

**“Follow the condoms and needles:”**

**What Previous Public Health  
Interventions Teach us about Future  
Deployments of an HIV Vaccine**

**A DISCUSSION PAPER**

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## Executive Summary

The Canadian AIDS Society (CAS) is committed to preventing the spread of HIV/AIDS in the Canadian population. As part of this commitment, CAS has been increasing awareness of the need for a viable vaccine as one strategy in a growing range of prevention tools to stop the transmission of HIV. Great strides have recently been made in the development of HIV vaccines, including the 2009 breakthrough of the Thai Trial that confirmed proof of concept and, in 2010, the isolation of highly effective and broadly neutralizing antibodies that are thought to be key in the development of an HIV vaccine.

Although Canada represents a small part of the global HIV pandemic – only 65,000 of an estimated 33 million infections worldwide – it nevertheless has a vested interest in curbing the global transmission of the virus. While Canada should be committed to halting the spread of HIV around the world for its own political and economic interest, closer to home, Canada is welcoming an increasing number of immigrants from countries where HIV is endemic in the adult population. This fact is beginning to contribute to a shift in the make-up of its own affected populations. In 2009, 5.5% of all HIV infections were attributed to heterosexual contact among individuals from an endemic country, despite the fact that these populations account for only 2.2% of the Canadian population.

No viral epidemic has ever been stopped without a vaccine, and the best chance to significantly reduce rates of HIV transmission around the world is to develop a viable vaccine. Comparatively, Canada's epidemic is small and it cannot contribute to the clinical trial process by providing thousands of trial volunteers. It can, however, contribute financially and scientifically to isolating an effective vaccine and should, because a well-targeted vaccine has the potential to reduce Canada's incidence rate, which is currently between 2300 and 4300 infections per year. The majority of infections in this country are concentrated in several identifiable populations, including gay men and men who have sex with men (41.8%); women (26%); people who use substances (21.6% among adult cases); and ethnocultural communities (5.5%). Given the stark reality of Canada's HIV epidemic, these populations have been identified as key stakeholders in this project. Recognizing that Canada's Aboriginal communities are also disproportionately infected and affected by HIV/AIDS – despite representing 3.8% of the population, they represent 33.3% of positive reports that specify ethnic data – and that people living with HIV/AIDS have a unique perspective on the prevention of HIV transmission, both of these communities have also been actively involved in shaping the work of this project.



Drawing on eight months of research, consultation and interviews, this paper outlines the major trends in lessons learned and best practices from current public health interventions among key communities at higher risk for HIV infection. Research demonstrates that, even in this preliminary stage of vaccine development, there continues to be a need to build partnerships between researchers and communities, as well as a clear need to elucidate the science of vaccines prior to a vaccine deployment. Access barriers to current HIV prevention methods exist and these same barriers pose challenges for future HIV vaccines. Community members indicated a deep concern that current standards of prevention be maintained during vaccine trials and that a vaccine, once it is deployed, be smoothly incorporated into the existing prevention arsenal. Finally, research indicates that mobilizing resources to provide relevant and culturally-appropriate messaging and outreach materials to individuals on how a vaccine will and will not protect them from HIV is a priority for the communities CAS represents.

CAS continues to advocate for the development of an HIV vaccine, while cautioning the scientific community and the government to include, at every step of the process, the communities that are most affected by HIV and that could benefit most from any future vaccine. Individuals need to be allowed to make their own informed decisions regarding their health, even if this means choosing not to adopt vaccination as a prevention tool. CAS is committed to ensuring that its members and the communities they serve are given the means to make these decisions for themselves.



## Preparing for an HIV Vaccine: An Introduction

**In 1984, Ronald Reagan’s Health and Human Services Secretary, Margaret Heckler, famously announced that a vaccine against HIV would be ready for testing within two years. Twenty-five years later, we are still waiting for a marketable vaccine.** Trials have been taking place since 1987. While promising candidates have progressed through Phase IIb and Phase III trials, it was not until the Thai Trial in 2009 that proof of concept for a vaccine to reduce HIV transmission was confirmed. The Thai Trial enrolled more than 16 000 low-risk Thai participants and found that HIV transmission rates in those who received the vaccine were reduced by 31% when compared to the placebo group. These results inaugurated a year of firsts in the science of HIV vaccines and other new HIV prevention technologies. In the last year, the first proof of concept of a microbicide was confirmed in the CAPRISA 004 trial, which reduced a woman’s risk of HIV transmission by 39%. The iPrEx Study, a global study of oral pre-exposure prophylaxis (PrEP), which released its results in November 2010, demonstrated that oral PrEP reduces the risk of transmission in men who have sex with men by 44% when used in conjunction with a wider HIV prevention strategy. In addition to these breakthroughs, highly potent and broadly neutralizing antibodies thought to be essential for the development of a vaccine were isolated in 2010 by U.S government scientists. These advances give promise that a vaccine might be available within a reasonable delay. According to Dr. José Esparza, Senior Advisor, HIV Vaccines at the Bill and Melinda Gates Foundation, the “collective goal” of those working in the field “should be a ‘practical’ vaccine within 10-15 years.”<sup>1</sup>

Despite promising advances in HIV vaccine science, as Newman and Logie demonstrate in a recent publication, acceptability of an HIV vaccine is far from assured. They suggest that among high risk North American adults, HIV vaccine acceptability ranges between 43% and 60%.<sup>2</sup> This finding has been confirmed in other public health programs where the availability of an intervention does not necessarily coincide with the acceptability and uptake of that intervention. Lessons learned from the recent licensure and roll-out of the human papillomavirus (HPV) vaccine and the continued difficulty of encouraging optimal adherence to highly active antiretroviral therapy (HAART) indicate that the availability of effective treatments does not guarantee their uptake.<sup>3</sup> This is especially worrying since HPV vaccines and HAART are highly effective. Since initial

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<sup>1</sup> Dr. Esparza made these comments during an IAVI-sponsored satellite entitled “The Search for an HIV Vaccine,” held at *AIDS* 2010 on 18 July 2010.

<sup>2</sup> Peter A. Newman & Carmen Logie, (2010), “HIV vaccine acceptability: a systematic review and meta-analysis,” *AIDS* 24: 4.

<sup>3</sup> The uptake of the HPV vaccine has been lower across the country than for other school-based vaccinations. In Ontario, only 53% of eligible girls received the first dose of the vaccine. The highest rate at 85% (Newfoundland) in the country is 10% lower than other school-based vaccinations.

HIV vaccines will likely not be as effective as either the HPV vaccine or HAART, they may potentially be less acceptable to those who would benefit most from their uptake.

The purpose of this discussion paper is to highlight the lessons learned and best practices from previous public health programs. In order to accomplish this, CAS completed a literature review, hosted a best practices symposium on HIV vaccines, which was targeted to community groups, hosted a satellite meeting at AIDS 2010, and conducted nine key informant interviews with service providers, public health officials and staff working at community clinics. Given that the Canadian epidemic is concentrated in certain identifiable populations, CAS has targeted five key populations for inclusion in this research project, namely gay men and other men who have sex with men (MSM), people who use substances, young women between 18 and 29, members of ethnocultural communities – primarily Canada’s African, Caribbean and Black (ACB) communities – and people living with HIV/AIDS (PLWHIV/AIDS). Recognizing that the epidemic also disproportionately infects and affects Canada’s Aboriginal and indigenous communities, CAS has actively included their feedback and knowledge to address the unique historical and social aspects of health promotion in their rural, reserve and urban communities.

