Panels Summary

Enhancing the Delivery of Comprehensive Care for People Living with HIV in Canada

22 March, 5 & 12 April 2019

McMaster University | **HEALTH FORUM**

EVIDENCE >> INSIGHT >> ACTION

McMaster Health Forum

The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 14-16 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. A citizen panel can be used to elicit the values that citizens feel should inform future decisions about an issue, as well as to reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

On the 22nd of March, 5th of April and 22nd of April 2019, the McMaster Health Forum convened citizen panels on enhancing the delivery of comprehensive care for people living with HIV in Canada. This summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible elements of an approach to addressing the problem; and
- potential barriers and facilitators to implement these elements.

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

Panellists identified eight challenges related to accessing care, managing multiple chronic conditions, addressing needs as people living with HIV age and/or in older adults with HIV, engaging hard-to-reach and/or stigmatized or marginalized groups, and providing social supports: 1) lack of comprehensive supports for HIV prevention; 2) limited access to point-of-care testing; 3) stigma is pervasive and layered; 4) lack of public awareness and education to address stigma; 5) privacy and confidentiality in testing and care are not respected; 6) limited access to social-systems supports; 7) the problem is magnified for the most vulnerable; and 8) lack of timely data and use of evidence in policy decisions.

In discussing the elements of a potentially comprehensive approach to address the problem, panellists expressed the need to provide equitable access to integrated comprehensive care, so that people can achieve optimal outcomes regardless of where they live and the challenges they face (element 1). Panellists viewed providing supports across social systems to address all of the challenges faced by people living with HIV (element 2) as being the most fundamental, yet potentially most difficult to achieve. Deliberations about this element stressed that actions towards strengthening social systems should be prioritized first, given that doing so would address the underlying challenges (e.g., housing, poverty and stigma) that put people at risk for HIV and make getting diagnosed and engaged in care challenging. While panellists struggled to some extent with the specific concepts included in element 3 (making small yet rapid changes to improve HIV care and supports over time), there was consensus across panels about the importance of a rapid-learning approach, which was thought to be more achievable than trying to reinvent entire health and social systems.

Panellists identified stigma as the biggest barrier to enhancing comprehensive care for people living with HIV. Many panellists also had doubts over the feasibility of larger and long-term changes given short political cycles. In discussing potential strategies to move forward, panellists emphasized leveraging HIV hubs of knowledge where there are clinicians and researchers working together. These knowledge hubs were viewed as opportunities to make research evidence accessible in a timely way. Panellists also felt that HIV could be used as an exemplar within health systems: "Get it right for HIV and get it right for everyone else."

"Stigma will always be there - the stigma that comes with having HIV. If I disclosed [my HIV status] in my hometown, it would not be pretty."

Discussing the problem:

Why is enhancing care for people living with HIV challenging?

During the deliberation about the problem, citizens were asked to share what they perceived to be the main challenges related to the delivery of comprehensive care for people living with HIV. They were also asked to identify any challenges that either they encountered personally, or that a member of their family had encountered with respect to: accessing care; managing multiple chronic conditions; addressing needs as people living with HIV age and/or in older adults with HIV; engaging hard-to-reach and/or stigmatized or marginalized groups; and providing social supports.

They individually and collectively focused on the following eight challenges:
- lack of comprehensive supports for HIV prevention;
- limited access to point-of-care testing;

- stigma is pervasive and layered;
- lack of public awareness and education to address stigma;
- privacy and confidentiality in testing and care are not respected;
- limited access to social-systems supports;
- the problem is magnified for the most vulnerable; and
- lack of timely data and use of evidence in policy decisions.

We review each of these challenges in turn below.

Lack of comprehensive supports for HIV prevention

Across the three panels, three main challenges were raised with respect to comprehensive HIV prevention: 1) limited investments in cheap but highly effective forms of prevention (e.g., harm reduction); 2) lack of access, provider knowledge and coverage for pre-exposure prophylaxis (e.g., Truvada); and 3) existing models present barriers to effective testing and prevention (e.g., limited number of anonymous testing services).

