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

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Background: The Canadian Institutes of Health Research (CIHR), the International AIDS Society (IAS) and the Canadian Foundation for AIDS Research (CANFAR) jointly sponsored team grants to find a cure for HIV. The two funded Canadian teams, respectively, plan to investigate: 1) unique HIV reservoir compartments, notably in myeloid cells, and 2) pediatric reservoirs after early treatment. Cures for HIV may be possible if collaborative research proceeds with community engagement. Much work remains to establish meaningful discussion between researchers and HIV-affected communities. Initiating community engagement discussions in Canada benefits the teams, and the Canadian experience may be relevant to other countries because of the variety of key populations.

Methods: Local networks identified key population participants for community engagement meetings in Montréal (French language, November, 2014), Toronto (January, 2015) and Vancouver (April, 2015). Enhanced privacy rules supported adolescent participation. Community knowledge users and researchers provided facilitation and educational content. Restricted meeting size allowed for discussion to:

1. Raise awareness about cure research;
2. Solicit responses to research questions, including: a) blood/tissue sampling practices, b) cultural, gender-based and other beliefs, and c) sampling recruitment/engagement outside urban centers;
3. Solicit ideas for long-term public communication infrastructure.

Additional feedback was collected via online surveys and written evaluation.

Results: People with HIV, MSM, women, youth, Africans, Caribbeans and Blacks (ACB), hemophiliacs, and Indigenous people participated and rated content and engagement favorably. Certain groups (e.g. HIV/HCV coinfecting, IDU, transgender populations) were not yet successfully recruited to participate to the intended degree. Participants reported high levels of comprehension and interest in research; some expressed concern with lack of engagement historically. Meetings produced concrete suggestions for long term communication infrastructure, favored means (e.g integrated social media for youth, regular in person meetings for specific groups), and connection to remote populations or other provinces. Opportunistic sampling was supported as was encouragement to address population dispersion issues typical in Canada.

Conclusions: Communities expressed great interest to support HIV cure research. Challenges remain to engage all groups equitably and address their specific needs. Researcher commitments to sustained and personalized engagement are critical to success and to advance discussion of research questions.