Because an HIV vaccine is not currently available, other vaccines and public health interventions were used as proxies for an HIV vaccine. Interventions were chosen based on their familiarity and availability to the communities concerned in this research project. The interventions include the roll-out of hepatitis B and HPV vaccines, adherence to tuberculosis (TB) prophylaxis treatment, the use of needle exchange and distribution programs (NEPs), and adherence to HAART. Research from Canadian and international HIV vaccine trials and studies on the acceptability of HIV vaccines have also informed this project. During the best practices symposium, lessons were also gathered from other interventions including HIV testing, H1N1 flu vaccination and the work of mobile harm reduction outreach units. Key informant interviews were guided by a draft set of questions that concerned general strategies for HIV prevention and key issues for a vaccine’s potential acceptability in the communities in which our informants live and work. Key informants were asked to draw from interventions with which they were familiar, in addition to those targeted by this project. As a result, discussions touched on condom distribution, direct outreach initiatives and HIV testing, including anonymous testing. This discussion paper will outline the most salient issues raised through the research process, including the primacy of community involvement, the barriers to accessibility that exist for future HIV vaccine deployments and the need to exercise cultural sensitivity in raising awareness of a vaccine.

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# 2

## “Citizens solving community problems”:

### The Value of Meaningful Community Involvement

**The need for meaningful community engagement was identified as the most important issue for any deployment of an HIV vaccine.** Given that we are surely more than a decade away from any such eventuality, this includes community engagement in HIV vaccine trials that might take place in Canada. In this section, the discussion of community involvement and engagement will centre on how communities have been involved, and should continue to be involved, in future vaccine trials, as well as in any future vaccine deployment. Lessons learned and best practices have been compiled from previous research on vaccine acceptability, research into previous vaccine trials and discussions with key informants from the community and from the HIV Vaccine Trials Network, commonly known as HVTN.

According to Ellen and his colleagues, community involvement is especially critical in the early stages of vaccine development because it “help[s] scientists prioritize approaches that have a greater likelihood of facilitating acceptance and use by community members,” if that vaccine were ever licensed.<sup>4</sup> It should also be pointed out that, in addition to facilitating acceptance of the specific vaccine being studied, community involvement helps to identify potential challenges to future licensed vaccine deployments and raises general awareness of the risks and benefits of HIV vaccines, contributing to a better informed community.

Inclusion in vaccine trials could also have the added effect of significantly reducing mistrust and skepticism among communities with a negative history of medical experiments. In Canada, this is particularly true with street-involved and substance using communities, in communities of MSM, in Black populations and in Canada’s Aboriginal communities. One informant from an Aboriginal community suggested that this skepticism, combined with a deep mistrust of the government, would inhibit her community from participating in vaccine trials. This informant added that these same communities would not, however, accept a vaccine that was not tested and proven safe and efficacious among indigenous peoples. An informant from one of Canada’s ethnocultural communities concurred, arguing that while members of his community often harbour a deep mistrust of the government, they need to be represented in vaccine trials in order to ensure that the vaccine is effective for them. In MSM communities, one informant mentioned that some gay men may be

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<sup>4</sup> Jonathan M. Ellen et al., (2010), “Community Engagement and Investment in Biomedical HIV Prevention Research for Youth: Rationale, Challenges and Approaches. Baltimore: Division of General Pediatrics and Adolescent Medicine,” *Journal of Acquired Immune Deficiency Syndromes* (54) S1: S8.

inhibited from participating in vaccine trials for fear of the disclosure of their sexual orientation and HIV status, especially in light of the increasing criminalization of HIV non-disclosure in Canada. Despite the reluctance to participate that lives in these communities, community representatives to the best practices symposium agreed that those recruiting for vaccine trials should not shy away from those perceived to be difficult participants, including the street-involved, substance users, former and current prisoners, and women.

In order to gain the perspective, credibility, expertise and support<sup>5</sup> that meaningful community involvement yields during HIV vaccine trials and that will ensure a successful HIV vaccination campaign, researchers and clinicians will need to negotiate with the communities in which a vaccine will be tested and eventually deployed. Informants were concerned that communities would need to negotiate favourable terms for trials, although one informant did argue that researchers needed to “broker” their research with communities to avoid over-inclusion of low-risk candidates. That said, all agreed that a successful HIV vaccine trial would require knowledge exchange between researchers and community leaders representing vaccine trial sites. They also agreed that it was important for this knowledge exchange to foster collaboration and emphasize the mutual benefit of conducting a vaccine trial.

Perhaps the best model to follow when discussing knowledge exchange between researchers and communities is that championed and developed by the HVTN. Their model, based on the primacy of including community advisory boards (CABs) at each trial site, fosters partnerships with community agencies and organizations that are already respected in the communities in which a trial takes place. In this way, trusted and well-known community members can begin the work of facilitating knowledge exchange between researchers and community members. These “key messengers and trusted voices” not only lay the groundwork that allows trials to take place with community support, but, when the trial concludes, provide long-term follow-up for individuals who received the vaccine, including research updates and health recommendations. Johnston Roberts et al., in a study of community understandings of HIV vaccines, argue that

[c]ommunity forums hosted by respected community agencies may allow researchers to present current and prospective HIV vaccine research, tailored to the community’s cultural and educational background, and allow the community to voice their concerns and beliefs.<sup>6</sup>

Combined with HVTN’s policy of community participation, this approach could provide a culturally-relevant, sustainable support system for communities discussing possible HIV vaccine deployment. The two primary concerns of our community informants – that the community will not be involved meaningfully in the entire process of vaccine development and deployment and that there will be inadequate education throughout this process – could be alleviated through the proper adaptation of HVTN’s community development model, and through the empowerment of community leaders to educate their communities on the risks and benefits of any potential HIV vaccine.

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<sup>5</sup> Susan Bronheim & Suganya Sockalingam, (2003), *A Guide to...Choosing and Adapting Culturally and Linguistically Competent Health Promotion Materials*, (Washington: Georgetown Center for Child and Human Development and the University Center for Excellence in Developmental Disabilities), p. 3.

<sup>6</sup> Kathleen Johnston-Roberts et al., (2005), “HIV Vaccine Knowledge and Beliefs among Communities at Elevated Risk: Conspiracies, Questions and Confusion,” *Journal of the National Medical Association* 97 (12): 1670.

## 2.1 Addressing the Science of Vaccines from a Community Perspective

The first concern for communities will be gaining an understanding of how an HIV vaccine was developed and how that vaccine will and will not protect community members against HIV infection. This means making the basic science of vaccines accessible and providing communities with the knowledge and expertise to maintain and disseminate this knowledge in ways that are appropriate and effective for them. It will also be important to engage regularly in basic plain-language discussions about the process of developing a vaccine, including frank discussions of why vaccines fail, as one did in the case of the Step Study;<sup>7</sup> how a vaccine works in our bodies and the bodies of people with HIV or with co-infections; and the meaning of partial efficacy and the importance of completing a vaccine schedule that requires multiple doses. Communicating the basic science of vaccines has the potential to empower communities at higher risk to recognize the important role a vaccine could occupy among existing prevention strategies.

The first step that scientists and clinicians must take in order to build trust and understanding between themselves and the communities among which they work is to recognize that myths and beliefs about vaccines exist within these communities that they themselves may not understand. According to some informants, fear that vaccines can cause HIV is a significant barrier to deployment. For some, the results of the Step Study, one arm of which was conducted at the Maple Leaf Clinic in Toronto, gave credence to the myth. In a discussion of meeting the needs of Aboriginal communities throughout the research process, the issue of previous failed vaccine trials was mentioned, and in particular the Step Study. One informant said that “since there was a trial that increased the risk of HIV, Aboriginal communities will be hesitant to accept or use an HIV vaccine.” These types of beliefs are not, however, isolated in the Aboriginal community. Scientists and clinicians must find ways in which to adequately dispel these myths and beliefs, without patronizing community members.

