Canadian AIDS Society  Société canadienne du sida

HIV Vaccine Preparedness: Capacity-Building Needs of Canadian Community-Based Organizations

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Background: Through a project funded by the Canadian Network for Vaccines and Immunotherapeutics (CANVAC), the Canadian AIDS Society (CAS) has conducted 23 key informant interviews among leaders in community-based HIV, Hepatitis C (HCV) and cancer movements to ask for their insights into the capacity-building needs of Canadian community-based organizations.

CAS is a coalition of more than 115 community-based AIDS organizations across Canada. CAS advocates on behalf of the Canadian community-based AIDS movement and undertakes capacity-building initiatives for its members.

CANVAC, a national network of researchers and institutions, is a National Centre for Excellence focused on the development of vaccines for the prevention and treatment of cancer, HIV and HCV.

What do we mean by capacity-building needs around HIV vaccines?

Sometimes, we refer to "vaccine preparedness", which encompasses a range of activities and program areas, including:

- raising awareness around vaccines
- building advocacy initiatives around vaccine development
- preparing communities for clinical trials
- anticipating the impact of new prevention technologies on HIV prevention, linking vaccines to broader prevention concerns

What are the pre-requisites for community involvement in vaccine advocacy and preparedness?

Given community groups are chronically under-resourced, most informants strongly believed that two conditions should be met to allow them to take on the issue of vaccines successfully:

1) A renewed Canadian Strategy on HIV/AIDS that includes a significant increase in resources for groups to meet existing needs effectively

2) A Canadian Strategy on Hepatitis C to ensure the survival and effective work of groups working on HCV

"I am pessimistic about our ability to build capacity in this area unless the community's capacity, generally, is increased."

"It sometimes seems very difficult for underfunded organizations to look five years down the line when we're worried about paying the bills at the end of the year. If we are needed to play a role in this, we need basic funding to do what we're already doing."

Some informants believed that community capacity to take on advocacy in general has been hampered by years of working in under-resources conditions.

"The capacity of most organizations to do advocacy and policy analysis has decreased drastically over the last ten years."

What are the challenges of engaging community on a very long term effort?

Often people cannot imagine the resources they would need in order to be able to conduct long-term vaccine preparedness and advocacy work. Their immediate needs are so pressing and they are so under-resourced that vaccine R&D seems remote and advocacy unattainable.

"We're all involved in crisis management on a day-to-day basis... (so how do you get people in that situation to work on a long-term project that could take 25 years?)... That's a good question. I don't have an answer for that; not in this community."

"I'd have to say that questions boggles me, and leave it at that."

"It's very hard when approached with something that seems remote and really not connected to the day to day realities of the people we're working with, it isn't very obvious that we should get involved in it. Or that we should devote resources to it at the expense of something that's more immediate and concrete for us."

In a context where there may be very few or no vaccine clinical trials in Canada, building capacity and maintaining interest in the community may be particularly challenging.

"The politics of research are that often the countries where the research is being done, and where the research is certainly successful, will be the countries that get faster access to the vaccine. Theoretically, I don't care [whether] the research for AIDS drugs [for example, is done here or overseas] either. But practically, I'm desperate to have those trials in Canada, because I know I can get some compassionate access ...I can get it more easily through the special access program in Canada, and I can get people on these drugs as a trial."

How does this fit on the prevention-care-support-treatment continuum?

Many informants argue strongly for the adoption of a broad conceptual framework in which vaccines are seen as part of a continuum between prevention and treatment, and which spans domestic and international concerns.

"We just have to accept the need to advocate for all of the above and that we need to figure out how we can best work with each other, and we do that by advocating for treatment and vaccines and microbicides."

"We certainly need the whole continuum of research, and that in my mind includes vaccines. But it's got to fit within that whole continuum of a response that takes into account prevention, research, support, care treatment, everything."

"(We should) at least consider ways that a domestic strategy at home can be linked into the global movement and can encompass aspects of equity which is supposedly a great Canadian value that we espouse and want to project to the world."

These comments often come in response to perceived competition between vaccines and existing prevention methods, between vaccines and treatment, or between preventive vaccines and therapeutic vaccines.

"My major frustration is that we are putting money into... and I'm not saying that we shouldn't, but how many dollars are going into vaccine research? We know how to prevent the transmission of HIV and hep C, and we've known that for a long time. We don't do enough of what we know we could be doing."

"I don't do much vaccine work. I've always seen it as kind of off somewhere, and I'm glad somebody's doing it, but it's not going to be me. It's very complex and if I put my energies there and really learn it well, I won't have enough space in my brain to do the shorter term stuff, which is really [....about keeping] me here until somebody else gets on with vaccines."

What leadership is needed?

"We're really crying out for leadership on vaccines."

"I think that we need to identify some people in Canada who are really leaders in vaccines."

