

Pieces of Glass: A Mosaic of Solutions

Report of the Forum on Refugees and Chronic Disease



Organized by HealthPartners and the UN Refugee Agency
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Preface: About the forum

On September 6, 2018, HealthPartners Canada and Office of the United Nations High Commissioner for Refugees in Canada, also known as the UN Refugee Agency, hosted the very first public conversation about the particular challenges facing refugees who are diagnosed with chronic disease, both in Canada and prior to their arrival.

The forum brought representatives of government, settlement agencies, and health charities together with refugees and other sectoral representatives to explore the scope of those challenges and work toward a plan of action to address them.

HealthPartners sincerely acknowledges the leadership of ProjectBe—an initiative of young federal government leaders and donors—around this issue.

Introduction: The Scope of the Challenge

The *Forum on Refugees and Chronic Disease* focused on the everyday challenges and structural barriers to good health facing refugees, both before and after their arrival in Canada, and the mosaic of solutions taking shape to help new arrivals gain access to appropriate care and support. Through panel presentations and group discussion, participants began crafting an integrated menu of strategies to help refugees connect with the services and community supports that anyone needs to live a healthy, productive life.

One panelist compared the mix of resources refugees need to pieces of glass, each of them coming from a different source, all of them essential to craft a complete mosaic. The pieces of that picture might come from innovation in government, from leadership by front-line agencies or non-profits, from refugees themselves and their local communities, from Canadians as a whole, or from a basic understanding of the social determinants of health. But they all share the same, essential starting point: chronic disease doesn't discriminate, and neither should we.

As the session got under way, HealthPartners Canada CEO Eileen Dooley noted that 87% of Canadians are likely to be affected by chronic disease at some point in their lives, which was verified by forum participants. "We see the direct impact of chronic disease and major illness on individuals," she said. "But what we've talked about up until now is the impact on Canadians." She thanked the Government of Canada Workplace Charitable Campaign (GCWCC) and members of the Youth Cabinet's Project Be Committee¹ for naming refugees and chronic disease as a significant issue, "identifying this as a priority for all of us to look at it as a cause we want to rally around and start a conversation."

A critical part of the work of HealthPartners and its member charities is to reduce the incidence of chronic disease. The organizations have identified the clear link between stress and certain chronic diseases, including mental health issues. "I can't think of a more stressful situation than being a refugee," Dooley added. "Having to leave your country of birth. Having to go through the process of moving to a new culture, a new country, a new way of living, sometimes with support, sometimes without adequate support." She pointed to health as "an issue that unites us all," noting that "it's profoundly individual, but we all want good health for our community and our country. Everyone has that desire in common."

Jean-Nicolas Beuze, UNHCR Representative in Canada, recounted the stress refugees and their families face when treatment for a chronic disease is unavailable to them, and the sometimes cataclysmic family impacts that result. "It's something we don't speak much about," he said. "We speak about the numbers," acknowledging that half of refugees are children and many of them are not in school. "But we rarely speak about what it means to be a refugee with a chronic disease."

¹ The GCWCC Youth Cabinet's Project Be rallies public servants to support refugees across Canada.

The Refugee Experience, Health, Wellness, and Chronic Disease

Settlement agencies believe that half of all refugee families have at least one family member with a chronic disease, making health a huge factor in the opportunities that family can tap into and its ability to stay out of poverty. Participants heard wrenching stories of families torn apart by despair when they could not arrange treatment for a loved one, new arrivals who often had to interrupt life-saving treatment before they arrived in Canada, and health and humanitarian aid professionals traumatized when they saw what the patients in their care were going through.

One panelist pointed to the aspects of the refugee experience that lead to greater health vulnerability, beginning with the poor hygiene, lack of privacy, and limited access to potable water in many refugee settings. Refugees are effectively shut out of the highly privatized health systems in some first countries of arrival, since they aren't eligible for publicly available services and can't afford to pay for care. These factors and many others add to a level of stress that is omnipresent for refugees and becomes a serious health risk in its own right.