In addition to the legacy of failed and potentially harmful vaccines, one of the significant challenges in promoting a vaccine is the belief that a vaccine proffers immunity. Two prominent researchers, Peter A. Newman and Barry Adam, in studying the socio-behavioural aspects of HIV/AIDS, have claimed in recent presentations<sup>8</sup> that it is not unreasonable for people to think that a vaccine would completely immunize them against HIV. Given that we are socialized to believe this from childhood, researchers and community organizations need to address the implications of a widespread belief that vaccines provide immunization from disease. The inevitable media hype and pharmaceutical

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<sup>7</sup> The Step Study, discontinued in 2007, was a Merck Phase IIb trial of its HIV vaccine candidate.

<sup>8</sup> Peter A. Newman did so at the Canadian AIDS Society's Vaccine Preparedness Best Practices Symposium held between 29-30 April 2010 in Toronto, ON and Barry Adam echoed it at the New Prevention Technology ancillary session held prior to the CAHR Conference on 13 May 2010 in Saskatoon, SK.

advertising around any HIV vaccine licensure may exploit this misunderstanding. Communities and community agencies will need to prepare to counter these forces with accurate and accessible information.

The fact is that the first licensed HIV vaccine is unlikely to be as effective in preventing HIV transmission as other vaccines have been at preventing transmission of other viruses. This makes it crucial to have honest conversations about the implications of delivering a partially efficacious vaccine, and indeed about the very meaning of partial efficacy. Research suggests communities at higher risk for HIV transmission, as well as the general public, have differing and varied notions of the term partial efficacy. Perhaps the most widespread belief heard at the community consultation was that a vaccine that was 50% efficacious would work 50% of the time in each individual. “For me, it means that I will be protected Monday, Wednesday and Friday and that I won’t be protected Tuesday, Thursday and Saturday,” claimed a youth delegate, who very clearly demonstrated how partial efficacy might be interpreted and thus affect risk calculations among youth at higher risk. One participant conceptualized efficacy as a form of gambling in which the people with whom she worked would play the odds.

Ultimately, very few participants understood partial efficacy accurately. A partially efficacious vaccine – say 50% efficacious – is one that gives at least 50% of those vaccinated some protection against HIV transmission. Although we are taught that a vaccine provides immunity, in the strictest sense, no vaccine works to completely prevent infection in everyone who is vaccinated. As a result, as our community consultation demonstrated, lay notions of efficacy are complicated, and in order to best address them, clinicians and community educators will have to work together to provide clear and understandable information that promotes an accurate reckoning of efficacy, while dispelling the current misunderstandings of the term.

In addition to the challenge of explaining partial efficacy, communities will need to develop resources and strategies to encourage those who do get vaccinated to complete their vaccine schedule within a reasonable delay. The vaccine tested in the Thai Trial required six doses, and while the first licensed vaccine for HIV will not require so many doses as that, it is not inconceivable that, like HPV and hepatitis B, the first HIV vaccine will require more than a single vaccine dose and perhaps as many as two follow-up shots.

Studies have shown that innovative outreach models targeted to specific health interventions might contribute to better adherence to vaccination schedules. Haley and her colleagues found, in a hepatitis B vaccination outreach project for Montreal’s street-involved youth, that use of “community-based vaccination sites and [the use of an] innovative recall system resulted in almost 80% of this very mobile population receiving at least two doses of vaccine and over 50% completing the hepatitis B vaccination schedule.”<sup>9</sup> This project achieved these results by providing personalized general sexual health and harm reduction information, by accelerating the vaccination schedule to four months, rather than the standard six, by developing and employing a creative reminder system and offering incentives for adherence. This is remarkable in a cohort of individuals who are often mistrustful of authority and generally itinerant.

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<sup>9</sup> Nancy Haley et al., (1998), “A Hepatitis B Vaccination Outreach Project for Street Youth in Montreal,” *Canadian Journal of Human Sexuality* 7 (4): 337.



Working outside the confines of traditional health provision in this way not only helps target the most marginalized. Hassle Free Clinic has shown that it works in more stable communities as well. A community sexual health centre in downtown Toronto, Hassle Free Clinic, has also found that using an alternative model has made their practice successful. Through the use of peer workers and non-medical staff, the clinic has achieved a near perfect vaccination completion record for hepatitis A and B. Leo Mitterni, who heads the program, credits the results to the empowerment of non-medical staff to provide medical services to their peers in a safe space and to the relaxed atmosphere in which people who miss their follow-up appointments are simply vaccinated at a later date.

Preparing communities for an eventual HIV vaccine deployment by illuminating the science of an HIV vaccine, explaining partial efficacy and valorizing strategies that demonstrate an investment in ensuring that individuals complete their dosing schedules could bridge the gaps among researchers, clinicians and communities of individuals at higher risk for HIV transmission. This demonstration of a commitment to collaboration would, at the very least, begin to emphasize that everyone is working toward a common goal. Demystifying HIV vaccine science provides researchers and clinicians, and community leaders an opportunity for knowledge exchange and will help to build long-term partnerships. And ultimately, involving researchers and clinicians in community discussions of vaccine science, partial efficacy and the importance of following a dosing schedule now makes good sense. There is both time and resources to prepare for a vaccine, given that licensure is some time away.

# 3

## “Go where people are”: Lowering Barriers to Vaccines

**Accessibility to an HIV vaccine and to information about an HIV vaccine is a serious concern among community groups who work with populations at higher risk for HIV.** Without minimizing the unique barriers to access faced by each of these communities, there are, nevertheless, observed trends among these populations. Given that few people identify solely with one of the communities that have been approached during this project, it is not unusual that the barriers to access would be echoed in each of the populations. That said, accessibility concerns largely centre on issues of standardized access to a future vaccine, on the need for a vaccine to be affordable, and finally, on issues of consent, confidentiality and anonymity. Admittedly, this is not an exhaustive list of barriers to access of future HIV vaccines. Closer to the moment at which a vaccine has been developed, there will be a need for further work to identify barriers, not only among the targeted communities, but in communities with unique challenges to vaccine preparedness and promotion, including Aboriginal and rural and remote communities.

Geography emerged as a significant barrier to access for a future HIV vaccine. Disparities in service provision between urban and rural Canada, in addition to disparities among the provinces, were both signaled as barriers to equitable access to a future vaccine. As one informant working in a rural ASO with a service area roughly the size of France mentioned, a future vaccine must be accessible in as many areas as possible, rather than just in urban and regional centres. This is especially necessary for Canada’s Aboriginal communities, where health care provision is sparse and where past public health interventions, especially those that may not affect all residents, have had limited availability. In a thought experiment about accessing HIV testing and HIV vaccination, one key informant described vividly the barriers to vaccine uptake in the indigenous communities she serves. Geography played a key role in this experiment: “If I was out in the small community [...], where the heck am I going to go [...] if I’m poor and I’m not working [...], how am I going to get to town?” On reserve, it is not unusual that residents must leave their communities in order to receive health care in larger centres. In other rural and remote communities, where access to health care services in general is limited, access to sexual health services is further limited by a dearth of specialized care and of family physicians.

There was also serious concern about maintaining a standard of accessibility, not only between rural and urban Canadians, but across provinces as well. Both HPV and hepatitis B vaccination costs vary among provinces, despite the federal government’s commitment to childhood universal vaccination for both viruses. While all girls are eligible for school-based vaccination for HPV, and while all infants are now vaccinated against hepatitis B, free access to the vaccines in the rest of the

population is not standardized in Canada. In all Canadian provinces, those who are not covered by the school-based scheme and who do not have private insurance cannot get subsidized access to the HPV vaccine. In some Canadian provinces, hepatitis B vaccination is only available to those communities deemed at high risk.

