

Toronto to Zero Community Consultation Report

November 1st 2018, the 519

Toronto to Zero is a collaboration between people living with HIV and other community members, community-based AIDS service organizations, clinicians, public health agencies, researchers, and government stakeholders working in partnership to successfully end the epidemic in our city.

Consistent with a firm commitment to GIPA/MEPA and the Ontario Accord, Toronto to Zero will actively engage the community in planning and implementing the strategy, giving those interested an opportunity to learn, engage and contribute to the work.

November 1st 2018 Community Consultation – What We Heard

On November 1st, representatives from the Toronto to Zero initiative gave an inaugural public presentation to more than one hundred community members at the 519 Community Centre. Presenters talked about the project's approach, principles and objectives.

After the presentation, community members participated in facilitated discussions focused on the central question, "What does Toronto To Zero's plan need to be a success?" This document is a summary of the input we received.

Information from the community consultation, along with input from future events, will be incorporated into the Action Plan that will guide the Toronto to Zero initiative in the coming years. We want to thank the community members who attended for contributing their thoughts, experiences and energy towards the project! We look forward to continuing to work with them as Toronto to Zero takes shape.

We would also like to thank our facilitators and recorders for helping to guide our discussions and gather the ideas of community members.

While it is not possible to exhaustively communicate the richness of the discussions that occurred during this session, we hope the following summary touches on the key points that were made across groups.

WHAT WE HEARD

Ending the HIV epidemic requires a holistic approach to the health and wellness of people living with HIV

Participants discussed the importance of high quality HIV care, provided across the city where it is accessible to all communities affected by HIV. They discussed the need to co-locate health care services with other supports (including but not limited to assistance with housing, mental health, employment, and substance use) to enable people living with HIV to stay engaged in care and have improved health and quality of life.

Participants also talked about the challenge of overcoming social isolation, particularly for people who have been recently diagnosed. Peer health navigators were recommended as a way to help people living with HIV connect to appropriate services and feel more connected to their community.

Significant gaps remain in access to care and treatment

Many participants noted that the current system for accessing health care and HIV medications leaves certain populations without access to necessary care. A number of participants highlighted the particular needs of newcomers, including international students, who may lack adequate health insurance to access care and/or medications and poorer health outcomes among racialized communities, Indigenous communities, trans communities and people who use drugs.

Participants noted that the complexity of navigating the Ontario Drug Benefit and the Trillium Drug Program presents a barrier to adequate treatment. In the short term, participants recommended (1) additional system navigation supports for people who are eligible for these programs, and (2) financial supports for those without adequate insurance coverage, to make treatment access more equitable. In the long term, participants recommended that Toronto to Zero stakeholders participate in ongoing discussions re: a universal national drug coverage plan for Canada.

Roundtable participants emphasized the urgency of identifying how communities are underserved within the existing prevention, engagement and care cascade, so that new initiatives can better address those gaps. Collaboration among service providers was encouraged, in order to ensure that services are welcoming to people from multiple communities affected by HIV.

Reaching undiagnosed people living with HIV requires revamping existing testing services and exploring new options

In discussions of HIV testing, participants described challenges including:

- Difficulty finding appropriate recommendations for how often/when to test
- Difficulty finding accessible testing
- Difficulty finding testing that is neither judgmental nor stigmatizing.

Participants discussed the need for more culturally appropriate testing services, with clear guidelines for how often/when to test, and additional service hours and locations to meet the needs of different

populations. Participants recommended the expansion of existing low-barrier testing options (e.g. point-of-care testing in community spaces), and the wide introduction of advances such as at-home testing. Participants also stressed the need for rapid linkage-to-care models at all testing sites in Toronto.

Decreasing new HIV transmissions requires better implementation of effective prevention tools

Pre-exposure prophylaxis (PrEP) was brought up as a critical tool to end the epidemic; participants discussed the need for increased availability of PrEP. Participants also talked about their experiences of delays in getting started on PrEP, because of (1) wait lists for care, and (2) being referred and rerouted to different care providers, which left them without adequate care and PrEP access.

Several groups discussed their understandings that many populations, including racialized communities, people who use drugs, women, and trans folks were still not being encouraged to use PrEP. Even among gay and bi men, participants expressed a feeling that ongoing stigma and poor understanding of individual exposure to HIV was limiting uptake. Participants recommended that Toronto to Zero (1) support the growth of PrEP delivery, and (2) encourage all people with significant exposure to HIV to consider PrEP.

Participants also recommended the growth and promotion of other effective prevention options – including (1) ongoing HIV treatment for people living with HIV, (2) condoms, and (3) harm reduction services – alongside PrEP, so that individuals feel empowered to select the prevention tools that best fit their needs.

The Undetectable=Untransmittable message is a powerful tool for addressing stigma and reshaping dialogue about HIV

Participants felt that the U=U message could help address a myriad of issues, including:

- Increasing general public knowledge about HIV
- Decreasing stigmatizing attitudes towards people living with HIV
- Creating more consistency in the messages health care providers and service providers give about potential transmission of HIV
- Helping to alleviate internalized stigma for people living with HIV.

Participants were supportive of “U=U” messaging, provided that it was geared to the needs of local communities affected by HIV.

Some participants expressed a concern that U=U be implemented in a way that proactively addressed structural barriers that prevent some people from achieving an undetectable viral load – to avoid stigmatizing individuals unable to achieve viral suppression. Participants also felt that U=U needed to incorporate messages about stigma based on race, gender identity, sexual orientation and substance use to more fully challenge the discrimination faced by communities affected by HIV.

There is optimism for Toronto to Zero to bring together a broad range of stakeholders and reshape our local response to HIV

Participants were optimistic about the general goals of the project, and many expressed a desire and excitement to see more concrete objectives. There was encouragement to engage in ongoing public presentations on progress, to keep the community engaged throughout the lifespan of the project.

It was recommended that the Toronto to Zero leadership engage directly with communities most impacted by HIV. Community members want the opportunity to be ambassadors of the project, to create an ongoing dialogue, and to have a real stake in and ownership of the project.

Participants also stressed the need for involvement from a broad range of stakeholders, including local, provincial and federal governments, and intergovernmental agencies like UNAIDS. Participants encouraged learning from the successes of other Fast-Track City programs, and the adaptation and implementation of globally successful models locally.

Overall, participants expressed support for taking a new approach to address HIV, and want to see the initiative attempt bold and new programs to achieve its goals.