Jean-Nicolas Beuze said the most common chronic diseases among the refugee population include diabetes, cardiovascular and chronic lung disease, cancer, and arthritis—much the same list practitioners would expect in the general population. But those conditions are often complicated by stress, poor living conditions, and lack of treatment for communicable diseases like tuberculosis, hepatitis, and HIV/AIDS. With only limited data to draw on, practitioners believe that 16% of Syrian refugees—who make up one-quarter of the global refugee population—have been diagnosed with a chronic disease. Out of 25 million refugees, half are children.

Beyond that figure, many refugees with chronic diseases remain undiagnosed because they haven't had access to health assessment or specialized medical treatment. That's partly because many refugees put other priorities first: they'll focus first on finding shelter, putting food on the table, and getting their children into school, even it means neglecting their own health. Furthermore, even if health is a priority, many refugees (and settlement agencies) don't know where to turn to get help.

Young refugees with chronic disease and disabilities, are considered among the most vulnerable within an already vulnerable population, said public servant Mohamed Zakzouk, a member of the GCWCC's 2017 Project Be Committee. Many of them end up abandoned, exposed to harsh physical conditions that make them even more susceptible to chronic disease. One panelist who had faced those challenges explained how important it was to come to a country where he could hope for better accommodation of his particular disability, but how difficult it had been to start a new life in a place where "you have to do everything differently".

He also urged refugee service providers to recognize that the people they are working with lived somewhere else before they came to Canada. "We do have a past," he said, although that past will differ significantly for people who spent two or three years in refugee camps compared with those who were born there.

University of Toronto student and advocate Habon Ali, a member of the Prime Minister's Youth Council, recounted the rude, condescending treatment her parent had received from a health care provider shortly after the family arrived in Canada.

That experience motivated her to work in advocacy and deliver cultural sensitivity training for a municipal public health unit. She said the challenges and barriers refugees face in Canada are similar to the issues confronting other populations with low socio-economic status.

Embracing Solutions: How Canada Responds

Canada generally sees itself as a world leader in resettling refugees with chronic medical conditions, making available places for people who can't get the medical treatment they need in their countries of first arrival. While the number of people involved will necessarily be limited by the ability of medical facilities to respond, one panelist said there are cases where "we have no other solution but to ask Canada" to provide life-saving support. One purpose of the day's discussion was to explore how we can collectively help smooth those new arrivals' treatment and integration once they reach their final destination in Canada.

That conversation unfolded against a backdrop of increasing urgency. "We're in a world where, unfortunately, the global resettlement need is growing, and the resettlement spaces available are not keeping pace," said one panelist. "So anything we can do to find new solutions to problems, new ways to look at traditional processes, and perhaps make them more efficient to get the solutions out there more quickly, is well worthwhile."

Immigration, Refugees, and Citizenship Canada (IRCC) is working with a 2018 objective of 27,000 refugees and protected persons, of whom 10,000 are referred by UNHCR and, of those, 5% are medical cases. "We want to make sure we're able to offer the appropriate supports to the refugees who are being resettled, and not overwhelm the system," explained Jean-Marc Gionet, Senior Director, Resettlement Operations at IRCC.

Michael McKinnon, IRCC's Senior Director, Migration Health Policy and Partnerships, explained the regulatory requirements on infectious disease and public health and stressed the information and knowledge gaps the department is working to address.

Private sponsorship of refugees has been a central part of the Canadian immigration system since 1979, when the country welcomed 60,000 people from Southeast Asia in 18 months. The private sponsorship network delivers immediate support to new arrivals, allows groups of Canadians to highlight and take action on international equity and human rights issues that matter to them, and demonstrates a level of interest and commitment that captures the attention of governments. It was noted that Canada has a great deal about which to be proud, given the support that private sponsors have provided. Canadian sponsors are encouraged to sponsor refugees with whom they share a similar medical conditions given their insights into available treatments and how to address the challenges they may face.

It was noted that refugee sponsorship also changes the lives of the volunteers who step up with their time, dollars, and commitment: "While we helped them transform their lives, it was also transforming us," said one program participant. "We change as we help." And when refugees arrive with chronic diseases, it changes the way their sponsors support them, advocate for them, and think about other people in the wider community.