First, panellists felt that while there are highly effective harm reduction approaches to support HIV prevention, there are limited investments by governments because of public stigma against drug use.

Second, panellists in the Winnipeg panel focused a significant amount of the problem deliberation on access to pre-exposure prophylaxis (PrEP). Discussion centred on lack

Box 1: Key features of the citizen panels

The citizen panels about enhancing care for people living with HIV had the following 11 features:

1. they addressed a high-priority issue in Canada;
2. they provided an opportunity to discuss different features of the problem;
3. they provided an opportunity to discuss three elements for addressing the problem;
4. they provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. they provided an opportunity to talk about who might do what differently;
6. they were informed by a pre-circulated, plain-language brief;
7. they involved a facilitator to assist with the discussions;
8. they brought together citizens affected by the problem or by future decisions related to the problem;
9. they aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. they aimed for open and frank discussions that will preserve the anonymity of panellists; and
11. they aimed to find both common ground and differences of opinions.

of access to Truvada, particularly for high-risk groups. Panellists in the St. John's panel shared experiences with family physicians lacking knowledge on PrEP and HIV care and treatment more generally. One panellist shared an experience with a specialist in a major city in Eastern Canada who was not familiar with PrEP. Lastly, panellists also had concerns with the extent of public coverage for PrEP and the barriers this may pose to accessing appropriate preventive measures.

The final challenge relates to barriers to effective HIV testing and prevention, including current models of care and access to point-of-care testing. Anonymous testing was preferred by panellists, but many experienced challenges with accessing these services either because they are not available in the community or because of limitations to the services provided (e.g., limited days or times and no after-hours services). While panellists preferred the overall ease and convenience of point-of-care testing, many shared experiences with barriers to accessing this type of testing.

Panellists also emphasized that these prevention challenges are magnified for marginalized and stigmatized populations (e.g., Indigenous peoples, Indigenous peoples living in remote communities, people who inject drugs and people who are incarcerated).

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants:

- **How many participants?**
  31

- **Where were they from?**
  Winnipeg panel consisted of panellists from western provinces (British Columbia, Alberta and Manitoba), the Hamilton panel consisted of panellists from Ontario and the St. John's panel consisted of panellists from eastern provinces (Quebec, Nova Scotia, New Brunswick and Prince Edward Island)

- **How old were they?**
  25-44 (8), 45-64 (15), 65 and older (8)

- **Were they men, or women?**
  men (21) and women (10)

- **What was the educational level of participants?**
  29% completed a Bachelor's degree, 19% completed a post-graduate training or professional degree, 19% completed community college, 19% completed high school, and 13% completed technical school

- **What was the work status of participants?** 32% working full-time, 16% working part-time, 6% self-employed, 6% unemployed, 26% retired, and 13% disabled

- **What was the income level of participants?**
  13% earned less than $20,000, 26% between $20,000 and $40,000, 10% between $40,000 and $60,000, 10% between $60,000 and $80,000, 26% more than $80,000, and 16% preferred not to answer

- **How were they recruited?** Selected based on explicit criteria from the AskingCanadians™ panels.

Limited access to point-of-care testing

Many panellists expressed frustration with barriers specific to accessing point-of-care testing. There was variability in the concerns raised by panellists between the citizen panels. In the Winnipeg citizen panel, panellists noted that while there are sexually transmitted infection clinics available, many have long wait lists and are only open during business hours, which creates barriers to timely access to point-of-care testing. At the Hamilton citizen panel, panellists shared some positive experiences with accessing point-of-care testing (e.g., in settings such as the Hassle Free Clinic), but they had concerns with the anonymity of the process. While they understood that the point-of-care test was anonymous, panellists were concerned that positive HIV test results are reported to the local public-health authorities, and about their perceived lack of control over whether and how their health information is shared. In the St. John's citizen panel, panellists were most concerned with the overall lack of point-of-care testing in Atlantic provinces.