Not surprisingly, one of the most frequently cited barriers to access for any future vaccine was the financial cost of the vaccine and the added cost of transportation and child care associated with a trip to the clinic. As one informant put it succinctly, when asked about the costing of a future vaccine: “It’s gotta roll out free. Or cheap.” This was seconded by an informant working among street-involved communities when commenting on their likelihood to pay for a vaccine: “If you’re homeless, living on the streets of [Canadian city], if you do have 400\$, you’re likely not going to spend it on a vaccination.” The significant cost of the HPV vaccine has hampered uptake in women who were not covered by the school-based program. To avoid this in future deployments of an HIV vaccine, HIV vaccines must be financially accessible to communities. While this is generally true, it is especially important among those communities with large numbers of undocumented immigrants who do not have access to free health care and in provinces where a vaccine is not covered by the provincial health plan. Even if cost does not inhibit uptake in most of Canada’s communities, it will do so for those that are poor, for women relying on their partners’ private health insurance and for youth wishing to get vaccinated without parental consent. A belief in equitable access demands that everyone be able to access the vaccine.

**A belief in equitable access demands that everyone be able to access the vaccine.**

In addition to geography and cost, the denial of the request for a vaccine was also cited as a possible barrier to roll-out of an HIV vaccine. One informant shared an extreme example in which the young women that she supports are sometimes discouraged from testing for HIV because their health care providers do not believe them to be at risk. Most examples of difficulty in accessing interventions and relevant information came, however, from discussions of positive individuals who had been denied access to appropriate and applicable sexual health information by their health care providers. This was often as a result of ignorance or through deliberate silence. In discussions of HAART uptake and adherence, there were several participants, especially among youth representatives, who suggested that HIV-positive youth in some instances were not getting adequate, current information about HAART treatment in an effort to encourage them to begin HAART as soon as possible.

The British Columbian government’s recent decision to fund a program called Seek and Treat for Optimal Prevention (STOP) may fuel calls in some quarters for more widespread implementation of this model in other public health interventions. Treatment as prevention has been championed most vocally in BC by Dr. Julio Montaner as a means to reduce the spread of HIV, but is interpreted by many youth – and others – as a paternalistic way to control what is perceived as their irrepressible sexual desires. It is plausible that similar programs might be supported by government when an HIV vaccine is available, as clinicians attempt to offer blanket vaccination to people deemed at higher risk for infection, as STOP attempts to do with HAART treatment. An informant working in Vancouver claimed that this has been a perennial problem with previous public health interventions, especially flu shots, as street nurses descend on the Downtown Eastside to vaccinate as many residents as possible. When an HIV vaccine becomes available, those accessing information on the vaccine will need to be encouraged to advocate for themselves and their right to decide whether vaccination is an appropriate option for them. Programs

for those who cannot advocate for themselves will have to be developed to ensure that complete and appropriate information on the vaccine is provided to everyone who requests it.

Youth are particularly vulnerable to access barriers to medical treatment. In the case of a future HIV vaccine, youth are hampered by the requirement to seek consent from their guardians. In their current form, Canadian laws do not provide clear directives for health care providers regarding youth's ability to consent to vaccination. Canada's provinces are guided by a body of common law that relates to medical consent (Taylor 2008). The consensus in the literature is that people "fourteen years or older are generally competent to consent to medical treatment,"<sup>10</sup> although whether vaccines qualify as medical treatment is uncertain. While Canadian law often informally recognizes that youth of fourteen years or older can make decisions about their own health, it attaches the ability to consent to an ability to understand the consequences of an intervention, rather than to the youth's age. This leaves even those youth older than fourteen vulnerable to interference from others.

In a survey of how mature minors were treated during the initial years of school-based HPV vaccination, only British Columbia recognized the rights of mature minors to consent to the vaccination for themselves (Health Link BC, 2009). That said, the guidelines concerning vaccinations that govern health professionals in that province could serve as a model for a future HIV vaccine for the rest of the country. Work to harmonize laws and policies on consent will need to be done prior to the deployment of an HIV vaccine so that youth feel empowered to take responsibility for their health without fear that their decisions will be known by their parents, if they do not wish them to be.

Finally, the last access barrier to an HIV vaccine is the potential for a lack of anonymity and confidentiality associated with vaccination. This was especially of concern among rural and remote participants and informants who access health care in environments where everyone knows one another. Lack of local access to health care in remote and reserve Aboriginal communities often leads to failed maintenance of anonymity and confidentiality when residents must leave their communities to access health care in the nearest centre. Confidentiality and anonymity in accessing previous public health interventions have also been compromised, which suggests that these barriers to confidentiality and anonymity may be issues when HIV vaccines are available. Currently in some provinces, hepatitis B vaccination, if it was not received in school, requires that those seeking free vaccination disclose their membership to a higher risk community, forcing them to reveal their sexual orientation, their housing status and/or their substance using behaviours. The rights of youth to confidential medical care are particularly vulnerable to compromise, especially if they are required to seek the permission of their parents to be vaccinated. If a youth must disclose his desire for a vaccine to his parents, a queer youth could be forced to emerge from the closet before he is ready, or a straight youth under duress could be coerced into revealing to her parents details about her sexual life and substance using behaviours. Such situations must be avoided. Ensuring access to confidential and, where possible, anonymous HIV vaccination for everyone who requests it, even in smaller communities, will mean that disclosure of sexual or drug using behaviours will not be required.

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<sup>10</sup> Catherine G. Taylor, (2008), "Counterproductive Effects of Parental Consent in Research Involving LGBTTIQ Youth: International Research Ethics and a Study of a Transgender and Two-Spirit Community in Canada," *Journal of LGBT Youth* 5 (3): 38.

### 3.1 Strategies to Eliminate Barriers to Accessibility

While significant access barriers to public health interventions remain, there are currently programs in Canada that have eliminated some obstacles to access. Many of these could be useful in creating models for future HIV vaccination deployments in the communities served. Models that engage peers in health promotion and harm reduction in their communities are arguably the most effective at increasing access to both public health information and public health interventions. Small and his colleagues, in a paper on the Washington Needle Depot, a needle distribution program of the PHS Community Services Society that is staffed by current and former substance users, suggest that peers are the key to providing public health interventions to the most vulnerable. Describing the Washington Needle Depot, Small et al. argue that employing substance users meant “[r]ecognizing that their experiences provided them with a unique insight and ability to deliver peer-based harm reduction services, including being easy to approach by IDUs seeking services.”<sup>11</sup> A key informant working in a community clinic echoed this, suggesting that peer outreach workers serving the street-involved in Toronto were integral to their outreach program’s success because “they have so much expertise.” This advice will be essential in promoting an HIV vaccine among the most marginalized because it will assist them in seeking information and making informed decisions about their own health care.

While peer-driven models have shown successes, programs that provide information and interventions with cultural competence and sensitivity have also proven successful in Canadian cities. These programs generally take a holistic approach to health, offering food, materials for safer sex and harm reduction, counseling, and referrals for more specialized services. Many of them employ mobile units. One of the more innovative programs is called Papalooza. Run twice a year from community centres and shelters in Vancouver, the program provides free Pap tests, as well as confidential health information and a free lunch, to the city’s most marginalized communities. Vaccination could be streamlined into this program and would allow women to keep their desire for a vaccine confidential. Given that the epidemic has an increasingly female face – in 2009, 26% of newly diagnosed cases of HIV were in women<sup>12</sup> – it will be imperative that vaccination campaigns provide ample safe opportunities for women to access the vaccine and information about vaccination. Papalooza could be one of these opportunities.

Models that engage community leaders and partners that have influence in communal and social space have also shown success. Operation Hairspray, an initiative of Ottawa Public Health, successfully trained nineteen peer volunteers who own hair salons and barber shops across the city in an effort to communicate HIV prevention messages to Ottawa’s African and Caribbean communities. The program trained volunteers to identify teachable moments and deliver HIV/AIDS prevention messaging to clients at their discretion. It also encouraged them to distribute condoms and print materials however they thought most appropriate. Barbers and hair salons were

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<sup>11</sup> Dan Small et al., (2010), “The Washington needle depot: fitting healthcare to injection drug users rather than injection drug users to healthcare: moving from a syringe exchange to syringe distribution model,” *Harm Reduction Journal* 7 (1): 5.

