

# New prevention technologies and vaccine development

Report: Satellite meeting Montreal March 4, 2010

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For CAS/CATIE/ICAD

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## Contents

1.0 Executive summary .....	2
2.0 Introduction.....	5
3.0 Acknowledgements.....	6
4.0 Terminology and acronyms.....	6
5.0 New prevention technologies: Presentations.....	8
5.1 HIV Prevention Research Landscape .....	8
5.2 New Prevention Technology Development.....	9
5.3 The Prime-Boost HIV Vaccine Phase III Trial (RV144), Thailand: A Community Perspective .....	10
5.4 Community preparedness: Implementing NPT research results in Canada .....	11
5.5 Ethics.....	12
5.6 HIV Vaccine Social Research.....	13
5.7 Merck HIV Vaccine Study (The STEP Study): What happened and what are the latest results? .....	15
5.8 Antiretrovirals for Prevention: Research update.....	16
5.9 Canadian HIV Vaccine Initiative (CHVI) .....	17
6.0 Host and other organizations - Prevention projects .....	18
7.0 Community engagement and feedback.....	20
7.1 Discussions at meeting: main issues .....	20
7.2 Reports by scholarship participants .....	23
8.0 Moving forward – next steps.....	24
9.0 Meeting evaluation.....	26
10.0 Conclusion.....	30
Appendix 1: Meeting agenda .....	31
Appendix 2: Presenter biographies .....	33
Appendix 3: Meeting presentations.....	36
Appendix 4: Meeting evaluation results.....	37

## 1.0 Executive summary

Research and clinical trials of new HIV prevention technologies, such as vaccines, microbicides and pre-exposure prophylaxis, provide hope for more effective prevention of HIV transmission. Communities are aware of research developments and need timely, accurate information which they can use to inform and engage their members.

In response to this need, the Canadian AIDS Society, the Canadian AIDS Treatment Information Exchange and the Interagency Coalition on AIDS and Development, in partnership with the Coalition des organismes Québécois de lutte contre le sida, hosted a one-day meeting in Montreal on March 4, 2010 with 74 registered participants from a variety of communities. International and Canadian presenters provided updates on research, ethics and community preparedness. Participants engaged in dialogue with the presenters and each other. The meeting was successful in achieving its objective of knowledge transfer and exchange. Ideas for continuing the dialogue emerged from the meeting.

Several presenters spoke about research developments in new prevention technologies. Highlights included:

- A variety of approaches will be needed to reduce HIV transmission because no single technology will fit all circumstances. Existing technologies such as condoms and clean needles will continue to be used along with new technologies such as microbicides, vaccines and pre-exposure prophylaxis.
- Clinical trials of new technologies are currently being conducted, often through international partnerships involving thousands of volunteer participants worldwide. Each trial teaches us something.
- A vaccine is possible, despite discouraging trial results (with the exception of the clinical trial in Thailand). Even a vaccine of relatively low efficacy might bring about a significant reduction in the number of new infections. New vaccine candidates are being developed, including those based on antibodies isolated from volunteers with natural neutralizing antibodies to HIV.
- The RV144 Prime-Boost vaccine clinical trial in Thailand is the first to show encouraging results: a 31% efficacy rate compared to the control group. The community engagement strategy for the Thai trial was an important element in the successful recruitment of volunteers, adherence to the trial and communication of the trial results.
- The earlier Merck STEP vaccine trial had a Canadian site at the Maple Leaf Clinic in Toronto. This trial was halted in 2007 when results showed no benefit from the vaccine and a possible increased risk of infection.

- Antiretrovirals used in medications to treat HIV are being tested for use in microbicides and pre-exposure prophylaxis. Clinical trials are currently underway.
- Treatment as prevention is based on the concept that persons living with HIV who have low viral loads as a result of treatment are possibly less likely to transmit HIV. This strategy is being studied. Recent research shows that although treatment can lower viral load to undetectable levels in blood, semen viral load levels may remain high enough to transmit HIV.

The psychosocial and ethical dimensions of new prevention technologies were discussed by several presenters. Some of the main points included:

- Community education and research literacy are vital to community engagement. Community engagement, beginning in the early stages of research and continuing throughout the research process, is essential to building support for HIV vaccine research and development.
- Studies conducted by the University of Toronto on the social dimensions of vaccine research revealed that potential volunteers may decline to participate in clinical trials because of fears about the risks involved, including uncertainties about vaccine efficacy, and the long-term commitment required. Mechanisms to support trial volunteers, such as an ombudsperson and public validation of volunteers, can counteract these fears. The studies also showed that risk behaviours are not influenced by participation in a clinical trial.
- New prevention technologies create several challenges for organizations in preparing their communities: equipping members of the community with knowledge and access to a range of appropriate technologies; developing strategies to deal with a possible increase in risk behaviours; and engaging in advocacy for access to knowledge and equitable access to technologies.
- Many ethical issues are raised by new prevention technologies. Debate is needed about such questions as who will have access, who will pay, whether it is ethical to use medications in new technologies when so many who need the medications do not have access to them, and how to respect the individual's right to engage in risk behaviours and to refuse or accept treatment.

The three host organizations provided details about their projects involving capacity building and community engagement in new prevention technologies, including their co-hosting a session to be held in May 2010 at the conference of the Canadian Association of HIV Research. The session will bring together researchers, community and health care providers to explore how new prevention technologies may fit within the continuum of existing prevention strategies.

Discussions at the meeting and other feedback from participants revealed four main themes of concern to communities:

- Knowledge translation and exchange: Organizations need accurate and timely information and require support in creating messages that are appropriate and accessible for their communities.
- Community engagement requires trained community educators, including persons living with HIV, who are important role models and communicators.
- Communities want and need to be involved as partners with researchers in all stages of research, dissemination of results and implementation of products and approaches. A diversity of communities must be involved in studies and clinical trials in order to ensure that research results apply to diverse populations.
- Communities need to engage with the media to ensure that research is communicated in an accurate way that avoids creating stigma and discrimination. The media are important partners in communicating with all those affected by HIV, including the general public.

Several suggestions for moving forward emerged from the discussions, including the creation of web-based information sites, use of new social networking tools, more in-depth forums on single topics such as vaccines and microbicides, opportunities for communities to dialogue and form partnerships with researchers, forums for discussion of ethical issues and community preparedness, and development of tools to help organizations translate research information into messages appropriate for their communities.

Participants evaluated the meeting positively, finding it informative, relevant and inspiring. In the words of two participants: *"The information was easy to understand. The presenters were clear and the information was communicated well. I understand my role in research and what I can do to empower clients to get involved"*.

## 2.0 Introduction

Research on new prevention technologies provides hope that a range of new methods will soon be developed to reduce or prevent HIV transmission. Communities affected by HIV in Canada have expressed the need for up-to-date information and engagement in the process of research, development and implementation of new technologies.

In response to this need, the Canadian AIDS Society (CAS), the Canadian AIDS Treatment Information Exchange (CATIE) and the Interagency Coalition on AIDS and Development (ICAD) organized a one-day invitational meeting on HIV vaccine preparedness and new HIV prevention technologies (funded by the Public Health Agency of Canada) in Montreal on 4 March 2010 in conjunction with the Sixth Canadian HIV/AIDS Skills Building Symposium. The Coalition des organismes communautaires Québécois de lutte contre le sida (COCQ-SIDA) partnered with the host organizations in planning the meeting and organizing later site visits for participants to research and community organizations.

The meeting objective was to achieve knowledge transfer and exchange and, in particular, to equip participants with information they could apply to their own organizations and communities. The meeting was structured to provide both expert presentations and discussions that engaged the participants with the presenters and other participants. The agenda is provided in Appendix 1.

International and Canadian presenters spoke to the participants from a variety of perspectives: biomedical and clinical research; psychosocial research; international coordination and promotion; community engagement; community-based research; and government policy.

Participants were invited from community-based organizations and professional associations working primarily in HIV prevention in Canada. A strong effort was made to invite persons living with HIV.

Following the meeting and the Skills Building Symposium, international participants made site visits to research and community organizations in Montreal and Ottawa to deepen their knowledge and build their capacity to apply research knowledge to their communities and organizations.