Some informants suggested a tiered, or complementary and parallel approach: some strong national voices, and some targeted local efforts, coordinated and reinforcing each other.

"We need to figure out who really needs to be involved. Ideally you would identify a few organisations that would take the lead (CAS, Legal Network)".

"We need a few people that know a lot, and we need a lot of people that know a little".

What types of capacity are needed?

The long-term nature of vaccine work and the current paucity of resources to meet existing needs meant it was difficult for many informants to provide clear or detailed direction on capacity-building needs. However, some common threads did emerge.

1) Knowledge & Information management

This includes the need for an independent, honest source of clear information, specific to communities.

"There's just no source of information. And essentially, their information is the mainstream press, or community press, and these are not good sources of information."

"People who are living on the streets are unbelievably bright. Their ability to absorb knowledge quickly never ceases to amaze me. If the person who's providing the knowledge is someone they trust; if there's an opportunity to dialogue back and forth during that sharing of information, it'll work."

"Unless you can build a genuine sense of trust, that whatever information is being put out there is balanced and impartial, you'll get a certain number of people who will buy what you say but the majority will just look at it with a skeptical eye."

2) Advocacy

If grass-roots advocacy is to occur, then the informants felt that the scientific information must be translated into understandable and accessible terms.

Discussion is clearly needed to define where community advocacy should begin and where it should leave off. At what level will the community become involved? Questions informants grappled with included: if we do lobby for more fundamental vaccine science, should we be lobbying government to conduct the research, or should we be supporting private industry?

Clearly, it was felt that the community will need to develop an expertise so that they can critique what the private sector is doing.

3) Planning for impact on prevention

Before communities can actively support HIV vaccine R&D, some informants felt that there is a need to know how this research (and ultimate vaccine delivery) might affect prevention and harm reduction programs.

How can we build on existing efforts?

There is a need to identify best practises in education and advocacy. For example, many resources already exist: reports and info sheets from CAS, the Legal Network, ICASO; IAVI and

AVAC web sites; workshops; internet, e-mail fora, listservs.

Integrating vaccines into existing work can help to overcome some of the barriers caused by the long-term nature of vaccine research and development.

"Nesting vaccines in the context of other work that is relevant to those organizations, understanding it in the broader prevention continuum, understanding it within advocacy efforts in the longer term, understanding it within the context of global issues, whatever happens to be relevant to those organizations."

However, a few informants felt that keeping to a focused vaccine skills-building and advocacy mandate is the best way to proceed. They maintain that a vaccine-specific focus will help to ensure that efforts to develop community vaccine preparedness and to build a coalition for advocacy are not hampered by inter-sectoral and intra-sectoral competition for perpetually inadequate resources.

What partnerships are needed?

Many informants expect governments, including public health, to play a role, despite some expression of distrust of public health officials. There is a widespread feeling that public health must be proactively involved with the community and help it to build capacity and learn from previous exprience.

"I think this is a time to learn from vaccines that have come before, for one thing. There's lots of people who have vaccine experience already, not in the HIV community, and so there's some learning to be done there."

For many communities, there are particular histories, beliefs, media and communications networks that need to be acknowledged. Different ethocultural communities, Aboriginal communities, people who use injection drugs, gay men will have to be targeted specifically in recognition of these differences. Partnerships with elders, religious and cultural leaders, gatekeepers, peer educators, icons in popular culture, may all form key strategies.

"In every community there are First Nations people who are concerned about these issues. But whether the leadership of a community is there [...] that's what makes the difference."

Likewise, the place of traditional medicines and healing in relation to vaccine research need to be considered in many contexts. including Aboriginal communtities, ethnocultural communities, and among people living with HCV.

Particular efforts may be required to build certain partnerships, as there are perceived clashes of cultures between researchers and community; and between industry and community.

Links with treatment activists and people living with HIV/AIDS were also seen as important.

In addition, a vaccine coalition of HIV, HCV, and cancer groups might present challenges.

"I would imagine that what would unfold is that the HIV and the Hep C advocates would say, "Ah, good to be sitting around the table, we have a lot in common," but that the cancer people would be on the other side of the room and would say, "I don't want to have anything to do with those people," and the Hep C and HIV people would say, "I don't know why these cancer people are here."

However, many felt these barriers could be overcome.

"I think that we all have similar approaches to empower people to deal with their own health and I think that we can find unity in that."

What are the next steps?

Following full analysis of the key informant interviews and a consultation of key stakeholders, CAS will develop a strategic plan on community capacity-building around vaccine advocacy and preparedness. This information will inform the work of CAS in this area, as well as provide direction for the development of Canada's HIV Vaccine Plan.

For more information on this project or on HIV vaccines, please contact Marc-André LeBlanc, Programs Consultant, Canadian AIDS Society, 1-800-884-1058, ext. 120 or at marcl@cdnaids.ca