention is not working

- 2. What are guidelines for treating co-infection taking into account: treatment efficacy, other health factors, drug interactions?**
 - How can we better reflect HCV and HBV related issues in research and surveillance?
 - Why is there not more of a focus on other health related factors pre-, post- and during treatment?
 - When co-infected, which infection do we treat first? HIV? HCV? Simultaneous?
 - Currently a discrepancy exists among caregivers and physicians which causes anxiety and confusion among patients. Illustrate better understanding of when to start/stop/continue HIV and HCV meds.
 - How do people that are co-infected do both treatments?
 - Are there interventions that can slow liver disease progression?

- 3. What is the impact of funding on programming, knowledge transfer and exchange to better the lives of persons living with co-infection?**
 - How can AIDS service organizations further programming/education when already stretched to their limits (i.e. funding)?
 - How do we bridge the gap in provincial and national epidemiological data collection?
 - Are co-infection rates/deaths under-reported? Why?
 - Describe impact of mandated role of ASOs to prevent/support co-infected individuals
 - How can the scientific knowledge we have today be most effectively used to direct government funding and treatment programs?

- 4. What are the health and social implications of aging/long term survivors with co-infection?**
 - What are the health and societal implications of aging with HIV/HBV/HCV co-infection?
 - What social determinants of health are most relevant in the lives of long-term survivors?
 - More research based on HCV and aging?!

5. **What are the best practices for testing in HIV/Hepatitis to ensure no opportunities for prevention are missed?**
 - What are effective interventions to address the co-infected following the time lag?
 - How can we target missed opportunities for prevention (HIV and HCV diagnosed at different times)? Who are they and how are they infected?
 - What do people who are co-infected think they would have needed to prevent becoming co-infected?

6. **What are the genetic and cultural determinants of co-infection disease progression and treatment outcomes?**
 - What are the genetic and cultural determinants of co-infection disease progression and treatment outcomes?
 - How does sexual transmission actually occur?
 - How much Hep C is sexually transmitted in MSM and heterosexual populations?
 - How can we find out how many HIV POZ MSM were co-infected with Hep C through sexual contact?
 - Epidemiology requires cultural groups to be broken down
 - Is ethnicity/genetics related to spontaneous Hep C clearance?
 - How do cultural factors influence a person's decision to engage in treatment for co-infection?
 - What are the rates of HBV vaccination among Aboriginal people? What are the implications for Aboriginal people based on modes of transmission?

7. **What are the relationships between different vulnerable populations and disease progression?**
 - Research on Hep C/HIV infection in non-injection drug users (i.e. people who inhale or snort)
 - Research on co-infection disease progression difference for men and women
 - Why are transgendered people not included in studies?
 - Why isn't gender specific data more available?
 - Research geared towards youth and women
 - Is there research done on HCV and the co-morbidities of co-infection – long-term, short-term and outcomes?
 - Research in rural areas
 - What impact is co-infection having on the prison population? How do we make research opportunities more palatable to doctors who are already taxed without making it "too much work"?
 - How do we ensure broader representation of vulnerable populations in research?

8. **How can we educate the population effectively regarding the question of STIs and of the benefits of harm reduction?**

9. **How do we create a model of rural/urban collaboration? What will it look like? Will it include equal funding, Canada-wide? If not, why?**
 - How can we learn more about rural communities and their issues?
 - Inclusion of all areas/regions and commitment to make it happen and a strong follow-up
 - Funding for Rural research/perspectives

10. Access to Treatment - How do you identify and address barriers:

- MH & Addictions
- Age
- Ethnocultural

11. How do we increase uptake and adherence to treatment?

- Better quantify uptakes of anti-HCV Rx and identify and mitigate barriers
- Gender-based research, intervention research; re-infection with different genotypes/strains; epidemiology in different groups. The research in HIV/HCV co-infection and even less in HBV. Sexual transmission of HCV. Need more testing in Ontario, better labs; two-step testing process and risk groups. Treatment guidelines few consensus guidelines – need updates. Need natural HCV and HIV-HCV consensus guidelines.
- If we provided treatment for Hep C/Hep B would it stop this epidemic? Treatment on demand, repeat treatment.
- Is HIV/HBV/HCV a gateway to accessing additional services (MH/A, primary care) and if so how can we better access clients proactively prior to co-infection/infection?
- What is going to be done for the aging population as people now turn 40, 50, and 60+?
- What are the barriers to effective and efficient prevention, detection, treatment, care and support re: HIV/ HBV/HCV?
- Do those being treated, co-infected or not, have appropriate mental health treatment?

