Linkage to Care, Retention & Adherence
Draft Recommendation Activity
February 11, 2020

Task Group Objectives and Process

The Toronto to Zero Linkage to Care, Retention & Adherence Task Group convened for five meetings between April and October of 2019 to outline key gaps in prevention services and formulate potential recommendations to address them. After developing draft recommendations, the task group organized a community think tank in November 2019 to ensure our recommendations reflect the needs of people living with HIV in Toronto. Notes from that session were reviewed and additional ideas were incorporated into our existing recommendations or developed into new recommendations. After a final review from the task group members, the following recommendations were submitted to the Toronto to Zero Champion Team.

As a task group, the objectives we set out for ourselves included:

- Identify gaps in the current delivery of services to link people diagnosed with HIV to care and to support people living with HIV to be retained in care and adherent to treatment;
- Recommend strategies to better deliver these services in Toronto, including how to incorporate innovative and effective new strategies;
- Tailor recommendations to meet the needs of identified priority populations and other sub-populations that face additional barriers to treatment, and collaborate with other task groups and/or community members from affected communities to incorporate their input;
- Deliver a report to the Champion Team that identifies this Task Group's membership, key discussions about these issues, and a list of recommendations to incorporate into Toronto to Zero's Action Plan.

As such, these recommendations span three of the five objectives of Toronto to Zero, including to link and retain people living with HIV in care, to improve the health and well-being of people living with HIV, and to stop HIV stigma.

Task Group Membership

Co-chairs:

- Rita Shahin, Toronto Public Health
- Suzanne Paddock, PWA

Think Tank Co-chairs:

- Alessandro Bisignano, Committee for Accessible AIDS Treatment
- Viviana Santebanez, Latinos/LGBTQ+ Community Advocate

Representatives of the following organizations/constituencies:

- Alessandro Bisignano, Committee for Accessible AIDS Treatment
- Amy Lin, Hassle Free Clinic
- Andrew Miao, Asian Community AIDS Services
- Anthony Leonard, Toronto Public Health
- Bruce Clarke, Toronto Public Health
- Catherine Rutto, PWA
- Colin Kovacs, Maple Leaf Medical Clinic
- Frederic Crouzart, Maple Leaf Medical Clinic
- Gary Rubin, Church-Wellesley Health
- Hartmut Krentz, St. Michael's Hospital
- Heather Mitchell, Fife House
- Jack Mohr, Ontario HIV Treatment Network
- James Owen, St. Michael's Hospital
- Joanne Lush, AIDS Bureau
- John Maxwell, ACT
- John Power, ACT
- Katherine Burress, Maple Leaf Medical Clinic
- Kenneth Poon, Asian Community AIDS Services
- Kyle Vose, PWA
- Linda Jackson, St. Michael's Hospital
- Michael Adia, St. Michael’s Hospital
- Michael Blair, Fife House
- Paul MacPhee, St. Michael's Hospital
- Rupert Kaul, University Health Network
- Ryan Kerr, Ontario HIV Treatment Network
- Simran Kaur, Ontario HIV Treatment Network
- Viviana Santebanez, Latinos/LGBTQ+ Community Advocate

Recommendations

1. **Advocate for changes to public drug policy and pharmaceutical assistance programs to create universal access to free HIV treatment**
    a. Universal, low-barrier access to HIV treatment is critical to ensuring all people living with HIV can lead long, healthy lives and to realizing the benefits of U=U to prevent new infections.
    b. Ontario currently relies on a patchwork system of drug plans for covering the cost of HIV medications. At an individual level, navigating this system can delay or prevent people from accessing medications for HIV treatment, and fails those who do not have private insurance or who have no coverage and do not qualify for social assistance.
    c. At a system level, it means that Ontario, and Toronto as the epicenter of the province's epidemic, will not see the same dramatic reduction in new HIV infections seen elsewhere.
    d. Organizations and healthcare providers in the HIV sector need to collectively engage policy makers at the provincial level to emphasize the significant impact universal, free access to HIV medication will have on ending the epidemic in Ontario.
    e. Sector partners should participate in ongoing dialogue about National Pharmacare to emphasize gaps that exist around HIV treatment and ensure specific issues in Ontario are addressed in any potential Federal program.
    f. Organizations also need to encourage pharmaceutical manufacturers (including generic manufacturers) to help fill these gaps with more generous forms of compassionate access.
    g. ASOs also require additional support to provide service navigation, particularly for newcomers who have gaps in coverage and people accessing the Trillium Drug Program, to ensure timely access to HIV treatment and generate the greatest community level benefit from increased coverage.

