

Planning and Community Engagement for HIV Cure Research in Canada: A Collaborative Program Between National Research Teams and Key Populations

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PLWHV/COMMUNITY

We conducted the first organized effort to engage key populations across Canada in newly funded and prioritized research for HIV Cure/Remission. Our steps were preliminary because of:

- 1) Novelty and difficulty of the research, and
- 2) Privacy concerns for first-time engaged adolescents and families.

Goals:

- Raise awareness about HIV cure/remission study
- Inform populations about global and Canadian research
- Solicit feedback how to conduct the research
- Plan long term, sustainable community engagement

On November 28, 2013, the International AIDS Society (IAS), the Canadian Institutes of Health Research (CIHR) and the Canadian Foundation for AIDS Research (CANFAR) jointly sponsored two national biomedical team grants. These aim to find cures for HIV and contribute to the global effort to put an end to AIDS. Inter-team collaboration was a condition of the grants.

The teams' study focus (2014-2018):

- CanCURE - Unique immune system compartments (myeloid cells/macrophages) that affect possible cure/remission strategies
- EPIC⁴ - Study of a Canadian pediatric cohort who underwent early treatment, and comparators, with longitudinal follow up into adolescence. Team grants for scientific research for HIV cure/remission were new to Canada. Community engagement in HIV cure research had not been conducted either for the teams or in the context of other Canadian HIV cure study. Our effort was the first inter-team collaboration project.

Targeting key leaders, organizations, and individuals to engage

Families Parents
Men who have sex with Men
Adolescent
Guardian Immigrant
Injection Drug User
First Nations Inuit Metis
Trans Men Pediatric
Hemophilia Bleeding Disorder
French African Caribbean

OUR ENGAGEMENT STRATEGY

- Three meetings: Montreal (11/2014), Toronto (01/2015), Vancouver (04/2015) – community facilitators
- Non-public meetings by invitation, and considerations for conjunctions of youth new to research with long-time advocates. Media/publicity not permitted; confidentiality preserved.
- Survey-monkey data collection for long term preferences in communication/engagement structure*
- Initial example questions to attendees about research designs**



*Survey topics: 1) Frequency of communications, 2) Methods to receive information, 3) Engagement exchange of research results, 6) Interest to form a nationwide coalition, 4) Means to recruit study participants outside urban centers, 5) Open access publishing and knowledge dissemination, 7) Support for Canadian teams, 8) Qualitative recommendations to improve engagement

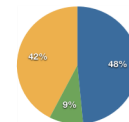
** Example Research Topics: 1) Biological sample collection, 2) Cultural preferences and beliefs, 3) Sex and Gender differences, 4) Recruitment and referrals, 5) Incidental results reporting, 6) Ancillary/collateral benefits

RESULTS AND RESPONSES

31 Online Survey Respondents/51 Meeting Participants
Note: Pie chart results are from Online Survey Responses

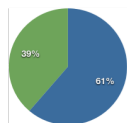
Quoted text as written by participant

How Often Would You Like to Receive Research Updates?



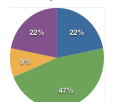
twice a year annually more frequently

Would You Like to Form a National Community Cure Group?



Yes Don't Know

Preferred Communication Method to Receive Updates



Face to Face Email/newsletter Online Webinar Social media/smartphone Online video/watch later

Compared to older participants, youth meeting participants expressed strong interest and preference for use of social media and smartphone technology, including social communication mixing discussions not siloed for cure research

Other Responses:

"Each university hospital with a "First Nations Program" should have a liaison nurse and team with the North"
"Lay language summaries are so important and I really appreciated the scientists being available to talk about the basics and to answer questions."

"Les défis de maintenir un groupe national dans les deux langues est énorme."

"Ne pas négliger la communication dans l'autre sens: vers les chercheurs et les scientifiques, pour que ceux-ci soient sensibilisés à l'histoire, la réalité et les enjeux de la mobilisation des communautés."

"Communication and planning events for youth may require extra resources to be successful (for example detailed planning on transportation)."

"Gatekeepers" of different communities... can execute optimal ways to generate buy-in... this working group can also help to alleviate distrust.

NEXT STEPS

As a preliminary effort to engage Canadian communities in the biomedical research program for HIV Cure/Remission, community and scientific stakeholders expressed great enthusiasm to continue and sustain an interactive program. One universal concern was the need to manage community expectations about the progress and the difficulties of cure research. Participants agreed a cooperative and community based program for effective communications to populations was needed. (One participant: "the news I received today wasn't the news I was hoping for. I thought the cure would be here sooner.")

Because these meetings were intentionally closed to the public, a natural extension of engagement to organizations, individuals, public meeting forums and welcome venues must follow using the recommendations we received. In Canada, geography, financial support and resource challenges must be

overcome to achieve that objective.

Meeting participants provided initial feedback encouraging study of population differences, e.g., based on sex and gender, genetics, ethnicity. Participants recognized the importance of biological sampling for research but urged close relationships with communities to promote that effort.

Youth participants expressed great appreciation for interaction with researchers and seek dedicated opportunities to continue that effort and to take on public education roles. All participants expressed an interest for capacity building to enhance engagement.

Following the conclusion of this grant funded effort, collaborators intend to develop a national and local plans responsive to the ideas shared by meeting attendees.

What is Community Engagement?

"The essence of "engagement" is... its recognition of the capacity of citizens to discuss and generate options independently. The term "citizen" includes interested representatives from the general public, consumers of health services, patients, caregivers, advocates, and representatives from affected community and voluntary health organizations. For CIHR, this involvement of citizens can span the full course of policy or program development, from agenda-setting and planning to decision-making, implementation, and review."

<http://cihr-irsc.gc.ca/e/41592.html>
See also: Stakeholder Engagement in HIV Cure Research: Lessons Learned from Other HIV Interventions and the Way Forward
Lo Ying-Ru, Chu Carissa, Ananworanich Jintana, Excler Jean-Louis, and Tucker Joseph D. AIDS Patient Care and STDs. "Not available", ahead of print. doi: 10.1089/apc.2014.0348.

What Did We Hear?

Where Do We Need to Improve?
"Augmenter la participation communautaire lors de conférences sur la recherche fondamentale"

"Faites plus de pression sur les organisations pour engager la communauté"

Trans men and women we contacted did not respond to invitations to meet, more needs to be done
"Need to implement GIPA principles."

"Talk to community based researchers... We know how to reach out."

AIDS Service Organizations, clinics and care centers must be included in KTE

Acknowledgments

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