### 3.0 Acknowledgements

The host organizations extend their thanks to all presenters and participants and to the following individuals who formed the organizing committee: Shayna Buhler (ICAD); Janet Dunbrack (facilitation, evaluation and meeting report); Michel Morin (COCQ-SIDA); Tim Rogers (CATIE); Bachir Sarr (CAS); David Thompson (Institut Thoracique de Montréal); and James Wilton (CATIE). Our special thanks go to the AVAC team, Mitchell Warren, Deirdre Grant and Kevin Fisher.

### 4.0 Terminology and acronyms

The following terms and acronyms are used in this report. Several are used in the PowerPoint presentations in Appendix 3.

**Clinical trial:** A study conducted to evaluate a new treatment or drug, usually involving human participants. Clinical trials usually proceed in three or four phases to test safety, efficacy, dosage and method of use.

**Medical male circumcision:** Surgical removal of the foreskin of the penis.

**Microbicide:** a substance, usually a gel or cream, applied in the vagina or rectum to reduce the risk of transmission of HIV.

**Treatment as prevention:** Treatment for persons living with HIV which reduces viral load and lowers risk of transmission to others.

**Vaccine:** A biological preparation that stimulates an immune response to protect against disease (preventive) or to modulate disease progression (therapeutic).

**AVAC:** [www.avac.org](http://www.avac.org). An international non-profit organization that uses education, policy analysis, advocacy, and community mobilization to accelerate the ethical development and eventual global delivery of AIDS vaccines and other new HIV prevention options as part of a comprehensive response to the pandemic.

**CAS:** Canadian AIDS Society. [www.cdn aids.ca](http://www.cdn aids.ca). A national coalition of over 120 community-based AIDS organizations across Canada dedicated to strengthening the response to HIV/AIDS across all sectors of society, and to enriching the lives of people and communities living with HIV/AIDS.

**CATIE:** Canadian AIDS Treatment Information Exchange. [www.catie.ca](http://www.catie.ca). CATIE champions and supports innovation and excellence in knowledge exchange for the prevention of HIV transmission, and the care, treatment and support of people with HIV.

CHVI: Canadian HIV Vaccine Initiative. [www.chvi-icvv.gc.ca/index-eng.html](http://www.chvi-icvv.gc.ca/index-eng.html). A collaborative undertaking between the Government of Canada and the Bill & Melinda Gates Foundation.

COCQ-SIDA: Coalition des organismes communautaires Québécois de lutte contre le sida. [www.cocqsida.com](http://www.cocqsida.com). A coalition of community-based organizations in Quebec united to bring about concerted action on HIV/AIDS issues.

ICAD: Interagency Coalition on AIDS and Development. [www.icad-cisd.com](http://www.icad-cisd.com). A coalition of over 120 AIDS service organizations non-governmental organizations, faith-based organizations, educational institutions and labour unions. ICAD helps Canadians contribute to international HIV/AIDS work and ensures that the lessons learned from the global response to HIV/AIDS are utilized by Canadian organizations to improve prevention, care, treatment and support work in Canada.

IDU: Persons using injection drugs.

HCV: Hepatitis C Virus. Also referred to as Hep C.

HIV/AIDS: Human immunodeficiency virus/Acquired immunodeficiency syndrome

IAVI: International AIDS Vaccine Initiative. [www.iavi.org](http://www.iavi.org). An international non-profit organization that uses education, policy analysis, advocacy, and community mobilization to accelerate the ethical development and eventual global delivery of AIDS vaccines and other new HIV prevention options as part of a comprehensive response to the pandemic.

KT: Knowledge synthesis, dissemination, exchange and application. Sometimes expressed as KTE.

MSM: Men who have sex with men.

NPT: New prevention technology

PEP: Post-exposure prophylaxis consisting of antiretroviral treatment for a short period of time following possible exposure to HIV.

PHA: Person living with HIV/AIDS (The Canadian AIDS Society uses PLWHIV/AIDS, Persons living with HIV/AIDS)

PrEP: Pre-exposure prophylaxis for those who may be exposed to HIV, consisting of antiretroviral drugs taken before exposure.

STI: Sexually transmitted infection.

## 5.0 New prevention technologies: Presentations

Presentations from eight speakers covered the main developments in global new prevention technology research, the Canadian experience, community preparedness and ethical issues raised by NPTs. In addition, short activity updates were provided by the Canadian HIV Vaccine Initiative, the three host organizations and the Canada Africa Prevention Trials Network. Short biographies of the presenters appear in Appendix 2. PowerPoint slides of the presentations are provided in Appendix 3.

### 5.1 HIV Prevention Research Landscape

Presenter: Deirdre Grant, AVAC

Main points:

- HIV prevention requires a comprehensive, integrated and sustained response using a variety of approaches: distribution of technologies already available (e.g. condoms, clean needles, male circumcision) and development of new ones (e.g. microbicides, vaccines, pre-exposure prophylaxis (PrEP)).
- Many options must be presented because one method will not serve everyone at all times in all situations.
- Clinical trials are ongoing around the world to test vaccines, PrEP, microbicides, and medical male circumcision.
- A vaccine is possible, despite discouraging vaccine trial results to date, with the exception of the RV 144 trial in Thailand.
- Research and development is an iterative, long-term process
- Large-scale clinical trials are important; each one teaches something but no single trial provides all the answers.
- Results are expected in 2010 from trials of PrEP, microbicides and vaccines; more trials will be launched, including a study on partner treatment.
- Community education and research literacy are vital to community engagement.

## 5.2 New Prevention Technology Development

Presenter: Prince Bahati, IAVI

Main points:

- A new prevention technology, especially a vaccine, is the best hope for altering the trajectory of the global AIDS pandemic. A predictive model to the year 2030 using the variables of no vaccines and vaccines of varying efficacy shows a significant reduction in number of new infections, even with a low-efficacy vaccine.
- The steps in AIDS vaccine development consist of basic research, pre-clinical development and clinical trials. Clinical trials usually proceed in four phases to test safety, dosage and method of use, and efficacy.
- AIDS vaccine development began in 1981 and clinical trials began in 1987. By 2009, more than 150 clinical trials were completed or ongoing throughout the world. Vaccine research is proceeding in a collaborative way, involving partnerships on all continents.
- The first vaccine to show encouraging results was the RV144 trial in Thailand (2009).
- The current Antibody Project gathered blood samples from an international test population of 2,000 people. 1% of volunteers were identified as elite neutralizers with potent broadly neutralizing antibodies to HIV. These antibodies will be used in research to generate vaccine candidates and lead to clinical trials.
- The integrated process of new prevention technology development requires political will and funding and community/civil society engagement at all stages of research, trials, production and uptake. Since most NPTs are still in the development stage, it is important to manage community expectations and help people to stay informed and engaged.
- The presenter showed a short animated film explaining the difference between types of vaccines.

### 5.3 The Prime-Boost HIV Vaccine Phase III Trial (RV144), Thailand: A Community Perspective

Presenter: Nusara Thaitawat, Armed Forces Research Institute of Medical Sciences, Bangkok, Thailand

Main points:

- The RV144 trial (2003-2006 with results released in 2009) was a randomized, double-blind, placebo-controlled trial involving more than 16,000 volunteers in several regions of Thailand from an initial screen of more than 26,000 potential volunteers.
- The trial was designed to determine whether the vaccine-boost combination protected volunteers from infection and whether the vaccine regimen lowered early viral load in volunteers who became infected during the course of the study.
- The trial was the first to show significant efficacy of a vaccine candidate. The rate of HIV infection among volunteers who received the experimental vaccine was 31% lower than the rate of HIV infection among volunteers who received the placebo.
- In addition to testing efficacy and safety of the prime-boost study vaccines, the trials sought to evaluate whether participation was associated with increased risk behaviour.
- The trial was sponsored by the US Army Surgeon General and funded by a consortium of US funding agencies. The trial was conducted by a partnership among the Thai Ministry of Public Health, Mahidol University and the US Armed Forces Research Institute of Medical Sciences. Community engagement was the responsibility of the Thai Ministry of Public Health.
- The vaccine trial approach provided a strong role for community; the Community Engagement Strategy was a crucial element in the approach. This strategy secured community involvement and counteracted the perception that Thai citizens might be used as “guinea pigs” in the trial. Community engagement was chosen as the approach rather than community consultation because engagement involves full and ongoing participation by community in the entire process.
- Community engagement proceeded in several phases: preparatory; screening and enrolment; vaccination and follow-up; preparing for release of trial

outcome; and unblinding (researchers and volunteers learned who received the vaccine or the placebo).