Several panellists also questioned why access to home-based self-testing cannot be made available, while others expressed concern with this approach to testing given the lack of direct linkage to needed care and supports following a positive diagnosis.

Stigma is pervasive and layered

One of the strongest themes to emerge from the deliberation about the problem was that stigma is pervasive and can lead to overt forms of discrimination. In discussing what makes HIV unique compared to other chronic conditions, panellists focused on stigma as being the defining challenge. For example, one participant in the Hamilton panel shared that other chronic conditions would not have prevented them from living in their home rural community where the fear of being stigmatized and discriminated against is significant. Another panellist shared that, "people with HIV are shunned and looked at as the scum of the earth." In addition, the criminalization of HIV non-disclosure was raised by a number of panellists as contributing to the increased stigmatization of living with HIV.

Stigma was described as layered. Individuals may live with multiple forms of stigma (e.g., people living with HIV who are gay), which can create significant barriers to care, including testing and engaging in care. A few panellists experienced stigma by health professionals after requesting HIV testing and thought that this type of stigma can also lead to avoiding testing. One panellist summarized this as, "because of the stigma that's attached to having

HIV, a lot of people will not get tested because they don't want it out there that they are positive."

In terms of marginalized groups, panellists felt that Indigenous peoples were the most marginalized and stigmatized of all the groups discussed. Panellists in the Winnipeg panel discussed the historical legacies of cultural dispossession and racism, and that many Indigenous peoples may be fearful of seeking care because of mistrust of government. One panellist also highlighted that two-spirit people used to be admired in communities, but that stigma has changed this.

Lastly, one panellist described challenges with social inclusion and provided an example of experiencing stigma when trying to find faith-based support in the community after diagnosis.

Lack of public awareness and education to address stigma

Many panellists described an overall lack of 'social education' as perpetuating stigma. High school health education was felt to be fear-based and perpetuating stigma associated with sexually transmitted infections. Panellists also thought that sex education was happening too late in high school, and that education was needed in middle school. Improving and offering health education earlier on was seen as a way to remove the shame and stigma associated with sex.

A few panellists also had concerns that HIV is no longer viewed by the public as a pressing problem as it once was. In particular, panellists indicated that they thought young people were not aware of HIV as an important issue. In addition, panellists felt that the public awareness generated though campaigns in the 1980s and 1990s has been lost. Similarly, some panellists felt that PrEP may give a false sense of security and that education in this area was lacking.

Privacy and confidentiality in testing and care are not respected

A number of panellists had concerns with privacy and confidentiality related to seeking HIV testing or care, particularly within rural and remote communities. For example, some panellists living in rural communities did not trust that their results would remain confidential and feared that health professionals or administrators within primary-care practices would disclose HIV status to the patient's family or members of the community.

One panellist cited this as the reason for leaving a small community and seeking care in a large city.

Limited access to social-systems supports

Limited access to social-systems supports was viewed as one of the biggest barriers to enhancing comprehensive care for people living with HIV. This challenge emerged most strongly in the Winnipeg panel where social supports were described as a core component (above health considerations) to providing comprehensive care for HIV. One panellist summarized the point as "you need the basics - it's survival."

Panellists also described limitations with community capacity, primarily lack of opportunities for meaningful engagement in policy/governance as well as the ability for self-determination to derive culturally appropriate policy and programs across health and social systems.

The problem is magnified for the most vulnerable

Throughout the deliberation on the problem, panellists highlighted that all of the challenges discussed are magnified for the most vulnerable. These include those who lack basic needs, Indigenous peoples, people who are or have been incarcerated, and/or people who use drugs. Panellists also noted that the social and structural challenges faced by vulnerable populations make it harder for them to seek testing and/or be engaged and retained in care.