12. How can we develop and evaluate models of care to overcome mental health and addiction barriers to treatment to increase HIV-HCV/HIV-HBV access, uptake, and adherence to treatment?

13. How can we better research treatment guidelines for HCV and HCV-HIV co-infected populations: including topics Liver transplants, Expanded HAART, Interferon-based treatment and treatment adherence?

- How can we better research treatment guidelines for HCV and HCV-HIV co-infected populations?
- What is the outcome of expanded HAART on HIV/HCV co-infection? (as it relates to STOP Pilot in Vancouver (PG) in relation to ELD)?
- More research on liver transplant outcomes for the co-infected
- How do HIV/HBV/HCV co-infections affect the Liver?
- Impact of HIV/HBV co-infection

14. What are methodological approaches to obtain better epi data?

15. Can we have better data on distribution of co-infection and determinants among: newcomers/immigrants, MSM, transgender, Aboriginal, women, incarcerated individuals, rural populations, exploring synergies and existing surveys, studies, systems, etc. (tracks), routine and enhanced surveillance, directed epi research?

- What funding is available to move epi research forward?
- Where are the Aboriginal-specific sub-analyses of existing datasets/cohorts?
- Need for gender specific research (100% female/100% male) (Patterns may be more evident)

- Why are HCV rates so high amongst the incarcerated? What's going on, where and why is it happening?
- Why don't we have more down path stats? (i.e. transgender are under-represented.)
- Research on ethno-specific, newcomers, and immigrants from endemic areas
- Population-based serosurvey for HBV and HCV. Identifying gaps in data on HIV/HBV/HCV in HIV+ patients in care
- What other information about vulnerable groups would give us a better idea of where the research and clinical priorities are?
- Active surveillance involving all demographics/populations without any barriers on location, lifestyle, and risk factors.
- Population-specific data needed: who has what (HCV, HCB, HIV); How to compel them to get tested; Identify supports.
- Factors that drive up health cost - what or how can health policy respond? Surveillance-comprehension by ethnicity/ etc.
- What is the biological mechanism for sexual transmission of Hep C in Gay Men?
- How much sexual transmission of HCV occurs in HIV- MSM?

16. Population-Specific Appropriate - Where are representatives from listed groups at-risk (Aboriginals, IDU, inmates, youth, women, immigrants, GLTTS) in all aspects of clinical EPI Research (implementation, researchers, participants, ethics boards)?

- How we can better address co-infection issues related to persons coming from endemic countries?
- Incarceration: perverse policy effects: harm production
- Need for reducing barriers for High Risk groups to access testing could be given education and support to encourage them to stay negative
- Aboriginal OCAP – let population ask question(s) – Clinical & Epi
- How can we reach the most at risk who have little or no contact with health care. Off radar populations, beyond marginalized.

Social Policy Development

1. How do we move evidence to policy?

- Impact of social conditions that affect health
- How the “mix” of disease can impact access to treatment, income programs, housing etc. (i.e. Hep B or Hep C mono-infected versus co-infection with HIV)
- How do we measure the capacity of the system and how much capacity is required?
- Is there room to use existing infrastructure and programs and, if not, how do we assess what new infrastructure and programming we need?

Social Behavioural Research

- 1. Using KTE, what strategies improve health policy that will positively impact practice settings including strategic social marketing approaches that will influence public opinion and affect positive health policy change?**
 - How do we translate research into policy and practice?
 - How can we translate knowledge of social context and the effects on risk to programs in different settings (urban, rural, reserves, etc.)?
 - How do we take research/evidence in one domain and share it with another; how to have more effective KTE?
 - How can we broaden involvement in research to build public buy-in to evidence-informed interventions?
 - How we change the way society thinks and deals with sicknesses (HIV/HBV/HCV, addictions, and mental health?)
 - How do we cater prevention messaging to different vulnerable groups (i.e. youth, experienced vs. novice users, gender, etc.)?
 - How can we disseminate information so that we can use prevention as treatment rather than trying to treat after infection including increased testing for HCV and HIV?