<sup>12</sup> Public Health Agency of Canada, (2010), *HIV/AIDS in Canada: Surveillance Report to December 31, 2009*, (available: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/2009/dec/pdf/2009-Report-Rapport.pdf>).

identified as important social and meeting places for these communities, and owners were engaged by Ottawa Public Health “in a way that work[ed] for them and at a pace that work[ed] for them.” This type of program could be a model for others who want to use trained peer volunteers to do outreach in places where communities congregate.

In addition to using peer-driven and mobile models to deliver public health information and interventions, accompaniment programs could reduce access barriers in certain communities and provide additional support for individuals who seek and need access to health information and interventions. A community representative from New Brunswick who works closely with PLWHIV/AIDS cited a court support program at her organization that provides accompaniment for women involved in the court system. She suggested that a similar medical support program could easily be developed to promote HIV vaccination.

All of these programs assume, however, that those at highest risk want to, or feel that they can, access these programs. Participants acknowledged that there are often self-induced barriers to accessing information and interventions. One community representative revealed that he often struggled with clients who had access to the best services available and continued to remain apathetic about their health. There was a consensus among consultation participants that other strategies would have to be devised to respond to these individuals at the point at which they had arrived in their desire for vaccine information and vaccine uptake.

Regardless of the way in which an HIV vaccine is deployed, confidentiality must be respected when a vaccine is available, in both rural and remote settings, as well as in urban centres. In fact, the provision of widespread anonymous vaccination across the country would be ideal. Equitable access must, furthermore, be assured insofar as cost is concerned. Lessons learned from hepatitis B vaccination especially demonstrate that providing free access to some groups and not others provides unequal access to prevention strategies and poses a significant problem of disclosure and privacy. In addition to equity of access, previous experience has revealed that there must be equitable access to information, which means ensuring it is relevant to each individual and community. Clinicians, counselors and peer workers must commit to the non-judgmental and objective provision of relevant information for those seeking an HIV vaccine.

### **3.2 “There will always be stigma”: Stigma as a Barrier to Access**

Community members agreed that stigma remains a significant barrier to effectively preventing the transmission of HIV. This stigma, if not addressed adequately before a vaccine is licensed, will be a further barrier to open discussion of an HIV vaccine as a viable means of preventing the spread of HIV. Despite the fact that not a single participant questioned the value of a vaccine, many participants re-iterated that their clients and their communities might not necessarily seek vaccination. Here, our community participants are supported by literature on HIV

**In addition to equity of access, previous experience has revealed that there must be equitable access to information, which means ensuring it is relevant to each individual and community.**

vaccine acceptability. Rudy et al., in the context of an HIV vaccine acceptability study, found that while a vaccine was perceived positively, stigma was often cited as a barrier to access among women at risk. This sentiment was perhaps best articulated by one of their key informants, who in her musings on the subject, said,

I imagine there would be a lot of people that would want to get it [the HIV vaccine], but would not want anybody to know that they felt that they were at risk. They could admit it to themselves, but nobody else could even come close to guessing.<sup>13</sup>

Among the African, Caribbean and Black community members that we consulted, several participants echoed Rudy's informant. Two working in Ontario admitted that in their communities, the perception would be that a woman deciding to get vaccinated against HIV must be doing something terrible to need to get a vaccine. It is unclear what the perception of a vaccine would be among men in these communities. MaBwana, a study on HIV prevention and Black, gay and bisexual men in Toronto, did not directly discuss the potential acceptability of an HIV vaccine. It did, however, conclude that MSM in the ACB community in Toronto "demonstrate concern about HIV/AIDS among Black gay men and their communities, and did articulate a commitment to HIV prevention."<sup>14</sup> Presumably, this would include support for an HIV vaccine, although there is a need to study this in more depth to gauge vaccine acceptability among these populations.

In rural and remote communities, stigma comes both in the form of denial and in the form of discriminatory assumptions. As one informant claimed, his community believes itself to be Petticoat Junction, a reference to a 1960s sitcom about a pastoral town in America's Midwest with few social problems. Another described the difficulty of raising awareness of HIV in a remote community by claiming that "people don't think that there's anyone with HIV here." This individual added that "people still think that HIV is a gay disease," explained that stereotypes overcome years ago in other cities are still a challenge in her community, and that her organisation is "still trying to fight to [...] prove them wrong. This perception that HIV only happens to others ("othering") is an explicit form of stigma and constitutes a significant barrier to providing a vaccine. If a community does not believe itself to be at higher risk, despite evidence to the contrary, there will be resistance to providing and accepting prevention, including a vaccine.

Stigma is not, however, just a challenge in rural Canada. Despite the revelation of the increased vulnerability to HIV in Canada's ACB communities,<sup>15</sup> stigmatization of those who are HIV-positive remains a major issue in these mainly urban populations. According to one informant, stigmatization of PLWHIV/AIDS is so strong in some ethnocultural communities that positive women refuse accompaniment to their doctors' appointments, even if this means a reduced understanding of their health status and their treatment options. An informant that works closely with prisoners and former prisoners highlighted that the stigma associated with HIV had the potential to interfere with the HAART adherence of those currently serving sentences in Canada's prisons and jails. His clients often

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<sup>13</sup> Ellen T. Rudy et al., (2005), HIV Vaccine Acceptability among Women at Risk: Perceived Barriers and Facilitators to Future Vaccine Uptake," *AIDS Education and Prevention* 17 (3): 260.

<sup>14</sup> Winston Husbands et al., (n.d), *MaBwana; Health, Community and Vulnerability to HIV among African, Caribbean and Black Gay and Bisexual Men in Toronto*. Toronto: The African and Caribbean Council on HIV/AIDS in Ontario and the AIDS Committee of Toronto, 71.

<sup>15</sup> According to PHAC's *HIV/AIDS in Canada*, (2009), positive test results in the Black community rose from 7.3% in 2002 to 11.6% in 2009.

claimed that they could not disclose their serostatus in prison for fear of reprisals among inmates. Indeed, many often asked for solitary confinement while in prison in order to take their medications safely.

In addition to tackling stigma around HIV, strategies to ramp up efforts to lessen stigma around homosexuality, substance use and incarceration will also have to be reinforced. A key informant working with street-involved communities in Toronto cited the rampant homophobia in this community as a barrier to disseminating HIV information and prevention materials that could eventually affect the uptake of a vaccine among her clients. Often those who have been tested and received positive test results would prefer people think they had cancer rather than HIV for fear of being labeled as gay, which often attracts violence in that particular community. A key informant who works with immigrant women living with HIV claimed that her clients were not comfortable accessing HIV treatment at exclusively HIV-focused health centres. They did not want to expose themselves or their children to either MSM or people who use substances and who are also receiving treatment at the same clinic. It should also be noted that former prisoners, in addition to MSM and people who use substances, also face stigmatization among their communities upon their release from prison. In contrast to prison, where they are stigmatized for their infection, on the outside, one key informant related that former prisoners face and fear discrimination because of their previous incarceration. One participant at the community consultation who works with these communities explained that often prisoners seeking treatment in Toronto's ASOs would not disclose their previous prison involvement for fear of stigmatization.

Breaking down stigma and discrimination around HIV, homosexuality, substance use and incarceration would embolden individuals from these groups who desire an HIV vaccine, to seek out information in order to make informed decisions about their health. Continued efforts to eliminate stigma must be maintained and reinforced. The general consensus among consultation participants was that messaging around an eventual vaccine must be as generalized as messaging for other matters of public health, such as H1N1, hepatitis A and B boosters and malaria tablets. Generic public health messages that include people of all genders, ethnicities and ages would help to reduce stigma around asking for information about an HIV vaccine. Inclusive awareness campaigns would allow everyone to think of themselves as at risk, rather than passively categorizing an HIV vaccine as a prevention method best suited for someone else.