2. **Advocate for the needs of people living with HIV in response to the housing crisis and build capacity of HIV care and service providers to support people living with HIV to obtain housing**
    a. Affordable, safe housing is crucial for ensuring all people living with HIV can lead long, healthy lives and realizing the benefits of U=U on individual and community health.
    b. Additional housing capacity is needed to ensure all people living with HIV have affordable, safe and stable housing that meets their needs.
    c. The ongoing crisis of affordable housing has meant many people living with HIV in Toronto struggle to find or maintain adequate housing.
    d. For people living with HIV, access to permanent housing is directly linked to better engagement in care, better treatment adherence and improved quality of life.
    e. Affordable and supportive housing providers have been seeking policy solutions to increase available housing stock for several years; ASO and service providers need to mobilize to support these efforts and emphasize the need for policy change for the betterment of people living with HIV.
    f. In the short term, local ASOs can better support clients' housing needs by working with key community agencies to develop shared training and resources for support staff, in

particular ensuring staff can educate clients about their rights and responsibilities as tenants and provide support applying for housing through the Access Point.

g. This navigation should be prioritized for newcomers or those new to the city, as they are the most vulnerable to landlord/tenant exploitation.
h. Fife House and LOFT, as leaders in HIV specific supportive housing, can also support ASOs through offering community housing clinics at different agencies.
i. Advocate that all people living with HIV, regardless of disease progression, be granted priority housing within the Toronto Community Housing system;
j. Advocate for increases to the ODSP housing allowance to reflect real cost of living in Toronto.

3. **All people newly diagnosed with HIV in Toronto are connected to HIV care and a PHA peer navigator within a maximum of 72 hours after diagnosis;**
    a. Rapid linkage to care can help to reduce loss to care and help improve the long term health and wellness of people living with HIV.
    b. Post-diagnosis period is also challenging to navigate, and quickly connecting people newly diagnosed with HIV can benefit greatly from peer navigation, education and support to address emotional impact of diagnosis and support decision making about care and treatment.
    c. Many agencies currently offer linkage to care supports and peer navigation supports.
    d. By coordinating services between agencies, Toronto could implement more rapid connection to care and to peer navigation support.
    e. Agencies currently providing linkage to care and peer navigation support would need resources to coordinate their service delivery.
    f. Development of a central referral line that anyone providing HIV testing could call would provide a shared access point for linkage services and peer support.
    g. This network could also maintain a list of specialists and general practitioners who can provide HIV care along with details on wait times.
    h. These services would also support connecting people who are uninsured to services that provide access to healthcare and medications; see recommendation 4.
    i. Establish securely funded/supported peer navigator program/roles.

4. **All POC testing sites have a dedicated linkage to care coordinator (either in-house or through partnership) that ensures newly diagnosed people are successfully linked to care, medication access and other identified supports;**
    a. Point of care testing allows for testing that is quick and easily deployed in a variety of settings. Community-based POCT frequently has high positivity rates and draws people who have never tested before.
    b. One challenge of community based POCT is ensuring that those who are diagnosed are connected to long-term care services.
    c. Coordination between POC testing sites and agencies providing linkage to care services would ensure that people engaging in POC testing have optimal supports including language translation services to get and remain connected to ongoing care.

d. The AIDS Bureau and OHTN can help to identify all local funded testing sites and connect testing sites to agencies providing linkage to care services.
e. Any new testing sites should require a partnership with agencies providing linkage to care services.
f. Consider helpline or direct access to Linkage to Care Coordinator position with extended operating hours.

5. **POC testing sites and community-based HIV organizations/programs have accelerated access to HIV primary & specialists, and mental health providers;**
    a. Reducing gaps in care and time to treatment requires that HIV testing providers have a clear referral pathway to HIV care.
    b. While existing HIV specialist and HIV primary care providers in Toronto are well connected to organizations providing POC testing and community based HIV organizations, flow into clinical care could be improved with more standardized sharing of information about wait times and care availability.
    c. Maintain a real-time list of specialists and general practitioners who can provide HIV care along with details on wait times.
    d. Include other key components of accessibility to allow for referrals tailored to the needs of people referred to care (e.g. details on languages spoken by provider, specialty working with different populations)
    e. Create memorandums of understanding between clinical & community providers to have accelerated access to primary care doctors;
    f. Co-locate community counselling services with HIV primary care services to offer low-barrier referrals to support with mental health and substance use issues to improve retention in care

6. **Build on ongoing initiatives to provide care and treatment to precariously insured people living with HIV.**
    a. People living with HIV who are newcomers to Canada may face a variety of barriers to care based on their immigration status.
    b. People living with HIV who rely on the Trillium Drug Program should be considered precariously insured given the enormous financial barriers of the Program.
    c. Gaps in coverage for basic medical care and prescription medication can lead to delays in care and inability to maintain treatment that negatively impact an individual's long-term health.
    d. Include those on Trillium in discussion of precariously-insured people.
    e. While ASOs, community-based organizations serving newcomers, and Community Health Centres have long worked with their clients to develop short-term solutions to individual issues, a system-wide change is needed to effectively engage all people living with HIV in Toronto in care.
    f. The Blue Door Clinic is a promising new service to provide more streamlined entry to care for precariously insured people living with HIV; as this pilot initiative has sufficient time to operate and collect data on its impact, additional resources should be provided to continue ongoing operations and expand services.

g. Physicians in the community, many of whom have been willing to see patients who are precariously insured on an ad hoc basis, can also be integrated into the Blue Door clinic network to receive referrals and help manage overall patient load.
h. Data collected from the Blue Door clinic should also be used to engage other service providers to operate in the space and form the basis for getting laboratory service providers and drug manufacturers to commit free lab testing and HIV medications to cover precariously insured populations.
i. In the long term, organizations and healthcare providers in the HIV sector need to collectively engage policy makers at the provincial level to emphasize the specific needs of people living with HIV and the public health argument for improving access to health services.
j. Require ASOs be aware of, and provide support where possible to, current mandatory provincial and federal requirements for refugees/precariously-insured HIV testing and care as part of settling process.