- 2. From a 'determinants of health' framework, how do we ensure prevention and treatment interventions meet the needs of hidden populations including recreational drug users, MSM, in various settings (community, clinical, rural, etc.)?**
 - Intervention Research: what works, peer vs. clinic based
 - Learn about effectiveness of treatment models in overcoming access and stigma for persons who are co-infected
 - How can we effectively engage people in the treatment program?
 - What is the transmission rate of HIV compared to HCV in recent immigrants?
 - How do different types of drugs affect risky sexual behaviour and what is the relationship between sex and drug use?
 - What is the link between crack use, oral health, and STI transmission?
 - How do we reach hidden populations who use drugs on a recreational basis?
 - What about steroid/intra muscular injection?

- 3. How effective are existing prevention and support interventions at addressing root causes of at risk behaviours that contribute or lead to infections?**
 - Is there a need for trauma-based therapy?
 - Have we looked at and helped clients identify root causes of addiction (i.e. sexual abuse and residential schools)?
 - Learned the factors that allow breaking the cycle/paradigm of ignorance/abuse that lead to addiction
 - How can we make this issue visible regarding the human costs rather than the financial costs?

- 4. How do we develop evidence-based research to demonstrate that harm reduction services can protect both prisoners and security staff?**
 - Explore contexts in prison via interviews with former inmates and employees
 - What are the contributing factors to infection rates in the prison populations?
 - How can we offer inmates in our prisons meaningful harm reduction services?
 - Learn how to access prison custody staff RE: proactive work and not being a barrier
 - How can we enlighten powers that be regarding prison issues (i.e. why do some enter healthy and are released infected with HIV/HCV)?

- 5. Why has current evidence not been implemented into effective policy, and how can we move evidence into effective policy?**
 - How can we positively shift public opinion and policy makers for more humane policy development?
 - What are the social and structural barriers to addressing the policy to programming disconnect in harm reduction (population specific)?
 - How can we translate research into policy and practice?
 - What would help policy efforts move forward?
 - How can the research impact policy development when policy makers have their own agenda?

- 6. Will cost benefit analysis improve use of resources and impact client outcomes including quality of life, harm reduction, treatment, care and support and appropriate policy development?**
 - Will cost benefit modeling have a greater influence on actually changing policy (i.e. harm reduction policy)?
 - Can we have an economical focus on research to do cost benefit analysis?
 - Why have we not used other outreach methods now that we know that we have reached a plateau on HBV prevention through vaccination?
 - Could we put more emphasis on environmental factors when researching risk behaviour rather than focusing on individual responsibility?

- 7. What is the impact of a holistic approach (mental, physical, emotional, and spiritual) on prevention treatment and support?**
 - Why is there a significant number of IDU who remain non-infected with HCV/HIV? What are they doing differently from those who are infected?
 - How has spirituality or religion helped or hindered ones journey with co-infection and what affect has it had on your life?
 - Resiliency and asset based research

Support Service Delivery

- 1. How can we better integrate all support services to mitigate social determinants of health?**
 - When do we implement Maslow's Hierarchy of Needs?
 - Treat your patients/clients like human beings
 - How may we get funding so that we may have appropriate housing for those who need it?
 - When do we start implementing the medicine wheel teachings?
 - How can we better integrate all support services to mitigate social determinants of health?
 - What and how are basic (human) needs being met?

- 2. How do you implement best practices with community care for all?**
 - Environmental scan to evaluate access to support services of the end user?
 - When does the current research get implemented?
 - How can we incorporate evidence based research into service delivery and support services?

- 3. How do we, as stakeholders, engage our at-risk community to create effective support programs?**
 - Less silos , more collaboration
 - What are the best practices of the exchange and transfer of knowledge between community programs and partnerships?
 - How do we marry medical modeled care with community care to create one-stop shopping?

- 4. How do we engage clients to find out what services and supports would be meaningful and valuable to them, and who would they say should be the service deliverers?**
 - How do we provide support after treatment or in transition between programs?
 - What outreach support service (peer driven, basic needs addressed) do we provide?
 - How do we help clients identified as "unstable" to become "stable"?

- 5. How do we make all levels of government and all service providers, both community and clinical, accountable for lack of effective accessible services?**
 - How can we make service providers accountable to clients?
 - How do we make ASOs accountable for lack of effective services?
 - Lack of consistencies on and off reserves?

- 6. How can we get research on: accountability, peer to peer, clinical provision, mental health and addictions, hardship of third party payment (FNIB) and lack of consistent service on and off reserve?**
 - How do we acknowledge and include the lived experience of clients in program development and support service delivery?
 - Engaging populations at risk survey and how do we reach them?
 - How do we engage youth involvement on all levels?
 - How do we encourage community engagement/empowerment in all levels of support delivery services?