- The Community Engagement Strategy worked through community leaders, word-of-mouth communication and collaboration with NGOs that provided advice on reaching the grassroots and raised HIV/AIDS awareness in study areas. Media, concerts and local festivals were among the communications methods used. A community advisory board provided advice. Organization was decentralized with provincial and district community outreach teams. Volunteers were organized into volunteers' clubs. Approaches were modified during the trial as experience dictated (e.g. health forums were redesigned from a one-way lecture format to two-way communication with volunteers).
- A communications strategy was developed for releasing the results of the trial. Release of materials was phased. Community health forums were used to disseminate results.
- Reaction to the release of trial results was mixed. The media hailed them as either a failure or a scientific breakthrough. NGO partners focused on data analysis and lessons learned. Volunteers expressed pride at their participation, despite their limited understand of the trial results.
- The legacy of the trial includes the development of a transparent participatory process, strengthening of ethical guidelines and integration of community engagement as a fundamental element in clinical trials.

## 5.4 Community preparedness: Implementing NPT research results in Canada

Presenter: Marc-André LeBlanc

Main points:

- Several late-stage prevention trials are underway or planned for the next two years involving pre-exposure prophylaxis, microbicides, treatments and vaccines. These raise several questions:
  - Will new prevention technologies (NPT) be available in Canada and how? Who will decide who has access? Who will pay?
  - Will receptive partners who use a partially effective NPT find it harder to get their partner to use a condom?
  - How will the health care system deal with increased testing?

- Ethical questions: Access inequality between provinces and territories; implications of limited access to prevention options to only certain groups; stigma of associating NPTs with high-risk populations; ethical implications of supplying antiretroviral drugs to HIV negative people for prevention (PrEP) when most HIV positive people who need these drugs do not get them.
- Challenges for community-based organizations:
  - Having sufficient knowledge of NPTs to explain them to others
  - Conveying information about multiple prevention options without confusing people
  - Determining whether or not the NPT should be made available in our community
  - Tackling questions of the effect of NPTs such as PrEP on risk behaviours, the development of drug resistant HIV strains with incorrect use, testing, illegal sales, making NPTs available to women, to name a few.
- Steps for community-based organizations to prepare their community for NPTs:
  - Join an advocacy group asking questions about NPTs
  - Engage in dialogue within your organization and with partners
  - Remain informed about research developments
  - Engage in dialogue to ensure better access to existing prevention options, better access to treatment and improved testing rates.

## 5.5 Ethics

Presenter: José Sousa

Note: a list of readings on HIV prevention-related ethics is posted on the websites of the host organizations: [www.cdnaids.ca](http://www.cdnaids.ca), [www.catie.ca](http://www.catie.ca) and [www.icad-cisd.com](http://www.icad-cisd.com).

Main points:

- Ethical questions are raised by all of the new prevention technologies: Is there a need? Who will receive them? Who will pay for them?
- In most cases, the rich will have access to NPTs and pharmaceutical companies will be the major beneficiaries.

- Issues raised by NPTs:
  - NPTs will not be foolproof and should be viewed as harm reduction rather than complete protection
  - Pre-exposure prophylaxis will not protect if the partner is resistant. There is a possibility of developing drug resistance if infection occurs before PrEP is used.
  - Medical male circumcision has proven efficacious in preventing female to male transmission of HIV through vaginal intercourse.
  - At a population level, treatment as prevention is based on lowering the community viral load to lower HIV transmission. Treatment as prevention works for tuberculosis but people cannot be forced to take treatment.
  - The rights of the individual must always be respected.

## 5.6 HIV Vaccine Social Research

Presenter: Peter A. Newman, University of Toronto

Main points:

- A safe, efficacious vaccine offers the greatest hope for controlling the AIDS pandemic
- Socio-behavioural research is vital to the development of HIV vaccines because:
  - Thousands of volunteers are required for vaccine trials
  - There is a need to mitigate social harms and increases in risk behaviours
  - Understanding individuals' acceptance of HIV vaccines is important to the effectiveness of future vaccines.
- Four qualitative research studies were described. The first three studies involved the STEP HIV vaccine trial housed at the Maple Leaf Clinic.
- The first study was conducted in Toronto with 13 individuals into their reasons for declining to enrol in the HIV vaccine trial. Reasons for declining included:
  - Fear of a false positive result which could lead to insurance refusal and stigma
  - Uncertainties about the risks involved

- Fear of side effects
- Inadequate payment for participation
- Fear of being placed in the placebo arm
- Long-term time commitment to the trial (4 years)
- Uncertainties about the vaccine efficacy.
- These results led to the development of measures to facilitate enrolment in trials:
  - Support and referrals for participants, including an ombudsperson to deal with insurers
  - Involving the local communities in development of recruitment materials
  - Alternate locales to the clinic for those who are uncomfortable in gay or HIV identified venues
  - Offering reasonable payment for participation
  - Community engagement in vaccine trial education and awareness
  - Acknowledging the contribution of trial participants through community events.
- A second study involving trial participants examined trends in risk behaviours over time. This study showed that trial participation resulted in predominately the same risk behaviours as before the trial.
- A third study, involving seven community-based organizations in Toronto, explored community perspectives on the vaccine trial. Perspectives included:
  - In the public mind, a vaccine provides total protection.
  - A vaccine would be beneficial, and could also be used by those at high risk of assaults and violence (e.g. sex workers).
  - Vulnerable communities will benefit most from a vaccine but some people are too vulnerable to be candidates for vaccine use.
  - Conspiracy theories exist (e.g. *The government is trying to wipe us out.*)
  - Communities must be engaged in all aspects and stages of the trial.
- A fourth study investigated the acceptability of a future vaccine. Participants were recruited from a variety of community health services. The study found that

vaccine efficacy had the greatest impact on acceptability, followed by considerations of side effects and cost.

- These studies show that meaningful community engagement from the early stages is essential to building long-term support for HIV vaccine research and development.

## **5.7 Merck HIV Vaccine Study (The STEP Study): What happened and what are the latest results?**

Presenter: Roberta Halpenny, Canadian Immunodeficiency Research Collaborative and Maple Leaf Medical Clinic, Toronto

Main points:

- The Maple Leaf Medical Clinic, a community-based clinic in the heart of the gay village in Toronto, was chosen as a site for the STEP vaccine trial because of its large population of MSM clients and its history of doing clinical research with Merck
- The STEP study was an international multicentre double-blind randomized placebo-controlled Phase II proof-of-concept trial conducted from 2003-2007. The vaccine used an adenovirus (responsible for many upper respiratory infections) and was intended to teach CD4 cells to recognize the HIV virus and fight it.
- A total of 3000 volunteers were recruited from seronegative populations at high risk of HIV infection: MSM engaging in high risk sexual behaviour and women at high risk.
- A Community Advisory Board provided input to the process. The recruitment strategy was built on lessons learned from an earlier vaccine trial and included: involve and educate the community and rely on a network of local physicians for recruitment. Posters were highly effective in recruiting.
- The study was halted in 2007 because the interim analysis showed no benefit from the vaccine and a possible increased risk of infection at more concentrated doses of the vaccine compared to the placebo arm. The increased risk of HIV acquisition appeared to be associated in men with lack of circumcision. There was no apparent vaccine effect in women.
- Trial participants continue to receive follow-up and risk reduction counselling but risk practices remain relatively high.