For many privately sponsored refugees, medical assessments conducted overseas help inform the decision about their eventual destination in Canada, and a settlement plan with funding is in place before they arrive. IRCC also works with sponsors to make sure they understand the health issues the new arrivals face, and can help them activate the appropriate local health networks. Canadian sponsors should be encouraged to sponsor refugees with whom they share a medical condition, thereby addressing the needs of the most vulnerable.

Reflecting a major theme of the forum, Nyiri DuCharme, Youth Co-Chair of the 2018 GCWCC Cabinet and Chair of Project Be, said the ideal integration plan for young refugees would make the transition to Canadian health care easier and clearer. Entering a system with more tools, services, and opportunities is an important advantage, but it can take years to learn how to navigate that system. At the same time, once relatively recent refugees have become familiar with the health services available to them, they can play an essential role in introducing and explaining the system to even newer arrivals.

Another panelist pointed to a solution that would be a welcome change to anyone who interacts with the health system: while refugees have access to exceptional health organizations and initiatives in different parts of the country, those programs often operate in silos, with only limited communication or coordination. She said a more effective institutional structure would help all patients, but refugees in particular, deal successfully with chronic disease. One service provider described a community where youth services are working well, with close integration across recreation, social outings, art therapy, health services, and the social media platforms where youth are a constant presence. He stressed the importance of communication and coordination between youth programs and the settlement sector to deliver on the unique needs of refugee youth.

How Multidisciplinary Strategies Create Access

Dr. Michael Stephenson, founder of the Sanctuary Medical Clinic in Kitchener, Ontario, talked about his work over the last 5½ years to build a system that creates access to health care for new arrivals in Canada. Since the day in April 2013 when Stephenson opened his clinic in a church library with six patients booked—only one of whom showed up—Sanctuary has grown into a program that serves nearly 3,200 people, in a much larger space that will soon be expanding again.

“This is a population that is so rewarding to work with from a humanitarian perspective,” “Dr. Mike” told participants. It’s an opportunity “to give of ourselves, to share experiences and hopes and dreams that we have as residents of Canada,” but also to see how those same hopes and experiences manifest around the world. “Sometimes we have different viewpoints, different angles,” he said, but “so many of us are the same.”

When Stephenson first arrived in Kitchener-Waterloo, he quickly realized the community had no facility or service that could help refugees with their ongoing health care needs, beyond an initial screening and the first few months of care. It was difficult for new arrivals to get language supports, cultural understanding, or a service where practitioners were willing to “figure out the whole person and strategize to help them improve their health.”

The solution was a “very multidisciplinary” clinic, starting from the understanding that “the issues are solvable, the issues are things we can tackle, but everyone has a part to play.” In addition to traditional health providers, Sanctuary employs or works with translators who also act as “cultural brokers”, helping patients navigate a Canadian health system that is complex, and different from what they experienced in their countries of origin. The larger team includes physicians, a physician assistant, nurse practitioners, social workers, settlement workers, an Ontario Works case worker, a dietitian, a psychologist, and a Local Health Integration Network (LHIN) care coordinator.

“It’s a different way of providing medicine,” Stephenson said. “It needs to be more flexible, more responsive.” The ultimate goal, he added, is for patients to come away with a “sense of good health” so they can go to school, start businesses, or do whatever else they need to establish themselves. When a patient drops in with the news that they’ve just become a citizen or bought a new house, “those are the really good things. It means the health barriers are no longer there” that would prevent them from fully participating in society.

Stephenson stressed the importance of a coordinated, multidisciplinary practice model, noting that people facing system access issues like homelessness or poverty respond differently to different practitioners: a new arrival might be more comfortable sharing important information with an interpreter, rather than a doctor, or a sponsor might be the first to flag an important issue. Information on different chronic diseases must be available in multiple languages, and the connection to the Kitchener-area LHIN was essential in elevating refugees as a priority population in the region, and in making primary health care available across languages and cultures.

Inclusion and Integration for All

Two of the most poignant messages from panelists and participants were that integration into a new society is a painful journey, and that refugees with chronic diseases face the same access and inclusion issues as members of other vulnerable populations who’ve been in Canada much longer.