**Breaking down stigma and discrimination around HIV, homosexuality, substance use and incarceration would embolden individuals from these groups who desire an HIV vaccine, to seek out information in order to make informed decisions about their health.**

## “Losing sight of prevention strategies”:

### Ensuring Standards of Prevention

**When it is on the market, a vaccine against HIV should not be promoted as the only prevention method available.** As one prominent researcher in the field argues, “HIV vaccines need to be conceived as part of the landscape of existing HIV preventive interventions,”<sup>16</sup> and must leave no room for the notion of a vaccine as a stand-alone solution to the problem of HIV/AIDS. Our informants actively wondered how an HIV vaccine would affect current risk reduction methods and current HIV prevention programs that are provided in their communities. Community informants were particularly worried about an increase in risk compensation and about the need to, and difficulty of, incorporating a vaccine into general prevention strategies.

Risk compensation is one of the most important reasons for maintaining and reinforcing current standards of HIV prevention before, during and after the deployment of any future vaccine against HIV. Risk compensation – or the reality that people evaluate and adjust their willingness to engage in risky behaviours based on new knowledge and understandings – is a significant consideration when introducing new prevention measures into the landscape of existing prevention technologies and strategies. New and effective methods inevitably cause those who use them to reevaluate their willingness to engage in activities of high risk.

When discussing HIV, this includes risky sexual behaviours – condomless sex, sero-positioning and sero-sorting – and re-using or sharing substance use paraphernalia for those who use substances. The introduction of a vaccine into the prevention landscape has the potential to have a significant impact on risk compensation in communities already at higher risk for infection. Community members present at our consultation were well-versed in the potential reevaluation of risk behaviour that could occur among their clients in the face of an HIV vaccine.

One of the common themes identified among the interventions was the concern that previous prevention strategies would be lost in the discovery and licensure of new prevention methods. This concern was raised during the HPV vaccination in Canada in 2007, when some women’s groups, including the Canadian Women’s Health Network, were concerned that promotion and uptake of Gardasil, Merck’s HPV vaccine, would increase rates of cervical cancer as a result of

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<sup>16</sup> Peter A. Newman, “HIV Vaccine Social Research,” presentation at CAS Vaccine Preparedness Best Practices Symposium, Toronto, ON., 29-30 April 2010.

“misunderstandings about what the vaccine does and does not do, [which could lead] to reductions in safer sex practices and Pap screening rates.”<sup>17</sup> In contrast, Short and her colleagues found that most women did not think that other women would change their sexual behaviour after receiving the HPV vaccine, although some did suggest that an “increase [in risk behaviours] would be limited to select groups of individuals, such as younger or uneducated people.”<sup>18</sup> Given that the HPV vaccine is relatively new and many of those who have been vaccinated have yet to reach the age of sexual debut, statistically significant data on this issue has yet to be gathered.

In addition to the questions raised by the HPV vaccine, some evidence has been generated on the potential effect of vaccination on risk compensation during clinical trials of HIV vaccines. There is, however, a tension in the literature. In a study of subjects enrolled in phase I and phase II clinical trials in 1997, Chesney and his colleagues determined that rates of unprotected anal intercourse rose from 9% to 20% among trial participants, despite participants having been cautioned that the vaccine would not protect them from contracting or transmitting HIV.<sup>19</sup> In a Phase III trial of the vaccine candidate VAX004, results indicated that MSM who believed they had received the vaccine “consistently reported a greater amount of unprotected anal sex”<sup>20</sup> than those who did not believe they had received the vaccine. However, research based on Canadian participants in the same trial demonstrated that there was “no significant change in high risk unprotected receptive anal intercourse between enrolment”<sup>21</sup> when compared to follow-up consultations.

Despite the results of the HPV acceptability study that indicated that the potential for risk compensation was low and the Canadian study that revealed no increase in risk compensation during the VAX004 trial, it will, nevertheless, be important to emphasize the maintenance of safer sex and harm reduction practices, especially to avoid an increase in other STIs and hepatitis C. Messaging will need to simultaneously highlight the benefits of vaccination, while stressing the need to maintain current safe practices after the vaccine has been administered. Especially if the vaccine is only partially efficacious, it will be imperative that those who are vaccinated understand that they remain at some risk for HIV infection and should take as many precautions against transmission as their circumstances allow.

One of the greatest threats to maintaining prevention messaging and reducing the effects of risk compensation after the introduction of a vaccine will be the development and spread of mythologies around vaccination. Two key informants working for a community clinic specializing in gay men’s health highlighted the importance of community mythologies to risk perceptions and prevention strategies in the community they served. The prevalent belief in the validity of sero-sorting and sero-positioning, strategies in which gay men either position negative partners on top during sex or have sex exclusively with partners of the same sero-status, highlights the presence

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<sup>17</sup> Abby Lippman et al., (2007), “Human Papillomavirus, vaccines and women’s health: questions and cautions,” *Canadian Medical Association Journal* 177 (5): 486.

<sup>18</sup> Short et al., (2010), “Adult Women’s Attitudes, op.cit., 1308.

<sup>19</sup> M.A. Chesney et al., (1997), “Risk behavior for HIV infection in participants in preventive HIV vaccine trials: A cautionary note,” *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 16: 271.

<sup>20</sup> B. N. Bartholow et al., (2005), “HIV Sexual Risk Behavior over 36 Months of Follow-Up in the World’s First HIV Vaccine Efficacy Trial,” *Journal of Acquired Immune Deficiency Syndromes* 39 (1): 97.

<sup>21</sup> T.M. Lampinen et al., (2005), “Sexual risk behaviour of Canadian participants in the first efficacy trial of a preventive HIV-1 vaccine,” *Canadian Medical Association Journal* 172 (4): 482.



of “quite a bit of information that gets...passed around on the street [...] without people having much actual knowledge” about the particular strategy. Given the perception that vaccines offer immunity to those who receive them, there is a likelihood that myths and beliefs that those who are vaccinated against HIV cannot transmit or contract the virus will spread. As less rigid safer sex and substance using behaviours become more commonplace, a new form of sexual sorting may arise as well, increasing the risk of infection in both those who are vaccinated and those who are not.

It will be important to develop new strategies to incorporate an HIV vaccine into the wider prevention dialogue. Discussions should encourage individuals and communities “to recognize that it [a vaccine] won’t be perfect and [...] will present its own set of challenges” that need to be addressed. Community workers and health care professionals will need to be briefed on how to effectively educate their clients about a vaccine that is partially efficacious and requires multiple doses. They will also need to be educated on the socio-behavioural consequences those two issues will present with respect to transmission among those adopting the vaccine as a prevention strategy. These subjects cannot be disconnected, and the communities that will be especially interested in vaccine promotion and uptake will need to be involved in the development and delivery of these new strategies in order to make them optimally effective.

# 5

## “We need stuff that’s pretty snappy”:

### Raising Basic Awareness of Vaccines with Cultural Competence

**Given the lack of appropriate education materials identified in the five interventions examined, the development of adequate education and awareness-raising materials and resources was signalled as one of the most important common elements, and thus a key issue in the effective roll-out of an HIV vaccine.** In the interest of a holistic, inclusive approach, education was loosely defined to include everything that might be relevant to preventing HIV and promoting awareness and possible uptake of an HIV vaccine in those most vulnerable to infection. The two most-frequently cited ways of preparing for a vaccine roll-out included raising basic awareness and using cultural competence to do so effectively.