## 5.8 Antiretrovirals for Prevention: Research update

Presenter: Kevin Fisher, AVAC

Main points:

- Antiretrovirals (ARVs) used to treat HIV infection are promising candidates for prevention because:
  - Studies in animals show reduced risk of infection when ARVs are administered before virus exposure
  - ARVs are effective in reducing vertical transmission (mother to child)
  - Post-exposure prophylaxis (PEP) using ARVs appears to be effective
  - Viral load reduced in HIV-positive persons through the use of ARVs decreases the HIV transmission rate to HIV negative partners.
- Research is being conducted into the use of ARVs taken before exposure (PrEP) and ARV based microbicides. 11 clinical trials are currently underway and new products are being developed.
- Research on the use of the female condom by MSM for anal intercourse indicates the possibility of anal bleeding.
- Emerging prevention approaches include treatment as prevention to reduce risk of transmission, including increased testing and early initiation of treatment. Three clinical trials are currently underway. Several mathematical models show the potential benefits of universal testing and treatment but also the unlikelihood that HIV transmission will be eliminated. A Swiss statement made in 2008 that persons with low viral load do not transmit HIV has been thrown into doubt by evidence that, while blood viral load may become undetectable with ARV treatment, viral load in semen may remain high enough for transmission to occur.
- New developments in 2010:
  - PrEP: Launch of two new clinical trials (phase I and II), completion of two Phase II and III trials and results from three other trials (Phase I, II and III).
  - Treatment as prevention: Launch of a feasibility study of an enhanced test-and-treat strategy
  - Microbicides: Results of a Phase IIb trial.

## 5.9 Canadian HIV Vaccine Initiative (CHVI)

Presenter: Lilja Jonsdottir, CHVI/Public Health Agency of Canada

Main points:

- The goal of the CHVI is to support a coordinated Canadian domestic and international contribution to global efforts to accelerate the development of a safe, effective, affordable and globally accessible HIV vaccine. This includes promoting the community and social aspects of vaccine research and delivery.
- CHVI works to promote greater collaboration between researchers in Canada and those in low- and middle-income countries and to enhance global capacity for clinical trials.
- CHVI has contributed to strengthening Canada's contribution to policy development and community engagement and has provided funding to the Global HIV Vaccine Enterprise.
- CHVI will continue to implement its projects despite the recent Government of Canada decision to cancel plans to build an HIV vaccine manufacturing facility in Canada.

## 6.0 Host and other organizations - Prevention projects

The three host organizations, CAS, CATIE and ICAD, gave brief presentations on their projects related to new prevention technologies.

### **Joint project: CAS, CATIE and ICAD**

The three organizations will co-host a day-long ancillary session on new prevention technologies at the 19<sup>th</sup> Annual Conference on HIV/AIDS Research (May 13-16, 2010). This session will bring together researchers, community and public health workers, community members and other stakeholders to explore how new HIV prevention technologies, including vaccines, microbicides and pre-exposure prophylaxis, may fit within the broader continuum of HIV prevention strategies already in use.

### **CAS**

Bachir Sarr, Programs Consultant for New Prevention Technologies and International Issues Portfolios, spoke on behalf of CAS.

CAS responds to its members' needs and will continue to take a holistic approach to HIV prevention with the goal of accelerating the discovery of an affordable, safe and effective alternative to existing methods and the development of tools. CAS will continue to partner with organizations in Canada and abroad, such as AVAC, to facilitate dialogue between various stakeholders. CAS will continue to listen and inform its members while promoting positions on issues such as pre-exposure prophylaxis. CAS plans to take advantage of HIV Vaccine Awareness Day (May 18) in collaboration with IAVI to voice the necessity for Canada to support vaccine and new prevention technology research to improve HIV prevention and treatment.

### **CATIE**

Tim Rogers, Director of Knowledge Exchange, spoke on behalf of CATIE.

CATIE currently provides information and resources on new prevention technologies (NPTs) through its e-bulletins: *CATIE News* and *Prevention in Focus*. CATIE also provides the workshop *Beyond the Banana*, which provides practical information for front line workers on the biomedical science of HIV transmission and the role of NPTs in HIV prevention work. CATIE maintains an extensive collection of links to online resources on NPTs at [www.catie.ca](http://www.catie.ca) to meet diverse information needs, from introductory factsheets and video presentations, to comprehensive research syntheses. CATIE is currently developing resources to fill information gaps in this collection, including the launch of a new series of in-depth factsheets for prevention workers. In the next year, CATIE will be working in partnership to develop an

integrated knowledge exchange strategy that situates NPTs within the broader framework of HIV prevention in Canada.

## **ICAD**

Shayna Buhler, Program Officer, spoke on behalf of ICAD.

ICAD is piloting three introductory workshops on new HIV prevention technologies: a one-day introduction co-hosted with the AIDS Committee of Toronto; a two-day workshop for students, co-hosted with the University of Ottawa Health Promotion Department; and a workshop that includes a human rights and ethics focus, co-hosted with the AIDS Committee of Nova Scotia and Oxfam Canada, Maritimes.

ICAD has received funding from the Canadian HIV Vaccine Initiative for *Building Community Engagement in Vaccines Efforts in Canada and Africa*. The project is being conducted in partnership with the Southern African AIDS Trust in South Africa and the New HIV Vaccines and Microbicides Advocacy Society in Nigeria. The three organizations will develop a toolkit and training package on HIV vaccines and other prevention research, and deliver training workshops to community and media representatives in Canada, Nigeria and Southern Africa.

## **Canada-Africa Prevention Trials Network**

Robert O'Neill of the Canada-Africa Prevention Trials Network (CAPT) provided a brief overview of their work. CAPT is a partnership of HIV researchers, clinicians and NGOs in Canada and Africa engaged in international HIV prevention research. With funding from the Government of Canada, CAPT is engaging in South-South and South-North relationships to empower African leaders in developing and executing studies that respond to local needs. The CAPT motto is *African Led, Canadian Enabled*. A number of research projects and clinical trials are underway.

## 7.0 Community engagement and feedback

A key objective of the meeting was to facilitate knowledge transfer and exchange for participants and their community-based organizations. The meeting was structured to provide the opportunity for participants to engage in dialogue with presenters and other participants. The following section summarizes the main issues raised by community participants at the meeting and in the reports submitted after the meeting by scholarship recipients.

### 7.1 Discussions at meeting: main issues

The main issues that emerged in the discussions concerned four themes:

1. Knowledge translation and exchange: the need for timely, accurate information
2. Community education and engagement
3. Community involvement in research
4. Public awareness and media coverage

#### **Knowledge translation and exchange (KTE)**

Many participants expressed the need for accurate, up-to-date information about new prevention technology development, research results and opportunities to become involved in research. Suggestions for improving KTE included communication networks and hubs, and forums for community members to engage in deeper conversations about NPT issues. A suggestion was made that CAS and COCQ-SIDA could work together at the pan-Canadian level to unify and disseminate accurate messages and thereby reduce confusion. Another suggestion was to use both existing communications networks and new social networking media such as blogs, Facebook and Twitter. A further suggestion was to develop a Canadian database of available prevention tools that could be adapted for use by each community.

Once information is disseminated, there is a need to translate it into a form that is appropriate and accessible to a diversity of communities. Many participants said that their organizations would like help with converting technical information into easily understood messages. Examples of this need were given by organizations serving MSM, African/Caribbean communities, women, people who use injection drugs, youth, sex workers, transgendered and at-risk populations in general.

## **Community education and engagement**

Information is an important tool in community engagement. An informed community can become an engaged community.

Participants pointed out the need for organizations to engage in two-way dialogue with their communities. It is important to hear the concerns and fears of community members about NPTs. In many communities, people are more concerned with basic survival issues such as food and housing; it takes understanding of their reality in order to transmit appropriate prevention messages.

Some communities may be suspicious of research because of negative past experience with research and governments. This climate of distrust must be taken into account in the development of education and community resources. The example was given of African/Caribbean communities who are sceptical of clinical trial results when trial volunteers are largely white; the community wonders if the results are applicable to them. Clinical trial volunteers must be recruited from a variety of populations in order to assure equal representation and applicability of trial results.