Dramatizing the scope of the challenge for new arrivals, settlement worker Paul Soubliere of Ottawa’s Catholic Centre for Immigrants recalled a Somali woman who told him that, if she’d realized how difficult it would be to integrate with a new society and culture, she “would have taken the bullets back home.” Housing, transportation, food security, and social isolation are all social determinants of health, and refugee support organizations do work closely with local health services. But ultimately, “our business is capacity-building,” he said. “We’re big on identifying challenges and filling the gaps to extend our arms to the newcomers to our communities, to give a nice, proper, and meaningful welcome to Canada.”

Soubliere and co-panelists Brian Dyck of the Mennonite Central Committee and Sabine Lehr of the Inter-Cultural Association of Greater Victoria stressed that supporting refugees with chronic diseases is not about building a one-size-fits-all service: every culture and population is different, and young refugees bring their own specific needs, often including the responsibility to interpret or advocate for their older relatives.

“The settlement sector is good at setting expectations, providing hope, and building trust,” Soubliere said. When it comes to health services, the task is to “find out who can be part of a healthy circle of support, address health challenges, reduce stress, and just watch the potential that comes out of it”. He added that a sense of hope is particularly important for young refugees with chronic disease who are also struggling with the resettlement process.

Two questions many Canadians often ask are why refugees can't just get the health services they need in their countries of origin, and whether the care they receive after they arrive displaces Canadians. Panelists pointed to the parallels in health needs across refugees and other populations, noting that Canada has always been a country built by immigrants and arguing in favour of a system that meets refugees' health needs in the first months after they arrive.

“If you make it here as a refugee, as far as I'm concerned you should have access,” said one service provider, noting that the concept of inclusion “improves everything for everyone,” adding that few people are not a member of some minority or special-need population, and that a successful strategy when anyone expresses opposition to refugee services is to invite them to meet some refugees and hear their stories of struggle and success.

A panelist stressed the need for targeted services for refugee youth with visible chronic diseases that put them at risk of exclusion and stigma, and may also place them in a delicate position with their parents, who might see their health conditions in a less sensitive, more critical light. “They want to be like any other youth,” but “people think they're weaker or can't participate” because of their health condition, he said. Young people in that position need opportunities to share their experience and understand what it means to live with a chronic disease: otherwise, they may refuse medication or avoid medical appointments, in a bid to sidestep social pressure and fit in with their healthier age peers.

Eileen Dooley noted that it is not well known that three out of five Canadians have a chronic disease profile by the age of 20, and there should be no difference in the opportunities available to refugee or Canadian-born youth. “We're seeing earlier and earlier onset of chronic disease, some of which is preventable, some of which is not,” she said. “It behooves us to step up and make sure there's access to these services, not just to health care, but to the services, programs, and supports that our health charities provide.”

Taking Action

Much of the discussion during the forum focused on the action items organizations could take away to begin addressing refugees' challenges with chronic disease over the next year. Panelists and participants suggested that:

Initiatives within the Health Community

- Health charities could open internal conversations to extend programming to refugees.
- The health system as a whole would benefit from a deeper understanding of cultures and cross-cultural communication.
- Health services still rely too heavily on refugee youth to interpret for their older family members, and have a long way to go to clear a heavy burden now being carried by children as young as 10.
- Public health campaigns can have a major impact on chronic disease and healthy practices as long as they run in different languages, emphasize community-building, respond well to different cultures, and advocate solutions that work well in practice, not just on paper.
- Health charities (and other prospective sponsors) can take advantage of the Refugee Sponsorship Training Program to learn more about the process.
- Sponsors are sometimes hesitant to take responsibility for a refugee with a chronic disease, either because they don't understand the disease or anticipate problems navigating the health system. Several panelists and participants pointed to the role health charities could play in connecting refugees with the health-related services they need, or by encouraging their supporters to offer private sponsorships for refugees with the same health condition or experience. One panelist offered to present that idea to patients and physicians in her organization.

