



## LISTENING FOR DIRECTIONS

### ONTARIO HIV TREATMENT NETWORK STRATEGIC PLAN CONSULTATION

#### STRIVING FOR EXCELLENCE, ACHIEVING IMPACT: 2010 – 2015

In June and July 2010, the Ontario HIV Treatment Network (OHTN) launched its new strategic plan, *Striving for Excellence, Achieving Impact: 2010-2015*. To ensure its strategic objectives and activities will meet the needs of the communities it serves, the OHTN held four Strategic Plan Consultations across the province – in London, Ottawa, Sudbury and Toronto.

These consultations gave people living with HIV, AIDS Service Organizations (ASOs), community members, researchers, clinic staff and HIV-related provincial organizations a chance to share their views and priorities, and help the OHTN refine its action plan.

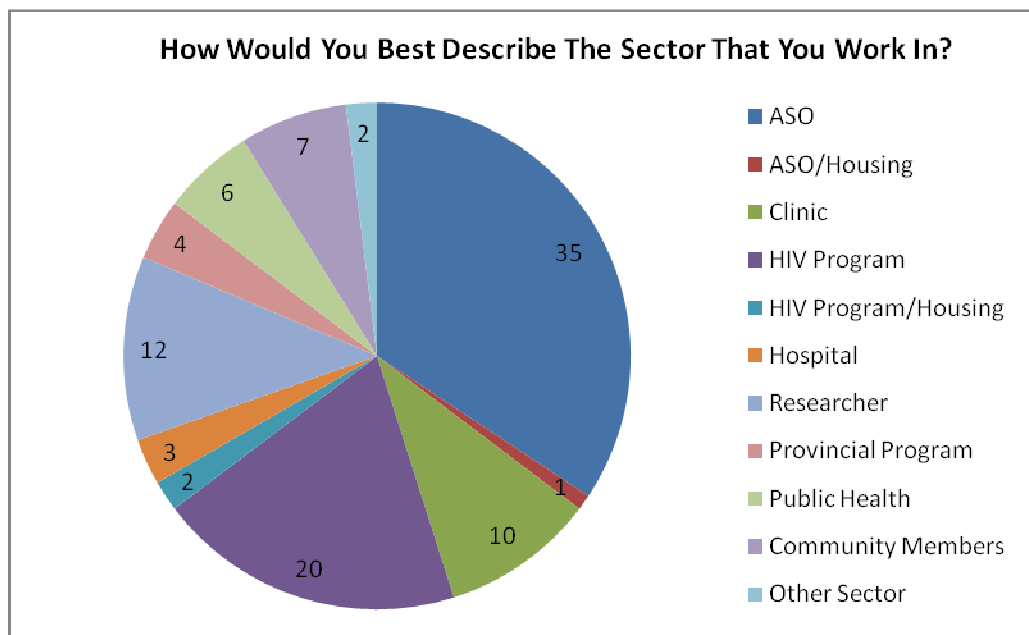
The OHTN's strategic plan is organized into four major themes: Strengthening our Network, Promoting Rigorous, Relevant Research, Moving Evidence into Action and Driving Change, and Ensuring Organizational Integrity and Accountability. At each consultation, participants were asked questions about the OHTN's strategic objectives and activities for each theme and how it reflects their priorities over the next five years. The fourth objective around ensuring our organizational integrity was not addressed in all the consultations so instead we will be announcing changes to our committees in the fall and inviting stakeholders to participate with us over the coming years.

The consultations helped participants be more connected to the OHTN and its work and the feedback we received will help the OHTN achieve its goals over the coming five years.

The following pages provide a summary of the common priorities of each of the four consultations as recurring ideas, themes, discussion points and potential research ideas.

## PARTICIPANTS

A total of 107 people attend the four consultations, and they were representative of stakeholders in the OHTN network: just over one-third were from community-based AIDS service organizations, 20% worked in an HIV program, 12% were researchers, 10% were clinicians and 7% were individual members of the HIV community.