Lack of timely data and use of evidence in policy decisions

A few panellists were frustrated with the lack of timely data in Canada and lack of consistency and standards in data collection across provinces and territories. In the Winnipeg panel, panellists wanted to learn how Canada compared to other countries with respect to the 90-90-90 targets. They were frustrated to learn that the UNAIDS country factsheet for Canada is empty, suggesting that the lack of timely Canadian data hinders cross-country comparisons.

Panellists also thought that research evidence was not used in many policy decisions and gave the example of point-of-care testing, noting that if decisions were based on evidence then the testing would be available more broadly.

"The idea of being under a common roof is so appealing for people who are just beginning to access services and need to figure out how to live with their health issue."

Discussing the elements:

How can we address the problem?

After discussing the challenges that together constitute the problem, panellists were invited to reflect on three elements of a potentially comprehensive approach to enhance the delivery of comprehensive care for people living with HIV:
1) strengthening comprehensive HIV care within the health system;
2) providing supports across social systems to address all of the challenges faced by people living with HIV; and
3) making small yet rapid changes to improve HIV care and supports over time.

The three elements can be pursued together or in sequence. A description of these elements, along with a summary of the research evidence about them, was provided to participants in the citizen brief that was circulated before the event.

Element 1 – Strengthening comprehensive HIV care within the health system

The discussion about the first element focused on improving the availability and accessibility of existing health services to address the complex needs of people living with HIV from diagnosis to death. As outlined in the citizen brief, this could include:

- improving point-of-care testing (for example, access to testing and who can provide the tests); and
- adopting patient-centred approaches to care that empower people living with HIV to become participants in their healthcare, such as:
  - the Chronic Care Model, which engages patients in their own care while preparing proactive healthcare teams,
  - patient-centred primary-care teams providing supports that are tailored to the unique needs of specific populations (for example, chiefs, elders, knowledge keepers and translators who can offer cultural and linguistic supports), and
  - geriatric models of care that are sensitive to the needs of the growing number of older adults living with HIV (including integration with long-term care settings).

> **Box 3: Values-related themes about strengthening comprehensive HIV care within the health system (element 1)**
>
> Five values-related themes emerged across the panels during the discussion about element 1:
> - fairness/equity in access to health services;
> - empowerment (e.g., for self-advocacy);
> - privacy (e.g., for HIV test results);
> - trusting relationships between patients, providers and organizations within the health system; and
> - collaboration among patients, providers and organizations within the health system.

Five values-related themes emerged during the deliberations about element 1 across the three panels: 1) fairness/equity in access to health services; 2) empowerment (e.g., for self-advocacy); 3) privacy (e.g., for HIV test results); 4) trusting relationships between patients, providers and organizations within the health system; and 5) collaboration among patients, providers and organizations within the health system.

A core theme across panels was the need to provide equitable access to integrated comprehensive care, so that people can achieve optimal outcomes regardless of where they live and the challenges they face. In emphasizing the importance of the patient-centred

medical-home model, one panellist stated that "the idea of being under a common roof is so appealing for people who are just beginning to access services and need to figure out how to live with their health issue." Preferences for enhancing access to comprehensive care included the use of interprofessional team-based care. Panellists also discussed improving access to nursing stations in rural and remote communities and using nurse practitioners to deliver point-of-care testing, follow-up and counselling on treatment options.

Second, panellists focused on empowering self-advocacy through education. Preferences for how to improve education included: 1) mass-media campaigns to normalize HIV and reduce stigma; 2) improving health education in school programs and offering it earlier (middle school); and 3) improving education regarding the criminalization of HIV non-disclosure. Panellists thought that improving education within these three areas would empower people living with HIV to advocate for themselves.

The third values-related theme was to ensure privacy of testing and increase the availability and equal access to anonymous and point-of-care testing across Canada. Panellists highlighted the importance of having standardized testing access across the country. One group summarized this as, "there needs to be clinics everywhere that allow for anonymous testing." Improving access to anonymous testing for married men was a particular area of focus, as they are a group that was viewed as often avoiding testing because of the stigma attached to it. Panellists also discussed proactive testing for at-risk groups through the use of mobile units and other forms of outreach. With regards to self-testing, some panellists felt that these types of tests could come with a 'what to do now' resource guide for positive results, whereas others were concerned with missing the built-in/immediate supports associated with testing in clinics.