A number of participants stated the need for helping clients deal with the results of their experiences as participants in research and with more generalized problems such as stigma. The need for trained counsellors was stressed.

The experience of front-line workers was raised in an interesting context. Front-line workers often become aware of how their communities are using prevention technologies. The example was given of underground use of pre-exposure prophylaxis and sharing or sale of medications for this purpose. Front-line workers are crucial links in the process of community education and conveying knowledge back to researchers.

The need to train community educators was repeatedly stressed. Community workers need to meet people where they live: in churches, cafes, hospitals and health care centres, schools, community centres and other gathering places, homes and on the street. Outreach workers need both training and accurate information that is adapted to the needs of their particular community. The crucial role of persons living with HIV/AIDS as community educators and role models was underlined.

Some participants raised the need for better sharing of information among community partners. The example was given of clients receiving counselling at one organization and health care at another organization. Information sharing about the effects of the counselling could provide useful feedback to the first organization. Safeguards of confidentiality and client agreement to information sharing would be needed.

The ethical issue of universal access to NPTs was raised and participants wondered how to engage in the debate about access. There may be a need for forums for this debate.

Finally, the need for strong community leadership and advocacy about NPTs was stressed, both in Canada and on a global scale. No specific mechanisms for engaging in leadership and advocacy were determined, which suggests the need for further discussion.

### **Community involvement in research**

Participants raised the need to build bridges between researchers and community. The need for partnerships at all stages of research and application of research was stressed. Mechanisms to promote partnership could include community-based research, community research advisory groups, access to ethics review by community-based researchers and pairing of community members with researchers. Some participants suggested that the research protocols and community engagement plan developed by the Ontario HIV Treatment Network for Ontario are needed in all regions of Canada. The session being organized by CAS, CATIE and ICAD at the conference of the Canadian Association for HIV Research in May 2010 provides an opportunity for engaging in a community-researcher dialogue about community engagement and the psychosocial aspects of research.

In this connection, participants raised the need for more equal representation of diverse communities in research. Examples were given of women, African/Caribbean and transgendered communities; clinical trial results obtained with largely white male volunteers may not be applicable to other populations.

### **Public awareness and media coverage**

Many participants spoke of misreporting and misinterpretation in media coverage. Some stated the need to engage the media in the initial stages of research through to release of results in order to avoid misinterpretation and sensationalism which can lead to public misperceptions and stigma. There is a need to engage the media in celebrating wins as well as reporting problems. The media play a role in reaching community members and raising awareness of issues. For the broader public, the media are the main source of information and it is important to ensure that information is accurate. The media can also play a role in combating the general population's HIV fatigue, stigma and prejudices.

## 7.2 Reports by scholarship participants

Participants receiving scholarships to attend the meeting were each asked to submit a brief report on what they learned and how this might be applied in their organizations and communities. These reports generally reiterated the main themes that had emerged during the meeting discussions.

Overall, participants reported that they found the information presented at the meeting to be important, pertinent, up-to-date and understandable. Many stated that the information was at a literacy level that could be shared with their community. Some said they would share what they had learned with their colleagues during staff meetings.

Some noted that their pre-existing notions were challenged and changed by the meeting. They reported that their view of research was now more nuanced and realistic in terms of the complexities of research. They now realize that no single technology, such as vaccines, will provide a complete answer to HIV prevention. A range of new technologies is needed to meet diverse needs and situations.

A participant stated that the meeting allowed her to interact with researchers and learn how dedicated, passionate, diverse and creative they were. This was a revelation. This participant hoped to take home the atmosphere of inspiration from the meeting and, in turn, inspire persons living with HIV/AIDS and colleagues in working in the field.

Participants stated that meetings like this are important, but are only the first step. Next steps include using the information to engage their communities and the public and advocacy for sustained funding for research. Many mentioned the need to share information in a collective, organized way and to continue engagement in advocacy around these issues.

## 8.0 Moving forward – next steps

The consensus of the participants at the end of the meeting was that improved mechanisms are needed for knowledge transfer, exchange and translation. A national network may be desirable, but appears to be premature at this moment. Participants said that they wanted to take the information gathered at the meeting back to their communities and engage in dialogue with their organizations and communities. As one participant stated in the evaluation, *A national network will be needed soon but you also need community buy-in for that and that's not there right now.*

Many participants expressed the hope that the host organizations could continue to engage them and their communities in order to prepare communities for participating in national networks for KTE, advocacy and discussion of issues. The meeting occurring in May 2010 at the CAHR conference is one way of moving forward.

Other concrete ideas for facilitating knowledge translation and exchange and community engagement included:

- National web-based information sites that provide accurate current, accessible information on NPTs
- Use of new social networking tools to reach communities (e.g. Facebook, Twitter)
- Collaboration among national organizations to ensure that communities receive accurate up-to-date information
- More in-depth forums on single topics such as vaccines, microbicides and PrEP
- In-depth forums on the ethical issues raised by NPTs and community preparedness
- Opportunities for communities and researchers to dialogue and work in partnership at all stages of research and implementation
- Development of resources that can help community organizations to translate research results into messages that are appropriate for their communities
- Opportunities for feedback from communities to national organizations about the lived experience at the grassroots.

Representatives of the host organizations stated that they would take into account this community feedback in planning their initiatives. The report from this meeting will be distributed to all participants and posted on the websites of the host organizations as another mechanism for information sharing. There was a high level of enthusiasm for continued community engagement and leadership from the host organizations. Participants asked that the host organizations continue to move forward with these issues and continue their activities to engage communities.

## 9.0 Meeting evaluation

Of the 65 participants registered for the meeting (excluding presenters), 31 completed evaluation forms, for a relatively high participation rate of 48%. The overall evaluation of the meeting was positive. A participant comment sums up the opinions of many: *The information was easy to understand. The presenters were clear and the information was communicated well. I got a clearer understand of the process of research.*

A detailed summary of the evaluation results is provided in Appendix 4.

Participants were asked to evaluate their experience of the meeting in nine categories using a four-point Likert scale (Strongly agree; Agree; No opinion; Disagree) and were given an opportunity to add comments in each category. Three additional qualitative questions were included in the evaluation. When no answer was provided by a participant, the question was rated *No opinion*. With a few exceptions, the majority of answers were rated *Agree*. The following summary provides the main points of the evaluation results. Positive ratings provided below are the total of *Strongly Agree* and *Agree* responses, unless stated otherwise.

### **Organization**

Most participants found that the information received prior to the meeting was helpful (87%), that the meeting was well organized (97%) and that the agenda contained the major items considered important by the participant (97%). Most comments stated that the meeting was informative, the presenters were well selected and that the information received in advance helped participants to prepare for the meeting. One comment noted that the agenda was full and that presenters seemed rushed.

### **Information presented**

Most participants found the presentations by all speakers to be informative and useful. The following presentations were rated highly (more ratings of *Strongly Agree* than *Agree*): overview of new prevention technologies (58% Strongly Agree (SA) of a total of 85% positive ratings), community preparedness (67% SA of a total of 94% positive), the Thai prime boost vaccine trial (52% SA of a total of 94% positive), the University of Toronto vaccine acceptability study (45% SA of a total of 87% positive) and the Maple Leaf Clinic vaccine trial report (48% SA of a total of 90% positive). Other presentations had a majority of *Agree* ratings. A small number of participants disagreed with respect to the presentations on overview of new prevention technologies, ethical considerations and pre-exposure prophylaxis (ARVs in prevention).

Comments ranged from positive to suggestions that some speakers presented too much detail or spoke longer than necessary. Some commented that they wanted more depth in the presentation on ethics, while others wondered how to raise awareness of their communities about the issues raised.

### **Discussions**

Most participants rated the discussions with presenters and in the afternoon plenary discussion as productive. Most opinions were rated *Agree*. A significant number (26%) found that the time allowed after presentations for clarification questions was inadequate. Comments included appreciation for the relevant and engaging discussions and observations that more time would have been good.