**Figure 1 - Total 107 Participants**

## COMMON THEMES FROM ACROSS THE PROVINCE

- It would be helpful for the OHTN to hold events in the regions that showcase locally-relevant research as well as potential to have regional representation on OHTN committees and boards.
- Communities would like OHTN support in brokering relationships with key players such as public health units and other decision makers. Community organizations would also like stronger relationships with academics, researchers and students.
- Hepatitis C (HCV) mono- and co-infection: What will be the impact on service systems and funding streams? OHTN could help raise awareness of the issue(s) both among service providers and decision makers.
- Respondents would like to see the OHTN work to build capacity and infrastructure in local communities, both among community members and among service organizations, to engage in the research process.
- The development of information repositories, databases or portals that could serve as a single point of contact for community members, researchers and students.

## POTENTIAL RESEARCH IDEAS

Potential areas for research identified during the consultations included:

- Youth at risk
- HIV-positive young adults in transition
- HIV and aging
- Co-morbidities and treatment adherence – advice for physicians
- Evaluate elements of supportive housing for people with HIV (including cost-effectiveness)
- Parenting & HIV
- Criminalization
- Sex workers and sex work

## OTTAWA

The Ottawa consultation took place on June 22<sup>nd</sup> at the Delta Ottawa Hotel. Twenty two people registered for this consultation including: academics, researchers, persons living with HIV, community members, ASO and HIV program staff, clinic staff and housing providers. Participants broke out into two smaller groups for discussions, and came back together at the end of the day to report on and share their breakout discussions. Along with stakeholders from Ottawa, ASO and HIV program staff from Kingston also attended the consultation.

### STRENGTHENING OUR NETWORK

#### **Question: How might the OHTN help you strengthen your networks?**

Eastern Ontarians, similar to stakeholders across the province, are concerned about regional representation in OHTN activities and would like the OHTN's support in developing stronger relationships with key local players in Ottawa and surrounding areas.

Stakeholders in Ottawa would like support in building capacity to collect, analyze and share locally relevant data regarding the epidemic in Eastern Ontario. In addition to making use of Ontario Community-based AIDS Services and Evaluation project (OCASE) and Ontario Community-based HIV and AIDS Reporting Tool (OCHART) data, participants suggested that the OHTN:

- seek opportunities to integrate HIV into larger strategies and research studies. This would help promote relationships with other sectors such as mental health and addictions and enhance case management services in the area.
- hold regional meetings or conferences that would engage local partners in the planning and showcase research that is relevant to different parts of the province
- restructure that annual research conference into multiple, smaller conferences in different locations.
- expand distribution of rapid responses and other knowledge translation and exchange (KTE) products to larger audiences. Eastern Ontarians appreciate the Rapid Response Service and other Knowledge Translation and Exchange (KTE) products
- provide support for agencies to help them enhance their media relations skills and use media outlets more strategically for knowledge exchange opportunities.

### PROMOTING RIGOROUS, RELEVANT RESEARCH

#### **Questions: How might the OHTN help you conduct Community Based Research?**

#### **How might the OHTN connect you to other research in your region?**

To build capacity for engaging research in Eastern Ontario, the OHTN could:

- provide opportunities for researchers to share methodologies
- use Research Days and Showcases to highlight tools and best practices such as web-based data collection and the use of anonymous identification numbers.

- Provide training and mentorship for frontline workers to become key members of research teams and meaningfully contribute to studies.
- walk communities through the entire research process from question formulation to results dissemination.
- house a community repository of research resources that could be searched by local players to identify potential partners, funding streams and data collection tools.
- create a process whereby peer research assistants could steadily increase their involvement in studies until they are experienced enough to become Principal Investigators of their own research.
- identify a local research champion who could facilitate community based research (CBR) in Eastern Ontario, connect community partners and funding bodies and ensure the timely and effective completion of CBR relevant to the region.