The final two values-related themes focused on building trusting relationships and collaboration between patients, providers and organizations within the system. Renewed public-education efforts were raised by panellists as a way to reduce stigma and build trusting relationships between patients and providers. Improving electronic health records was viewed as a way to allow for seamless transitions in care (e.g., a universally accessible electronic health record system that is easy-to-use, secure and that all parties involved in care have access to). Lastly, bringing care to the individual was an important component of building trusting relationships and collaboration between patients and providers. The use of mobile units or virtual care were preferred, especially for marginalized and hard-to-reach populations.

Element 2 – Providing supports across social systems to address all of the challenges faced by people living with HIV

The discussion about the second element focused on ensuring that efforts to diagnose people living with HIV and involving them in their own care are comprehensive. This will require combining care from health systems (element 1) with care from social systems to address the unique challenges associated with living with HIV. As highlighted in the citizen brief, this could include activities focused on integrating delivery arrangements (how care is organized), financial arrangements (how money flows from taxpayers to government to organizations and professionals) and governance arrangements (who can make what types of decisions) in health and social systems.

> **Box 4: Values-related themes about providing supports across social systems to address all of the challenges faced by people living with HIV (element 2)**
>
> Three values-related themes emerged across the panels during the discussion about element 2:
> - fairness/equity in access to social services;
> - trusting relationships between clients, providers and organizations within social systems; and
> - collaboration among clients, providers and organizations within social systems.

Panellists viewed this element as being the most fundamental, yet potentially most difficult to achieve. There was consensus among participants at the panel in Winnipeg that actions towards strengthening social systems should be prioritized first, given that doing so would address the underlying challenges (e.g., housing, poverty and stigma) that put people at risk for HIV and make getting diagnosed and engaged in care challenging. Deliberations about this element also emphasized that strengthening social systems is particularly important for hard-to-reach and marginalized groups, and that engaging peers with lived experience in providing supports and assistance with system navigation is crucial.

Three main values-related themes emerged during the deliberations about element 2 across panels: 1) fairness/equity in access to social services; 2) trusting relationships between individuals, professionals and organizations within social systems; and 3) collaboration among clients, professionals and organizations within social systems.

The values that emerged were inter-related and panellists focused on enhancing coordinated care by combining health- and social-systems supports under one roof. One specific suggestion was to develop and implement community health teams for coordinating needed supports, especially following diagnosis when people are often vulnerable and need support. For example, it was emphasized that when people leave a physician's office, they need to be connected with someone from the social system to ensure they can help with getting access to needed medications, healthy food and stable housing, as well as help answer questions or get access to resources that are needed.

Supporting system(s) navigation was identified as a critical component to enhancing comprehensive care for people living with HIV. Panellists thought this could be done through community workers or peers with lived experience. For example, a buddy-system approach was identified as being important in each of the panels, especially for smaller areas where there may not be trained people to help with system(s) navigation.

Lastly, in terms of equity of access to needed services, panellists highlighted the need to increase access to affordable supportive housing as well as investments in food banks. Panellists also thought that there could be more strategic use of services to engage hard-to-reach populations. One example was to combine and mobilize existing supports, such as offering food when running a health clinic, or needle exchange vans offering point-of-care testing.

Element 3 – Making small yet rapid changes to improve HIV care and supports over time

The discussion about the third element focused on an approach called rapid-learning systems that focuses on making many small yet rapid changes to health and social systems at all levels. For example, changes could be to self-management, interacting with care providers, programs, organizations, regions within a health system and government policy. As covered in the citizen brief, the rapid-learning approach is:

- anchored on the needs, perspectives and aspirations of people living with HIV through the 'Greater Involvement of People Living with HIV/AIDS/ Meaningful Engagement of People Living with HIV/AIDS' (GIPA/MEPA) principles;

- driven by up-to-date evidence and data;

- supported by coordinated governance, financial and delivery arrangements; and

- enabled with a culture of and competencies for rapid learning and improvement.