#### 5.1 “Save the Humans! Get Vaccinated!”: Raising Basic Awareness

Community-driven strategies that raise awareness and make campaigns personally relevant, while avoiding the stigmatization of one group, are key strategies for raising basic awareness of the value of an HIV vaccine. One of the strategies that community members outlined was the involvement of communities in developing the materials that will eventually be disseminated in their organizations. While this seems obvious, previous public health interventions indicate that health promotion materials, campaigns and resources have not been community-driven. A study of hepatitis B vaccination risk perception in MSM communities in North America revealed that “[p]articipants lacked sufficient knowledge of HBV to adequately judge the severity of, and their susceptibility to, infection.”<sup>22</sup> This occurred despite the obvious risk to which their community is exposed and the fact that “participants acknowledged that they received some information about HBV in the form of posters and brochures at bars.”<sup>23</sup> This same research revealed that while many MSM were being bombarded at public events and in the bars they frequented with information about the risks of hepatitis B infection, outreach materials “were not tailored to attract their attention and did not provide practical information about local resources and sites for vaccination.”<sup>24</sup> Researchers argued that this did not personalize the risk of infection, leaving the population no better informed about the benefits of the hepatitis B vaccine.

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<sup>22</sup> S.D. Rhodes & K.C. Hergenrather, (2002), “Exploring Hepatitis B Vaccination Acceptance among Young Men who Have Sex with Men: Facilitators and Barriers,” *Preventive Medicine* 35: 130.

<sup>23</sup> Ibid 132.

<sup>24</sup> Ibid 130.

In a discussion of how to promote testing and the use of prophylaxis among those who test positive for TB, similar issues were raised. Community informants reiterated the benefit of harnessing community resources to raise awareness. The literature on the subject suggests how this might be accomplished. Gibson and her colleagues, in an examination of the socio-cultural factors that influence prevention of TB, agree that using “lay resources – people recovered from TB, family members of recovered patients, [and] lay health communicators”<sup>25</sup> – might shift perspectives and increase awareness. Furthermore, San Sebastian and Bothamley observe, that “subjects might pay greater attention to explanations that were personally relevant.”<sup>26</sup> The lay educators that Gibson and her colleagues recommend would provide culturally and perhaps even personally-relevant information regarding how to recognize and treat TB effectively, just as San Sebastian and Bothamley suggest. These types of strategies might increase participation in beneficial public health programs, such as the roll-out of an HIV vaccine.

While it will be important to personalize messages, this must not isolate one single group as the target of messaging. When asked about how HIV vaccine awareness should be raised, one key informant, who works with the ACB community in Toronto, insisted that the central message in any campaign needs to be inclusive and claimed that, “[i]f it [a vaccine] is used, let it be used by everyone.” This appeared to be what members of the ACB community in general identified as the proper messaging for an HIV vaccine. The current racialization of the epidemic in the media and the focus of efforts to halt its spread in the countries of sub-Saharan Africa – countries from which many of our informants once emigrated – underlies their desire to paint a generalized portrait of the epidemic.

The characterization of the problem of HIV as an African issue only further discourages an honest discussion of HIV prevention in the wider Canadian context. A participant at the community consultation insisted several times that stigma must be addressed by positioning HIV as a public health issue that is everyone’s responsibility. Some participants to the community consultation, as well as several key informants, called for the normalization of discussions of HIV and future prevention options, including a vaccine, among communities and families, and between patients and physicians in order to universalize the issue. One informant from an Atlantic province who has done outreach in local schools found that youth were not receptive to prevention messages because of the widespread notion that AIDS is not a local issue, despite the presence of PLWHIV/AIDS in their community. In addition to increasing risk for transmission in this population, this informant signaled that this misperception further stigmatized those who were already infected by denying their very existence.

**It will be important to develop new strategies to incorporate an HIV vaccine into the wider prevention dialogue. Discussions should encourage individuals and communities “to recognize that it [a vaccine] won’t be perfect and [...] will present its own set of challenges” that need to be addressed.**

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<sup>25</sup> Nancy Gibson et al., (2005), “Socio-Cultural Factors Influencing Prevention and Treatment of Tuberculosis in Immigrant and Aboriginal Communities in Canada,” *Social Science and Medicine* 61: 940.

<sup>26</sup> M. San Sebastian and G.H Bothamley, (2000), “Tuberculosis Preventive Therapy: Perspective from a Multi-Ethnic Community,” *Respiratory Medicine* 94: 652.

It is clear that awareness campaigns around an HIV vaccine will need to be thoughtfully considered to ensure everyone can make the decision as to whether an HIV vaccine will strengthen their ability to prevent infection. Peer-to-peer outreach will surely be one of the ways to spread the word. One key informant urged that when a vaccine is ready, we must “[r]eally think about outreach planning in conjunction with campaign planning more broadly as a key component” in order to maximize community outreach. Public awareness campaigns need to speak to their audience in a way that is engaging and provides the needed information. As one participant commented, when thinking of how this lesson can be applied to an HIV vaccine, an HIV “[v]accine introduction requires ‘good,’ effective education campaigns.” As another claimed, “[w]e need stuff that’s pretty snappy. It has to be pretty creative.”

## 5.2 “Consider that each group has its own way to be”: The Need for Cultural Competence

To make awareness campaigns effective, they must be undertaken with a commitment to cultural competence. This includes ensuring the engagement of community members and opinion leaders and covers linguistic, spiritual and cultural inclusion. Again and again, community informants indicated that any dissemination of information on vaccines whether in print, on the radio, internet or on television must “be sensitive to language barriers.” This includes ensuring access to materials in both English and in French in all of Canada’s provinces and territories, as well as in minority languages in ethnocultural communities and in Aboriginal, Métis and First Nations communities. As one key informant indicated, education and awareness-raising materials must be “in the languages we use.”

Research has shown that ineffective public health messaging often fails to acknowledge the important role language plays in the internalization of information. In a study conducted among the United Kingdom’s major immigrant communities, Marlow, Forster and Waller found that immigrant women who had the least awareness of HPV were those who did not speak English at home.<sup>27</sup> A similar observation was made in a study by Wagner among the United States’ Spanish-speaking populations. She found that the inability to speak English is “cited most frequently as the greatest obstacle for proper health care”<sup>28</sup> among the populations with whom she works.

The strong correlation with basic understanding and language further underlines the need for any messaging around an HIV vaccine to be linguistically accessible to all Canadians. This would not only include making information available in languages other than English, but would also extend to the common language used in different communities. Awareness-raising needs to be done

**It is clear that awareness campaigns around an HIV vaccine will need to be thoughtfully considered to ensure everyone can make the decision as to whether an HIV vaccine will strengthen their ability to prevent infection.**

<sup>27</sup> Laura A.V Marlow, J.Wardle, A.S Forster and J. Waller, (2009), “Ethnic Differences in Human Papillomavirus Awareness and Vaccine Acceptability,” *Journal of Epidemiological Community Health*, 63: 1010-1015.

<sup>28</sup> Janette Wagner, (2009), “Barriers for Hispanic Women in Receiving the Human Papillomavirus Vaccine: A Nursing Challenge,” *Clinical Journal of Oncology Nursing* 13 (6): 672.

and awareness materials need to be available in plain language and using the idiom of that particular community to guarantee that even those whose only language is English have access to information that engages them. Many of the communities that will be targeted by future HIV vaccines are marked by low education levels and poverty. We must ensure that these do not create barriers in accessing information that will help them decide whether to get vaccinated against HIV or not.

**“[i]f it [a vaccine] is used, let it be used by everyone.”**

In addition, vaccine deployment, and the materials that explain it, must be supported by the community’s spiritual leaders. As Newman and his colleagues from Women’s Health in Women’s Hands discovered in an investigation of the HIV prevention discourse among Black women in Canada, “unless it comes from the pulpit, it is not happening.”<sup>29</sup> An informant to the best practices symposium echoed these comments and claimed that “[a] vaccine for HIV must absolutely consider the community’s involvement, as well as consider its religious, spiritual and cultural traditions.” Sensitivity to a community’s spiritual traditions is not, however, the exclusive right of Canada’s ethnocultural populations. The very first article in the guidelines set out by Canada’s Institutes of Health Research (CIHR), which guides how research should be conducted among Aboriginals in Canada, stipulates that researchers need to “understand and respect Aboriginal world views, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge.”<sup>30</sup> Reinforcing existing best practices that govern research in trials and health care provision during the deployment of an actual HIV vaccine will help begin to address the legacy of mistrust that exists in many of the populations targeted by this research.