#### MOVING RESEARCH EVIDENCE INTO ACTION AND DRIVING CHANGE

**Question: What products and processes might the OHTN better provide for you to translate evidence into action?**

To help translate evidence into action, the OHTN could:

- hold regional research showcases or conferences
- improve communication methods
- provide mentorship at many levels (including community members, frontline workers and policy makers). Opportunities for mentorship included: mentoring community scholars to engage in CBR, mentoring community members and service providers to join research efforts, and mentoring academics to focus their research on other areas of the province
- help create a culture within the HIV community that values research evidence and using data to make policy and practice decisions. In addition to building local capacity, these efforts will work towards the aim of changing organizational and political culture to value and utilize research evidence.
- continue to use techniques such as the Deliberative Dialogue model used as part of the KTE strategy to explore policy implications of HIV, housing and health research.
- explore ways to have a bigger presence at the policy level and contribute to decision making.

## LONDON

The London consultation took place on June 23<sup>rd</sup> at the Delta Armouries Hotel. Nineteen people registered, and participants broke out into two smaller groups for discussion, coming together at the end of the day to report back. Stakeholders came from a variety of backgrounds, such as: academics, researchers, community members, persons living with HIV, ASO and HIV program staff and clinic staff. Cities and regions represented at the London consultation included Hamilton, London, Windsor, Niagara, Brantford, Kitchener/Waterloo and Huron County.

### STRENGTHENING OUR NETWORK

**Question: How might the OHTN help you strengthen your networks?**

To strengthen network in Southwest Ontario, the OHTN could:

- ensure stronger representation from Southwestern Ontario on its Board of Directors, on key committees and in decision-making
- hold a regional conference or research showcase to help build awareness and capacity in Southwestern communities and increase understanding of the work of the OHTN.
- help community agencies broker relationships with social services agencies, hospital and prisons as a way to improve services for individuals at high risk and enhance the network of support available
- help community agencies identify effective ways to engage LHINs and public health units in their work. There is a strong desire to develop an avenue to communicate emergent research findings to Medical Officers of Health. The OHTN should identify its role in brokering these types of relationships and working with provincial and federal level partners to enhance local service systems for people with HIV.
- help explain the intricacies of HCV co-infection with HIV, the impacts of mono-infection on individuals and communities and the future of service and research dollars for these two infections in Ontario. As with most Ontario communities, the Southwest is seeing a surge in HCV infection. There is little community awareness of the funding streams that support Hepatitis C services or understanding about the implications of the AIDS Bureau taking HCV under its mandate.
- continue to support students and future generations of HIV researchers
- enhance training initiatives by developing training modules for professionals new to the field of HIV that would build their knowledge base quickly and efficiently.
- clarify the ongoing role of the OHTN Ambassador Program, and provide more information on this program.

### PROMOTING RIGOROUS, RELEVANT RESEARCH

**Questions: How might the OHTN help you conduct CBR?**

**How might the OHTN connect you to other research in your region?**

To promote CBR and other research in the Southwest Region, the OHTN could:

- increase the involvement of clinics in HIV research in Ontario, thereby maximizing resources in smaller communities. Nurses and nurse practitioners comprise the largest body of health care

providers in the area, representing an untapped resource for researchers. Capitalizing on the resources already present in smaller communities will allow for greater participation in research and more robust results for rural communities.

- support more locally relevant research, whether that be data specific to a region but within a larger study or studies based in Southwestern communities that would focus explicitly on the lived experiences in the area.
- help link stakeholder communities to community based research projects. In do this, basic capacity must be increased through activities, such as presenting *CBR 101* workshops, hosting a CBR Summer Learning Institute or disseminating products explaining CBR and the potential roles of community members. Individual community members as well as AIDS Service Organizations would benefit from such events or products.
- Develop new and innovative knowledge translation vehicles to disseminate research findings: to policy makers, service providers and people with HIV including social networking media, a searchable database of research findings available to community members and an electronic registry listing names and affiliations of researchers and research resources.

These ideas led to a discussion of the dilemma of over-researching a relatively small sample of individuals. What are potential approaches to drawing in a larger sample of people with HIV rather than always relying on the same respondents? What role can the OHTN play? In addition to preventing research burn-out, these kinds of efforts will enhance the robustness of research findings.