### **Relevance to the concerns of participants' organizations and communities**

Most participants agreed that the meeting was relevant to their organization and community. The majority chose *Agree* in response to the questions. The total positive ratings were: the major issues of concern were covered (87%); the information and ideas would be useful their organization and community (90%); participants would be able to apply what they learned in their work (90%); and the next steps discussed at the meeting were realistic for their organization and community (61%). A small number of participants (6%) disagreed that the meeting covered major issues of concern, that they would be able to apply the information to their work and that the next steps discussed at the meeting were realistic for their organization/community. A significant number (31%) had no opinion on whether the next steps discussed at the meeting were realistic for their organization and community. This may reflect the fact that the consensus at the meeting was that concerted national action or a network may be premature.

Comments included a desire for more community involvement and education. Some noted that the results presented were too complex, uncertain and inconclusive to be applied to their communities, while others noted that persons using injection drugs needed to be a priority for research and community involvement. One comment expressed the concern that promising research results might lead to an increase in risky sexual practices.

### **Participation**

Most participants agreed that they were able to participated and offer their opinions (90%).

## **Networking**

Most participants chose *Agree* with respect to their opportunity to network at the meeting and its potential positive impact on their work. Participants rated positively their opportunity to discuss common concerns (81%), the impact of the networking on their work (71%) and their comfort with contacting other participants and their organizations in future (97%). A small number (6%) disagreed that they had the opportunity to discuss common concerns and that the networking would have a positive impact on their work. A significant number had no opinion about whether the networking would have a positive impact on their work (23%). One participant noted that more networking time was needed.

## **Translation/Interpretation**

The meeting provided simultaneous French-English interpretation and meeting materials and most presentations were provided in both languages (slides were translated). Most presenters (11) delivered their presentation in English and two presented in French. Most evaluated the translation/interpretation as effective (74%), while 23% had no opinion and may not have required translation. A comment noted that a better balance was needed between presentations in French and English.

## **Facilitation**

The meeting facilitation was highly rated, with a 97% positive rating, of which 61% were rated *Highly Agree*. The facilitator was praised for keeping the meeting flowing, on topic and on time in a diplomatic manner and giving everyone equal opportunities to participate.

## **Environment**

Most participants agreed that the facilities were supportive of an effective meeting, with a total positive rating of 87%. Some disagreed (13%), with many comments noting that the room was too cold.

## **The most useful aspect of the meeting**

The variety of comments received fell into the following categories, ranked according to the number of times they were mentioned:

1. Information provided: up-to-date overviews
2. Focus on community preparedness and engagement
3. Diversity of perspectives and types of research presented
4. Sharing information

5. Contacts made
6. Feeling encouraged by the ongoing research progress
7. Participation by persons living with HIV; relevance of information to the Canadian context; relevance to participant's work; success in bringing together researchers and community.

One comment summed up those of many: *Understanding my role in research and how I can empower clients to get involved.* Another participant said that, *Generally updating myself on these relevant issues will breathe new life into an environment where education and understand are outdated.*

### **Suggestions for improving future meetings**

The following suggestions were made, ranked according to the number of times they were mentioned:

1. Offer meetings on specific topics in greater depth (one topic per meeting): vaccines; microbicides; circumcision; pre- and post-exposure prophylaxis; partner notification; using social networking technologies; communication and messaging to communities; STI control; perspectives of those who have participated in trials as volunteers.
2. Great participation by persons living with HIV, including travel and accommodation subsidies for meetings and encouragement to PHAs to engage in studies
3. More discussion time in small groups
4. Offer more meetings like this for civil society – more education for communities on research and vaccines
5. Review presentations in advance to ensure that they fit the meeting objectives and the time allotment designated.

## 10.0 Conclusion

This meeting on new prevention technologies and vaccine development was a successful means of informing communities about new developments and engaging them in issues of ethics and community preparedness. The meeting facilitated dialogue among community representatives, researchers, policy makers, advocates and national organizations. The meeting showed clearly that communities are eager for information and ways of becoming engaged in NPT research and implementation issues.

The enthusiasm for the topic was clear. As one participant said, *I want more!* Despite the long, information-packed day, most participants stayed for the entire meeting and a high percentage participated in the meeting evaluation. These are strong indicators of a high level of interest.

The meeting achieved its objective of knowledge transfer and exchange and opened new possibilities for building on this objective. Community participants asked for more such forums for information and exchange in addition to accessible sources of timely accurate information and help with translating information into messages that would be appropriate to their communities. Communities also expressed a strong desire to engage in dialogue and partnership with researchers at all stages of research.

The three host organizations will take this into account in planning their initiatives and, in partnership with other Canadian and international stakeholder organizations, will continue to support knowledge transfer and exchange and community engagement.

## Appendix 1: Meeting agenda

### AGENDA

**HIV vaccine preparedness and new HIV prevention technologies**

**Satellite session: March 4, 2010**

**Room Regence B, Delta Hotel Centre-Ville, 777 University St, Montreal QC**

**Facilitator: Janet Dunbrack**

<b>Time</b>	<b>Session</b>	<b>Presenters</b>
8:15 – 9:00	<b>Registration</b>	
9:00 – 9:10	<b>Welcome</b>	Laurie Edmiston, CATIE
9:10 – 9:35	<b>Overview of the HIV prevention landscape</b>	Deirdre Grant, AVAC
9:35 – 10:00	<b>Research, discovery process and global action and coordination</b>	Prince Bahati Ngongo, IAVI
10 :00 – 10:25	<b>The Thai Prime Boost Vaccine Trial, results, process and community perspectives</b>	Nusara Thaitawat, Armed Forces Research Institute of Medical Sciences, Bangkok
<b>10:30 – 10:50</b>	<b>Health break</b>	
10:50 – 11:15	<b>Ethical considerations for communities</b>	José Sousa, Consultant
11:15 – 11:40	<b>Community preparedness</b>	Marc-André Leblanc, Consultant
11:40 – 12:30	<b>Discussion on prevention technologies – plenary discussion</b>	All presenters/ Participants/Facilitator
<b>12:30 – 1:30</b>	<b>Lunch</b>	

Time	Session	Presenters
1:30 – 1:50	<b>Canadian HIV Vaccine Initiative</b>	Lilja Jonsdottir, CHVI
1:50 – 3:05	<b>Research updates</b> University of Toronto: findings of the vaccine acceptability study. The Maple Leaf Clinic: vaccine clinical trials in Canada and community engagement. AVAC: Pre-exposure prophylaxis	Peter Newman, University of Toronto  Roberta Halpenny, Maple Leaf Clinic  Kevin Fisher, AVAC
3:05 – 3:20	CAS, CATIE and ICAD – planned initiatives  Canada Africa Prevention Trials Network - overview	Bachir Sarr – CAS Tim Rogers – CATIE Shayna Buhler – ICAD Robert O’Neill - CAPT
<b>3:20 – 3:40</b>	<b>Health break</b>	
3:40 – 4:30	<b>Going forward – next steps</b> <b>Plenary discussion</b>	All presenters/ Participants/Facilitator
4:30 – 4:45	<b>Closing remarks</b>	Laurie Edmiston, CATIE
4:45	<b>Evaluation</b>	Participants

## Appendix 2: Presenter biographies

### **Deirdre Grant, AVAC**

Deirdre Grant is Program Manager for AVAC. She oversees AVAC's web presence, Advocates' Network and contributes to the writing and editing of AVAC publications. She also co-leads AVAC's domestic HIV prevention advocacy leadership work. She is currently serving as the co-coordinator of the US-based Pre-exposure Prophylaxis Committee and is a member of the PrEP and AIDS Vaccine Communications Working Groups.

### **Kevin Fisher, AVAC**

Kevin is the Policy Director of AVAC. He focuses on new regulatory, legislative, financial and scientific approaches to accelerating the development new HIV prevention options. He also serves as the principal researcher and author of the annual resource tracking reports from the HIV Vaccine and Microbicide Resource Tracking Working Group. He serves as a member of the AIDS Vaccine Research Subcommittee, and as co-chair of the Research subcommittee of the Federal AIDS Policy Partnership.

### **Prince Bahati Ngongo, IAVI**

Prince Bahati Ngongo is the Senior Program Manager of Country and Regional Programs at the International AIDS Vaccine Initiative based in New York. He provides leadership and technical assistance on IAVI's sponsored clinical research center support; civil society engagement; global advocacy and social science projects in Africa, Europe, Asia and North America.