Culture includes the mores, values and history of communities in addition to their language and spiritual traditions. As one community participant mentioned at the symposium, “[c]ultural and ethnic awareness are key factors in planning for the delivery of a vaccination program.” In Canada’s ethnocultural communities this entails not only engaging opinion leaders and training them to deliver public health messaging in their neighbourhoods, spiritual spaces and gathering places, but more importantly, includes harnessing their knowledge of their own culture to guarantee relevance. Moreover, this must be done in a way that promotes health and healthful living, as Bronheim and Sockalingam argue in a guide to developing culturally competent health promotion:

A key challenge in health promotion with diverse populations is honoring traditions and beliefs of the intended audience, while recognizing that some of those beliefs and practices may not be congruent with emerging knowledge of what supports healthy outcomes. Culturally competent health promotion supports and honors those practices and beliefs that are protective or benign, and respectfully helps identify and change those beliefs and practices that have a negative health impact.<sup>31</sup>

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<sup>29</sup> Peter A. Newman et al., (2008), “HIV Prevention for Black Women: Structural Barriers and Opportunities,” *Journal of Health Care for the Poor and Underserved* 19: 837.

<sup>30</sup> Canadian Institutes of Health Research, (2007), *CIHR Guidelines for Health Research Involving Aboriginal People*,” (complete guidelines available <http://www.cihr-irsc.gc.ca/e/29134.html> accessed 9 August 2010).

<sup>31</sup> Bronheim & Sockalingam, (2003), *A Guide to...Choosing and Adapting Culturally and Linguistically Competent Health Promotion Materials*, op.cit., 3.



It is important to recognize that while clinicians, researchers and community advocates and workers must change beliefs and practices, they must not do so in judgment of others and must only offer help when it is solicited.

In Canada's MSM population, cultural competence includes the recognition that such an identity is not uniform. While this is true of all the groups included in the research for this project, it came up in particular with several key informants in discussions about MSM and identity. To assist MSM in internalizing intended messages, one of the unique considerations isolated for this population was the need to understand that there are MSM sub-communities— including non-gay identifying MSM – within the larger MSM community that may need specifically targeted awareness campaigns. This was underscored in a study of HIV prevention among Toronto's ACB MSM, in which many Black men who have sex with men do not identify as gay and therefore might not consider campaigns directed at Black gay men relevant to them. Understanding this subtlety in self-identification and its impact on how HIV vaccine messages are disseminated can only come from understanding the culture in which these trends develop.

Cultural competence in a wider discussion of HIV vaccine deployment must also be underscored among people who use substances. People who use substances in general, according to Steffanie Strathdee, have “a complex belief system,” and display “considerable mistrust in the government and other authorities.”<sup>32</sup> Engaging current and former drug users who understand the culture in which these beliefs develop is key to delivering messaging about HIV vaccination to these communities. As one key informant who coordinates peer outreach workers in a major Canadian city claimed, “[w]e rely on building relationships,” to deliver services, and “[p]eer workers are a huge part of that.” This sentiment was echoed during the best practices symposium where use of peers to do outreach and education was highlighted as one of the unique features necessary to provide services to people who use substances in this country. One informant spoke forcefully in support of making certain that any interventions among communities of people who use substances follow a model in which members of that group solve community problems.

Being culturally competent and using a community's willingness to involve itself in the development, implementation and dissemination of public awareness materials should be standard best practice. In raising public awareness about an HIV vaccine, one participant contended that we must “[a]ppreciate that distinct cultural populations at high risk for HIV have distinct strategies for outreach, social justice, prevention and ethics.” Heeding this may very well ensure that the community is both behind the intervention and at the forefront of promoting it.

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<sup>32</sup> Steffanie A. Strathdee et al., (2000), “Factors Associated with Willingness to Participate in HIV Vaccine Trials among HIV-negative Injection Drug Users and Young Gay and Bisexual Men, *AIDS and Behavior* 4 (3): 276.

# 6

## Conclusion: Lessons Learned?

**According to IAVI and the Futures Institute, even a partially efficacious vaccine with low coverage has the potential to reduce the number of new HIV infections by 24% in low and middle-income countries.**<sup>33</sup> This type of vaccine may very well have a similar impact in Canada. To reach this potential, it is essential that the deployment of a vaccine be as successful as possible. Raising awareness of an HIV vaccine and preparing communities for its deployment are essential to maximizing this opportunity. Community and international consultation, as well as targeted key informant interviews with community-based organizations, public health officials and community clinics, suggest that an effective future vaccine campaign can be achieved by drawing upon many important lessons learned and by engaging in the best practices identified during these consultations. CAS' consultative process produced several recommendations.

- Communities and clinicians must build stronger relationships that allow for mutual understanding and respect and ensure community ownership of any vaccine deployment strategy that is developed. This type of partnership should give rise to a widespread understanding of vaccine science, including how a vaccine will and will not protect against HIV transmission.
- Access barriers to an HIV vaccine, including geographic and financial barriers, must be eliminated as much as possible. Guidelines for allowing minors to consent to vaccination without their parents' knowledge also need to be developed. In addition, the availability of confidential, and where possible, anonymous, vaccination must be ensured in order to offer anyone who wishes to be vaccinated an affordable, anonymous and acceptable way to do so.
- Efforts to reduce and eliminate stigma and discrimination around HIV, homosexuality, substance use and incarceration need to be ramped up and expanded. Stigma remains one of the most pervasive barriers to reducing HIV transmission. Reducing stigma will be key to facilitating discussions and increasing awareness about the potential impact of an HIV vaccine on an individual's ability to protect himself or herself against infection.

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<sup>33</sup> International AIDS Vaccine Initiative, (2009), *Estimating the Impact of an AIDS Vaccine in Developing Countries*, Policy Brief 20, (available [http://www.iavi.org/Lists/IAVIPublications/attachments/5ebd3b8f-532f-44fa-8bbc-d2d3e14fb2e6/IAVI\\_Estimating\\_Impact\\_of\\_AIDS\\_Vaccine\\_in\\_Developing\\_World\\_2009\\_ENG.pdf](http://www.iavi.org/Lists/IAVIPublications/attachments/5ebd3b8f-532f-44fa-8bbc-d2d3e14fb2e6/IAVI_Estimating_Impact_of_AIDS_Vaccine_in_Developing_World_2009_ENG.pdf) accessed 9 August 2010).

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- Current standards of prevention need to be maintained and it is imperative that a vaccine is incorporated into the existing prevention arsenal in a way that is effective. A vaccine will not reverse the increase in new HIV infections if current levels of safer sex and harm reduction are not sustained.
  - Public awareness campaigns for an HIV vaccine need to be carefully planned, complete with outreach strategies. They need to be culturally competent—which includes respecting and integrating programs into the existing norms of Canada’s subset communities of MSM and gay men, ethnocultural communities, and of substance users. Most importantly, these programs need to reduce stigma and normalize the discussion of HIV so that everyone internalizes the need to inform themselves about whether or not a vaccine is an appropriate prevention strategy for them.

The central question of this research has been how to build on existing knowledge and experience to raise awareness and promote acceptability of vaccines in the future. We can do so by following these recommendations and in particular by consulting communities at every stage of the process. This will make certain that they are invested in the successful development and deployment of an HIV vaccine and will create optimal conditions for its roll-out. In order to understand the consequences of not following these recommendations, we only have to look as far as Canada’s failure to deliver the HPV and H1N1 vaccines to everyone who might have benefited.

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