> **Box 5: Values-related themes about making small yet rapid changes to improve HIV care and supports over time (element 3)**
>
> Six values-related themes emerged across the panels during the discussion about element 3:
> - accountability;
> - collaboration among patients/clients, providers and organizations within health and social systems;
> - basing decisions on data and evidence;
> - basing decisions on citizens' values and preferences;
> - continuously improving (e.g., quality of HIV-related data); and
> - ensuring excellent health outcomes.

While panellists struggled to some extent with the specific concepts included in this element, there was consensus across panels about its importance, with one panellist in St. John's indicating that "it seems like a common-sense approach." A rapid-learning approach was thought to be more achievable than trying to reinvent entire health and social systems. Other panellists noted that important aspects of the approach are that small changes that are successful can be grown into larger initiatives, and that it seems to fit better for political cycles that also function on short timelines. Another panellist noted that using this approach for system redesign is reminiscent of when HIV medications where first starting to come out given that they had to be rapidly evaluated and adjusted.

Six main values-related themes emerged during the deliberations about element 3 across panels: 1) accountability; 2) collaboration among patients/clients, providers and

organizations within health and social systems; 3) basing decisions on data and evidence; 4) basing decisions on citizens' values and preferences; 5) continuously improving (e.g., quality of HIV-related data); and 6) ensuring excellent health outcomes

Panellists identified six preferences for the implementation of rapid-learning systems, which are underpinned by the five values-related themes discussed above. First, panellists discussed creating an accountable organization(s) that can identify what changes could be made, and then independently monitor, evaluate and intervene right away to make needed changes within the system. Second, panellists emphasized the need to develop and implement an interconnected database that is standardized across provinces and territories. The database would ideally provide timely access to continuously updated and anonymous HIV-related data and evidence to promote increased learning and sharing across the country. Third, panellists emphasized the role of local solutions that can then be adapted for use elsewhere based on data and evidence and the values and preferences of citizens. Similarly, panellists felt that communities need to be empowered to set their own priorities and create tailored responses to local issues. Fourth, structures are needed to ensure processes are led by communities and meaningful engagement of people living with and affected by HIV (e.g., community councils that support people getting involved). Lastly, the development of a common language and understanding is needed in order to facilitate collaboration among patients, providers and organizations within health and social systems.

"Moving from helplessness and hopelessness to empowerment and hope."

Discussing implementation considerations:

What are the potential barriers and facilitators to implementing these elements?

After discussing the three elements of a potentially comprehensive approach to enhance comprehensive care for people living with HIV, panellists discussed potential barriers and facilitators to moving forward. Panellists identified the limitations of political cycles as preventing meaningful change. Many panellists had doubts over the feasibility of larger and long-term changes given these short political cycles. Finite financial resources were also viewed as a barrier to change as some of the elements discussed may require additional investment. Suggested reframing by panellists was to instead focus on how to use existing resources in the best way. The biggest barrier identified across all three panels was stigma, which one panellist summarized as, "stigma - that's what prevents so many things from being implemented."

When turning to potential facilitators for moving forward, panellists emphasized leveraging HIV hubs of knowledge where there are clinicians and researchers working together. These knowledge hubs provide opportunities to make research evidence accessible in a timely way. Panellists also felt that HIV could be used as an exemplar within health systems, with one panellist stating that "get it right for HIV and get it right for everyone else." Lastly,

panellists focused on the important role of social media and that it provides many opportunities to build awareness, which could also be used to push rapid-learning approaches forward. One suggestion from the Hamilton panel for the use of social media as a facilitator was to use #imokay to build awareness and reduce stigma associated with living with HIV.

Acknowledgments