#### MOVING RESEARCH INTO ACTION AND DRIVING CHANGE

**Question:      What products and processes might the OHTN better provide for you to translate evidence into action?**

To help translate evidence into action, the OHTN could:

- increase the capacity of researchers to engage in KTE and disseminate their findings by, for example: offering workshops or trainings on new KTE products and events, requiring researchers to think of KTE from the inception of research studies, requiring a KTE plan as part of a funding proposal and maintaining a line item in the budget for KTE. In this way, the OHTN can begin to develop a culture of knowledge exchange in which the impact of research is as important as the data collected.
- develop and identify best practices and intervention standards for clinics, community based organizations and health care providers. Having evidence based guidelines by which to make practice decisions will ensure that research is driving service delivery and all Ontarians have access to best standards of care. It was noted that best practices may have to be regional as what works well in large urban settings such as Toronto may not work in smaller communities such as Norfolk or Haldimand.
- consider using OCASE and OCHART data as the basis for an annual report of emerging issues and then using these current trends to inform the development of best practice guidelines.

## NORTHERN ONTARIO

The Northern Ontario consultation took place on July 13<sup>th</sup> at the Howard Johnson Plaza Hotel in Sudbury. Seventeen people registered for this conference, and participants broke out into two smaller groups for discussion, coming together at the end of the day to report back. Participants came from a wide range of backgrounds and locations including: academics, researchers, community members, ASOs and HIV program staff and clinic staff from Sudbury, North Bay, Sault Sainte Marie, Thunder Bay and Cochrane.

### STRENGTHENING OUR NETWORK

**Question: How might the OHTN help you strengthen your networks?**

To help strengthen networks in Northern Ontario, the OHTN could:

- help communities in the north build stronger connections between HIV and HCV services/communities by providing support in raising awareness among policy makers of the impacts of HIV/HCV co-infection. There is also concern about the impact of HCV mono-infection on current HIV funding streams and service delivery.
- Consider adapting public awareness campaigns for the north to help address stigma in rural communities. While significant effort has been put towards reducing stigma in urban settings, these efforts have not reached the more remote parts of the province.
- provide more opportunities for regional engagement and dialogue around emerging research issues. Stakeholders would like to see a Northern research conference that highlights data relevant to the North and engages a broader sector of the community, rather than only the limited few who can regularly travel to Toronto.
- help improve access to primary care in the region. The OHTN's role could be complemented by efforts to enhance primary care physicians' knowledge about HIV and co-morbidities.
- help understand why services such as TeleHealth are underused in the North by investigating the barriers to their use and then working to overcome them. Special attention must be paid to barriers specific to women.
- develop closer working relationships with First Nations communities. The OHTN was applauded for its close working relationship with the Ontario Aboriginal HIV/AIDS Strategy (OAHAS) and off-reserve First Nation communities. It could work with the Union of Ontario Indians and Nations such as the Anishnawbe and Mohawk to develop relationships with on-reserve populations.

Enhance awareness about HIV and its impact in decision makers creating policy for the North. Decision makers are often aware of the epidemic and its impact on urban centres but are less aware of how those impacts play out in remote communities.

### PROMOTING RIGOROUS, RELEVANT RESEARCH

**Questions: How might the OHTN help you conduct CBR?**

**How might the OHTN connect you to other research in your region?**

To promote CBR and other research in the region, the OHTN could:

- provide resources that would allow service providers to participate in research. Service providers in remote communities are often spread quite thin with large catchment areas and heavy workloads. To become part of research programs, they need resources to buy out their time and provide adequate compensation.
- improve infrastructure supports for research. In some areas of the North, CD4 counts can only be taken one day of the week at a single location. Due to the limited nature of this resource, it is not feasible for these communities to contribute to any research study that requires CD4 counts as part of the data collection.
- provide support for stakeholders in creating, funding, completing and disseminating their own research projects. Support is needed from the very initial stages of moving from community concern to research question through the full process to dissemination. This would help communities feel ownership over the research. This can be achieved through a number of methods including regional conferences and trainings or effective KTE products such as tool-kits and 'how-to' guides.
- help stakeholders broker relationships with Medical Officers of Health and Public Health Units.
- create more meaningful research partnerships in order to move away from what they referred to as 'painted equity' – the tokenizing involvement of community organizations and people with HIV.
- broker relationships between academics and rural communities.
- enhance rigorous, relevant research by exploring the implementation of indigenous research methodologies and paying greater attention to Francophone communities.
- address regional priorities by creating Regional Meetings at the OHTN conference whereby stakeholders could come together face to face, share their concerns and strategize for future action/research.