### **Nusara Thaitawat**

Nusara Thaitawat is Senior Expert, Community Engagement, Department of Retrovirology, Armed Forces Institute of Medical Sciences, Bangkok, Thailand. Ms. Thaitawat was Director of Communications and Community Engagement of the Phase III RV144 clinical trial for the Ministry of Health, Thailand. She is a former journalist for the Bangkok Post and is the author of a book about the cuisine of Cambodia.

### **José Sousa**

José Sousa is Chair of the CIHR Canadian HIV Trials Network Community Advisory Committee. He also represents Quebec on the Canadian Treatment Action Council and is a member of the Ontario HIV Treatment Network. He has participated in a number of clinical trials.

### **Marc-André LeBlanc**

Marc-André has a long involvement in HIV/AIDS and was involved in the development of both the Canadian HIV Vaccines Plan and the Canadian Microbicides Action Plan. He has been involved with the Global Campaign for Microbicides for five years, coordinating partnerships, advocacy and community mobilisation efforts in North America, Europe and Australia for the past three years. He has recently developed a series of community-friendly materials on pre-exposure prophylaxis (PrEP) and antiretroviral (ARV)-based prevention. He is a co-founder of International Rectal Microbicide Advocates.

### **Roberta Halpenny, Maple Leaf Medical Clinic**

Roberta Halpenny is the Research Manager, Canadian Immunodeficiency Research Collaborative (CIRC), at the Maple Leaf Medical Clinic in Toronto.

### **Peter A. Newman, University of Toronto**

Peter Newman is Associate Professor at the Factor-Inwentash Faculty of Social Work, University of Toronto. Dr. Newman's research addresses HIV and global health, with a focus on social and structural challenges of biomedical HIV prevention. He is engaged in field research in Canada, India, South Africa, Thailand and the U.S. in collaboration with women of color, men who have sex with men, male and female sex workers, and injecting drug users. Newman's work also addresses Lesbian Gay Bisexual Transgendered Queer challenges in social work research and education.

### **Lilja Jonsdottir, CHVI**

Lilja Jonsdottir is Senior Policy Advisor, Office of HIV Vaccines, Public Health Agency of Canada (Canadian HIV Vaccine Initiative), Ottawa.

### **Laurie Edmiston, CATIE**

Laurie Edmiston is Executive Director of the Canadian AIDS Treatment Information Exchange, Toronto.

### **Bachir Sarr, CAS**

Bachir Sarr is Programs Consultant of New Prevention Technologies and International Issues Portfolios for the Canadian AIDS Society, Ottawa.

**Tim Rogers, CATIE**

Tim Rogers is Director of Knowledge Exchange for the Canadian AIDS Treatment Information Exchange, Toronto.

**Shayna Buhler**

Shayna Buhler is Program Officer, Interagency Coalition on AIDS and Development, Ottawa.

**Robert O'Neill**

Robert O'Neill is Executive Director of the Canadian Association of HIV Research (CAHR) and Director of the CAPT Network (Canada Africa Prevention Trials Network), Vancouver.

**Janet Dunbrack, Facilitator**

Janet Dunbrack is a bilingual Ottawa-based health policy consultant who has worked on HIV/AIDS issues for the past 20 years. Her involvement in HIV/AIDS includes staff work for front-line and national community-based organizations and the Canadian government and, as a consultant, for a variety of clients. She is also a visual artist and works to bring art activity into health care settings.

## Appendix 3: Meeting presentations

See PDF version of this report for PowerPoint slides

## Appendix 4: Meeting evaluation results

HIV vaccine preparedness and new HIV prevention technologies meeting  
Montreal, March 4, 2010

### EVALUATION RESULTS

Participation rate: 31 forms were completed of a total number of 65 participants  
(excluding presenters) for a participation rate of 48%

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Please circle the answer that best reflects your opinion on the following:

#### 1. Organization

a. The information I received prior to the workshop was helpful

Strongly Agree-10                      Agree-17                      No opinion-4 Disagree

b. The meeting was well organized

Strongly Agree-14                      Agree-16                      No opinion-1 Disagree

c. The agenda contained the major items I considered important

Strongly Agree-12                      Agree-18                      No opinion-1 Disagree

d. Comments:

- Would have been good to have slides of all the presentations.
- I believe all presenters were well prepared and they answered all questions to my satisfaction.
- It was well presented and the presenters were very informative, when questions arose they had all the answers.
- Very informative.
- Thank you for choosing such great presenters.
- Very good presentations but they seemed rushed. Maybe less presentations with more time each.
- Thanks to the organizers. Job well done!
- J'ai trouvé que les réponses au courriel avant l'événement étaient rapide, clair, concis. De recevoir le plan de la présentation une semaine à l'avance m'a permis de lire sur le sujet.

- Unfortunately this was not the best session for me to attend – very interesting and informative but I don't foresee involvement in trials anytime soon.
- Lots of great information to take back home with me and I look forward to any future updates.
- I am unclear how presenters were selected. All speakers were great but there are others in Canada who are actively involved in NPTs and could have contributed.
- Because I knew so little prior so very informative.
- I especially liked the log in which enabled me to go through the entire program to prepare myself.

## 2. Information Presented

### The following presentations were informative and useful:

- a. Overview of the HIV prevention landscape – AVAC and CATIE  
 Strongly Agree-18                  Agree-8                  No opinion-3 Disagree-2
- b. Vaccine research and global action - IAVI  
 Strongly Agree-13                  Agree-15                  No opinion-3 Disagree
- c. Community preparedness – Marc-André Leblanc  
 Strongly Agree-20                  Agree-9                  No opinion-2 Disagree
- d. Thai prime boost vaccine trial – Nusara Thaitawat  
 Strongly Agree-16                  Agree-13                  No opinion-2 Disagree
- e. Ethical considerations for communities – Jose Souza  
 Strongly Agree-11                  Agree-15                  No opinion-2 Disagree-3
- f. Canadian HIV Vaccine Initiative  
 Strongly Agree-10                  Agree-15                  No opinion-6 Disagree
- g. Research updates:
- h. University of Toronto: vaccine acceptability study  
 Strongly Agree-14                  Agree-13                  No opinion-4 Disagree

i. Maple Leaf Clinic: vaccine clinical trials in Canada – community engagement

Strongly Agree-15                      Agree-13                      No opinion -3 Disagree

j. Pre-exposure prophylaxis – AVAC

Strongly Agree-7                      Agree-17                      No opinion-5 Disagree-2

k. Comments:

- I learned a lot and will be glad if conferences like this would come around more often.
- We need to get this information on the ground level in communities in a language that people can understand.
- Jose: I thought there would be more new information. I already knew a lot as general information. CHVI: slides would have been good. AVAC prep – speaker went into too much detail or had too many slides – the presentation was too long.
- The presentations were informative and useful. The presenters were good. The presentations followed well i.e. organised. I like it. Excellent.
- La présentation de M. Sousa était celle envers laquelle j'avis le plus d'attente. Malheureusement elle ne faisait qu'effleurer et nommer les enjeux éthiques, sans développer. De plus, ce n'était pas une excellente présentation. Je suis persuadé que le présentation était adéquat pour le sujet, cependant, pour une seule présentation sur les enjeux éthiques, c'était trop peu, trop rapide, trop sommaire.
- Very informative, articulated in plain language and understandable to general communities who are not researchers.
- All afternoon presenters needed more time! A bit too much info in such a short period. They were rushed and difficult to understand.
- Même si je suis complètement en accord avec les informations et les expériences partagées, je me rends compte qu'on n'est pas toujours à la première étape. Donc il reste beaucoup à faire. Oui les scientifiques et les experts font beaucoup, mais la population est-elle consciente? Là est ma grande question. Je crains que non et c'est d'ailleurs ce qui complique beaucoup et compliquera dans le futur la réalisation des objectifs.
- All great!
- Maple Leaf Clinic: Very keen on learning more.