7. **Develop shared tools and processes for service providers to assess retention in care and provide supports for PHAs to stay engaged in care;**
    a. Service providers, including both clinical and community services, need to develop retention in care protocols for PHAs;
    b. These protocols should include regular follow-up guidelines for all PHAs, how to identify when/why someone has dropped out of care and steps to re-engage PHAs in care;
    c. Retention protocols should include the greater involvement and meaningful engagement of PHAs as peers as crucial parts of retention in care;
    d. These retention in care protocols should also identify partnership opportunities between clinical, ASOs and other community services;
    e. Data should be collected as to the reasons why PHAs drop out of care in order to inform specific interventions for PHAs that are culturally responsive;
    f. AIDS service organizations, as community agencies, often maintain connections with people living with HIV even as they transition in and out of medical care, and have a unique role in assessing and supporting retention to care for PHAs.
    g. ASOs and other providers should explore offering common/joint intakes with the expressed permission of PHAs; MOHLTC has encouraged ASOs to assess their clients' current connection to care or efforts to seek care.
    h. Develop linked medical record system throughout the province and municipalities including emergency, Public Health and family care physicians to expedite patient/primary care physician understanding and to ensure efficient, timely treatment pathway.

8. **Develop resources and training for ASO staff to support clients with treatment adherence;**
    a. Training for clinical, ASO/community staff to be able to engage people living with HIV in conversation about their care and treatment and how best to connect clients with care or internal and external linkage to care supports.
    b. Investigate why PHAs struggle with treatment adherence and develop evidenced-based, culturally specific interventions.

c. Create greater involvement and meaningful engagement of PHAs as peers as crucial components of treatment adherence.
d. Using Ontario's Community Hepatitis C treatment resources and TB Supports resources developed by Toronto Public Health as a guide, create model of HIV care with those who struggle with mental health and substance use to support their adherence.
e. Define pathways to above recommended multidisciplinary support models - including linkage to care coordinator, peer navigator, primary care, infectious disease specialist, case manager, mental health counsellor using a harm reduction lens.
f. Make available plain-language versions of these resources that can be client facing and distributed.
g. Look to successes in other jurisdictions to implement practical interventions including text-message reminders to encourage medication adherence and work with community to determine more convenient medication dispensation possibilities: ie blister packs.
h. Advocate for auto-refills or extended refills (at least 6 months) of HIV medications.
i. Consider medication lockers at ASOs to store medications for those precariously housed or who do not wish to disclose their status to family/housemates.

9. **Expand access to HIV primary care through increased engagement of healthcare providers and promotion of training via mentorship and existing consultation supports**
    a. Primary care providers have had an increasing role in providing healthcare to people living with HIV as effective treatment has shifted the health needs of people living with HIV towards addressing co-morbid conditions and common age-related diseases.
    b. Continuing to increase engagement of primary care providers in HIV care can also expand accessibility to HIV care given the limited number of available infectious disease specialists.
    c. Specific programs to train primary care providers (including those in hospital emergency rooms) to offer HIV care such as the OHTN's Residency in HIV Care, helping to expand the number of HIV primary care providers in Ontario.
    d. Infectious disease specialists and HIV primary care providers involved in medical education at the University of Toronto and McMaster University have also helped to include more content about HIV into medical school curricula; the OHTN should work collaboratively with these medical professionals to continue these efforts.
    e. Efforts should also be made to engage existing primary care providers to build their capacity to provide HIV care, in particular focusing on expanding access to HIV care outside the downtown core.

10. **Collect data on populations that are not linked or retained in care, and monitor changes over time to boost linkage and retention supports where needed**
    a. Efforts to reach and surpass the UN AIDS 90-90-90 targets have necessarily brought focus on identifying the "10-10-10" of people who are living with HIV but not engaged in care.
    b. Other Fast Track Cities have made identifying these populations a priority in order to better understand and address barriers that limit people from engaging in care.

c. Toronto to Zero can look to other Fast Track Cities for models to identify who is not engaged in care and models to engage them in care.
d. Individual hospitals and clinics in Toronto such as St. Michael's Hospital and the Maple Leaf Medical Clinic have reviewed patient records to identify patients lost to care; these efforts should be expanded to the city level with each clinic reviewing patient records to identify patients lost to care and clinics setting targets for increased engagement in care.
e. Commit to ongoing exploration of community needs (and populations disproportionally affected) to identify 10-10-10 underserved in the epidemic.

11. Implement a task force using preliminary data to bolster identified community needs around underrepresented communities, including Latinx/Arabic newcomers and others

a. Expand language/based, culturally relevant programming to meet language, housing and health care needs of newcomers from Latinx and the Middle Eastern communities.
b. Commit to working with these and other emerging communities to identify unmet HIV needs.