#### MOVING RESEARCH EVIDENCE INTO ACTION AND DRIVING CHANGE

**Question:      What products and processes might the OHTN better provide for you to translate evidence into action?**

To be more effective in translating evidence into action, the OHTN could use methods similar to those recommended to strengthen networks and promote research:

- increase regional representation on OHTN committees and Board, and invite regional community input on products that come out of the OHTN
- create a rural/remote subcommittee of the CBR Review Committee to help represent Northern interests
- hold a Research Showcase Day specific to the region
- use plain language KTE activities to ensure evidence is accessible to all communities as well as the Deliberative Dialogue approach was advocated
- consider mainstream campaigns to raise community awareness of HIV and reduce stigma
- re-invigorate the Health Care Providers Network to help address the barriers to care discussed in earlier conversations.

## TORONTO

The Toronto consultation took place on July 14<sup>th</sup> at the Oakham House at Ryerson University. Forty nine people registered for this consultation, making it the largest of the four. Participants broke out into seven smaller groups for discussion, and came back together at the end of the day to report on and share their breakout discussions. Stakeholders came from a wide range of backgrounds, such as: academics, researchers, persons living with HIV, community members, ASO and HIV program staff, clinic staff and housing providers. Cities and regions represented at the Toronto consultation included Toronto, Hamilton, Halton and Durham Region.

### STRENGTHENING OUR NETWORK

**Question:      How might the OHTN help you strengthen your networks?**

To strengthen the network, the OHTN could:

- focus on relationship building with allied sectors (i.e., health care providers whose practice is not specifically HIV-focused, researchers addressing other health challenges, policy makers working in ministries that affect people with HIV)
- develop information repositories or databases that could serve as a single point of contact for community members. Suggestions for databases range from repositories of research findings, collections of contact info, or opportunities for researchers to connect with community members and vice-versa.
- focus on returning research findings to the communities that contributed in ways that are accessible (i.e., plain language) and useful (i.e., what's in it for me and my program?). Ideally, affected communities will act as partners in developing dissemination strategies from the very beginning.
- take a leadership role in identifying and communicating emerging issues – to community members, service providers, policy makers and people with HIV. By raising awareness of the most cutting edge issues and results in HIV research, the community stands to gain by quicker action on hot topics.
- continue to invest in professional training of students, young professionals and other young leaders in the field. HIV physicians new to the field could substantially benefit from mentorship from more senior practitioners. ASO's would like more opportunities to strengthen relationships with HIV researchers and with clinicians. Stronger connections between these stakeholders will build research capacity in the community.
- hold targeted networking sessions in the evenings at the research conference where stakeholders from similar communities and sectors can connect. More focused efforts such as these could have a greater impact than large networking sessions that include all the varied participants from the conference.
- be a catalyst for developing relationships between public health units, hospitals, LIHNs, medical professionals and community organizations. Having a stronger network within the HIV community will serve to strengthen efforts to engage other networks and allied sectors.
- continue to implement the greater involvement of people with HIV/AIDS (GIPA) and meaningful involvement of people with HIV/AIDS (MIPA) principles in HIV research. The Region supports the

Peer Research Training Institute and other structured supports to increase leadership opportunities for people with HIV.

- create networking opportunities for people with HIV to connect with one another will help to identify regional priorities and address local concerns.