### 3. Discussions

- a. The time allowed for clarification questions after each presentation was adequate:

Strongly Agree-2                      Agree-19                      No opinion-2    Disagree-8

- b. The morning discussion on prevention technologies with all presenters was productive:

Strongly Agree-11                      Agree-20                      No opinion    Disagree

- c. The afternoon group discussion about Going forward – Next steps was productive:

Strongly Agree-7                      Agree-19                      No opinion-3    Disagree-2

- d. Comments:

- More work to be done involving youth as they are either affected or infected and they are the future of the world.
- Not new information but good updates.
- All productive discussions, liked how participants were involved and discussions relevant, engaging too.
- No questions for some presentations.
- Only the first presentation had questions following it.
- Good recapitulation by the facilitator to keep the participants focused on the subject. Bravo.
- Obviously presentations were longer than all others. I felt the presenters, especially in the afternoon, felt rushed.
- Good comments and observations.
- I think this is a difficult discussion to have but I think this was a good start to a very important topic.
- It's great to be part of this phrase. Doing so at such a forum allows for a lot of inclusiveness.

### 4. Relevance to the concerns of my organization and community

- a. The meeting covered the major issues of concern to my organization and community:

Strongly Agree -8                      Agree-19                      No opinion-2    Disagree-2

- b. The information and ideas from the meeting will be useful to my organization and community:

Strongly Agree-11                      Agree-17      No opinion-3      Disagree

- c. I will be able to apply what I learned today to the work of my organization and community:

Strongly Agree-9                      Agree -19      No opinion-2      Disagree-1

- d. The next steps/action plan from the meeting are realistic for my organization and community:

Strongly Agree-4                      Agree-15      No opinion-10                      Disagree-2

- e. Comments:

- Next steps?
- Point C ci-dessus: Trop de complexité, trop d'incertitude, peu de résultats concluants.
- Les moyens manquent des fois pour aller de l'avant.
- Our clients aren't ready for adherence to studies or even preventative interventions/education. But IDUs are/should be a key area for research/study – social/community involvement and responsibility.
  
- Manque d'informations sur les conséquences possibles de l'émergence de ces résultats (ex hausse possible des comportements sexuels à risque.
  
- A national network will be needed soon but you also need community buy-in for that and that's not there right now.
  
- Community involvement throughout the whole process and educate them.

## 5. Participation

- a. I was able to participate and felt comfortable offering my opinions

Strongly Agree-9                      Agree-19      No opinion-3      Disagree

- b. Comments:

- Very accommodating environment.
- Le niveau était accessible à tout le monde.

## 6. Networking

- a. I had an opportunity to discuss common concerns with people from across the country

Strongly Agree-7                      Agree-18      No opinion-4    Disagree-2

- b. The networking I did at this meeting will have a positive impact on my work

Strongly Agree-6                      Agree-16      No opinion-7    Disagree-2

- c. I will feel comfortable in contacting organizations and other participants in the future

Strongly Agree-9                      Agree-21      No opinion -1    Disagree

- d. Comments:

- Not enough networking time.
- Everyone was very open to network.

## 7. Translation/Interpretation

- a. The translation/interpretation services were effective

Strongly Agree-10                      Agree-13      No opinion-7    Disagree-1

- b. Comments:

- Nécessité d'équilibrer les présentations en français et en anglais.
- I would like to use them for our own meeting. Very good.

## 8. Facilitation

- a. The facilitator helped the meeting to run smoothly and productively

Strongly Agree-19                      Agree-11      No opinion-1    Disagree

- b. Comments:

- Good work.
- She was nice.
- Travail épatant, bonne gestion. Bravo.
- Great job: soft-spoken, patient and diplomatic time keeper.
- Not on time.

- Gracefully allowed all to comment and gave equal question and answer opportunity.

## 9. Environment

- a. The facilities were supportive of an effective meeting

Strongly Agree-11                      Agree -16                      No opinion      Disagree-4

- b. Comments:

- Très bonne organisation.
- [room was] way too cold
- Too cold
- I would have preferred a better telephone access. There were only a couple of public phones but I had no coins with me.
- Good display of presentations.
- The room was too cold.
- There were audiovisual issues with some microphones transmitting too quiet. Volume not consistent throughout.
- The room was very cold.
- Cold room.
- Room too cold.
- The room was too cold.
- Room was too cold. Brrrrr!

## 10. What was the most useful aspect of the meeting for you and your community?

- Community engagement
- Diverse nature. Passion is contagious.
- Hearing from other PHAs
- It was important to hear from individuals representing various sectors. As with other disciplines we often tend to speak with each other.
- International/interprovincial contacts made
- Literature references given.
- Printed info
- Tous les aspects étaient utiles.
- Actualisation des informations sur les vaccins.
- De voir qu'il existe des initiatives et qu'on travaille fort pour arriver à mieux stopper l'épidémie. Donc c'est réconfortant de savoir que la communauté scientifique, les chercheurs ne baissent pas les bras.
- Generally updating myself on these relevant issues will breathe some new life into an environment where education and understanding are very outdated.
- Learning about all the different trials past and present.

- m. Overall, good info and up to date and relevant on vaccine development and new prevention technology.
- n. Hearing about the number of trials, future possibilities, PEP, etc are very exciting. There is hope, as distant as that may be. But at least it is being worked on.
- o. Tour d'horizon de la prévention du VIH. Préparation communautaire (excellent).
- p. Networking
- q. Sharing knowhow
- r. Scientific updates
- s. Q & As
- t. Vaccines
- u. All presentations.
- v. Hearing about research results.
- w. Research process and global action: why it is important.
- x. The presenter from Thailand who spoke about mobilization and community involvement.
- y. Understanding my role in research and what I can do to empower clients to get involved.
- z. Sharing of the various information among colleagues about the new prevention technologies.
  - aa. Up to date information on trials
  - bb. Background info on vaccines
  - cc. Applicability to Canadian context
  - dd. The whole day was fully packed with important information.
  - ee. All the different presentations were very helpful in getting different perspectives.
  - ff. The update on vaccines that have been done
  - gg. The participation of community in the vaccine studies.

## 11. Suggestions for improving future meetings

- a. None – great
- b. more discussions – breakout groups
- c. Encourager les personnes qui dévoilent leur statut dans la communauté pour pratiquer HIV GIPA principes.
- d. Bringing communities and researchers is always a challenge. I think this was achieved in this session. Thank you.
- e. Le transport et l'hébergement soient mis à la disposition des PHAs.
- f. Organiser des rencontres très axées sur des ateliers de production de messages.
- g. Organiser beaucoup plus de séances des conférences informatives. La société civile se sent soulagée.
- h. Engaging Canadian PHAs in studies – working with IDU communities – how would we engage/involve with so many issues outside of having or at risk of getting or transmitting the virus.

- i. Tour d'horizon. Vaccin; présentation d'étude; conséquences. Microbicides, circoncision, PPE et PrEP. Nous offrir des présentations sujet par sujet.
- j. Keep on doing the good work.
- k. Add classical ways such as partner notification. Add social/electronic methods. Add STI control in general.
- l. Review decks prior to presentation to ensure they will fit meeting objectives and that they meet the time allotment designated.
- m. The perspective of someone who was involved in research as a study/subject.
- n. A warmer room!
- o. Smaller group segment to talk about their communities in relation to the materials presented.
- p. More breaks.
- q. Limit to one question per person.
- r. Warmer room.

**12. Additional comments:**

- a. Good job!
- b. Very positive and open-minded atmosphere overall.
- c. Je reste sur ma faim.
- d. I would have preferred handouts from all presenters.
- e. Bravo, une journée fort intéressante, j'ai grandement apprécié dans l'ensemble. Mention d'honneur : Deirdre Grant; Marc-André LeBlanc, Peter Newman; Roberta Halpenny.
- f. Continue the good work.
- g. Thank you to all presenters, facilitator, organizers. Good job. I enjoyed this satellite session.
- h. The information was easy to understand. The presenters were clear and information was communicated well. I got a clearer understanding of the process of research.
- i. Thank you. Well done.
- j. Well done. Now we want to see more education to community on research and vaccines.