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

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RESULTS AND RESPONSES

31 Online Survey Respondents/51 Meeting Participants

Note: Pie chart results are from Online Survey Responses

Quoted text was written by participants.

PLWH/COMMUNITY

We conducted the first ever concerted 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 on 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 biobank teams. 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 (peripheral cells/macrophages) that affect possible cure/remission strategies
• EPIC – Study of a Canadian pediatric cohort who underwent early treatment, and comparison, 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, organizers, and individuals to engage

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**

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, the 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://www.cihr-irsc.gc.ca/e/43179.html

What Did We Hear?

Where Do We Need to Improve?

“Augmenter la participation communicative lors de conférences sur le microbiome/biodiversité.”

“Enrichir le contenu de l’organisation, pour engager le communauté.”

“Trous entre hommes et femmes se contestait et ne répond pas à l’invitation à mieux communiquez.”

“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.

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