#### PROMOTING RIGOROUS, RELEVANT RESEARCH

**Questions:      How might the OHTN help you conduct CBR?**

**How might the OHTN connect you to other research in your region?**

To help the region participate in CBR and other research, the OHTN could:

- assist in developing Best Practice guidelines for a number of different research-related activities. This could include suggested data collection tools, community-based research processes, harmonizing multiple research projects in a single community, or research proposal formulation.
- provide support for the community to further develop capacity to engage in and utilize research. In addition to infrastructure support, the community would benefit from mentorship and support in articulating a research question out of concerns that arise from the community, support in the proposal writing process and guidance on communicating with funders who have declined an application in order to improve the proposal for future resubmission
- encourage the use of evidence-based data collection tools for program evaluation in the community
- play a role in linking students looking for research projects with community-based organizations who have research questions in mind but lack the capacity to engage a research project.
- focus on building a culture of KTE in all OHTN-funded research. By requiring that KTE plans be developed from the beginning, research studies can have greater impact and spread their research dollars further.
- establish “regional-point-persons” on the OHTN staff so that stakeholders across the province would know who to call for information or guidance
- create a “methodological consultation service” to which community members could refer should they need help at different stages of research formulation and execution. This could be complemented by a standardized process or program that educates community members about research and then systematically engages them in CBR.
- do more to help the community understand what is meant by evidence and how knowledge is produced.
- provide guidance to CBR projects on how to communicate progress throughout the course of the study to affected communities and informants, as well as key allied sectors
- ensure that the investment in basic and clinical science continues to be a priority in addition to community based research
- provide financial and structural support to community coalitions to ensure their viability and success.

## MOVING RESEARCH EVIDENCE INTO ACTION AND DRIVING CHANGE

**Question:      What products and processes might the OHTN better provide for you to translate evidence into action?**

To help translate evidence into action, the OHTN could:

- create innovative and alternative vehicles for the dissemination of evidence and research findings. engage social networking mediums such as Facebook and Youtube
- create a Researchers Speakers Bureau or film researchers talking about the purpose and impact of their research findings in plain language.
- invest in cost-effectiveness research as a useful tool for policy change
- improve the accessibility and navigability of the OHTN website and consider creating an email list whereby stakeholders can be notified of changes to the website
- expand the Rapid Response Service.
- offer training and mentorship to researchers in identifying the best target audience for their outcomes and framing the key messages for more effective uptake
- synthesizing the research presented at the Research Conference including an overview of implications for policy and practice
- create more focused KTE opportunities such as small group sessions, peer-based learning and topic-focused sessions.

**LISTENING FOR DIRECTIONS**  
**ONTARIO HIV TREATMENT NETWORK STRATEGIC PLAN CONSULTATION**  
**STRIVING FOR EXCELLENCE, ACHIEVING IMPACT: 2010 - 2015**  
**SETTING REGIONAL PRIORITIES**  
**AGENDA**

**WELCOME AND INTRODUCTIONS**

- Working Together
- Overview of the Day

**OVERVIEW OF THE OHTN STRATEGIC PLAN 2010 – 2015**

***“STRIVING FOR EXCELLENCE, ACHIEVING IMPACT”***

- Dr. Sean B Rourke, Scientific and Executive Director  
*Questions and Comments from Participants*

**OVERVIEW OF SMALL GROUP EXERCISE**

**STRENGTHEN OUR NETWORKS**

- How might the OHTN help you strengthen your networks?

**BREAK**

**PROMOTING RIGOROUS, RELEVANT RESEARCH**

- How might the OHTN help you conduct CBR?
- How might the OHTN connect you to other research in your region?

**MOVE RESEARCH EVIDENCE INTO ACTION AND DRIVE CHANGE and ENSURING ORGANIZATION INTEGRITY AND ACCOUNTABILITY**

- What products and processes might the OHTN better provide for you to translate evidence into action?

**REPORT BACK – IDENTIFYING TOP PRIORITIES**

- Strengthening our network
- Promoting rigorous, relevant research
- Move research evidence into action and drive change
- Ensuring organizational integrity, accountability and engagement with our stakeholders

**REFLECTION AND EVALUATION**