Program Development and Implementation

- With conditions like Type 2 Diabetes, care and self-management programs for refugees must take account of the stress and post-traumatic stress they face—as a factor in the onset of the disease, and a possible limit on the selfcare they can take on.
- Programs for refugees must factor in their frequent economic vulnerability as a barrier to healthy housing, food security, exercise and physical activity, medications, child care, and transportation, and as an impediment to health care visits that require time off work. Krista Baranskiak, Manager of Research and Public Policy at Diabetes Canada, noted that a healthy built environment that enables walking and transit use can help protect people from the onset of Type 2 diabetes, but not everyone has access to that kind of housing or neighbourhood.
- A number of local programs have had good success with intensive case management, and should continue sharing best practices across different sites, and between rural and large urban communities.

- Front-line organizations can host social or recreational activities that deliver culturally appropriate health messages to different groups of refugees. They can and should also seek advice and feedback on their publications for specific audience groups, and make prevention visual by using specific, culturally appropriate photos and images.
- Cultural training for anyone who works with refugees with chronic diseases must include opportunities to understand an individual's living conditions and their concept of health and illness.

Empowering Refugees with Chronic Disease

- Refugees with chronic disease, particularly refugee youth living with disabilities, need opportunities to tell their stories and express themselves.
- Refugee parents need opportunities to advocate for their children with chronic diseases, and support for the work and opportunity costs they face in taking care of them. That work will continue and become more complex as children with some conditions grow into adolescence, and parents will need community support over the long haul.

Integration Support

- Past sponsors are often the best advocates and resource people for government-assisted refugees.
- Chronic disease prevention, early screening, and treatment are as important to refugees as they are to any other population—more so, given the range of life stresses refugees are dealing with. Programs and policies should promote and enable diet modification and healthy physical activity in ways that are culturally appropriate. Screening should be available outside doctors' offices, where people already gather.
- Subsidies for healthy foods would make better nutrition more affordable for people with low incomes.
- The fiercest, most effective advocates for refugees with chronic diseases or disabilities are often the members of sponsorship groups who have the same conditions. After a faith community in Winnipeg agreed to sponsor a family from South America, a church member who uses a wheelchair focused on an individual refugee who was in the same position—she knew what services he would need, could anticipate how difficult he would find it to navigate snowy streets in winter, and brought her own experience and passion to his resettlement process.

Public Infrastructure

- Built environments should be designed with health in mind, with emphasis on green spaces, safe walking trails, destinations of interest within walking distance, and better public transit. To avoid exacerbating health inequities by gentrifying existing poor neighbourhoods, urban planning should work in partnership with affordable housing organizations, transit advocates, and settlement service providers.

Next Steps

At the end of the forum, participants expressed appreciation for the opportunity to begin the conversation about issues related to refugee health and chronic disease. HealthPartners committed to circulate this report to all participants as well as to share the list of those participants, as well as to do its part to foster continuing collaboration in this extremely important area. Participants and forum organizers and sponsors expressed a shared, urgent interest in fostering further connections, dialogue, and action to shift the way Canada sees—and responds to—the issue of refugees and chronic disease.

Appendix: List of Speakers

Co-chairs:

Eileen Dooley, CEO, HealthPartners Canada

Jean-Nicolas Beuze, UNHCR Representative in Canada

Habon Ali, Student and Member of the Prime Minister's Youth Council

Hani Al Moulia, Student and Alumni of the Prime Minister's Youth Council

Krista Banasiak, Manager of Research and Public Policy, Diabetes Canada

Brian Dyck, Migration & Resettlement Program Coordinator, MCC Canada

Jean-Marc Gionet, Senior Director, Resettlement Operations, Immigration, Refugees and Citizenship Canada

Lise Latulippe, Adi Shakti Yoga Centre

Sabine Lehr, Inter-Cultural Association of Greater Victoria

Michael MacKinnon, Senior Director, Migration Health Policy and Partnerships, NHQ - Migration Health, Immigration, Refugees, and Citizenship Canada

Paul Soubliere, Program Manager, Catholic Centre for Immigrants, Ottawa

Dr. Michael Stephenson, Physician, Sanctuary Refugee Health Centre, Kitchener

Mohamed Zakzouk, Analyst, 2017 GCWCC Youth Cabinet