

WHITE PAPER

Bridging Gaps: Advancing New Immigrant Participation in Clinical Trials to Enhance Diversity

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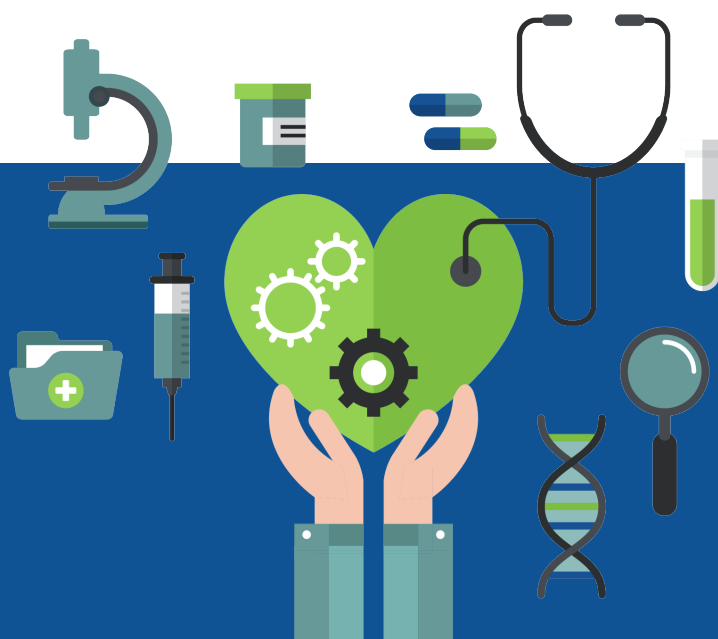
BACKGROUND

Clinical trials play a pivotal role in advancing medical research and shaping the future of healthcare by evaluating the safety and efficacy of new treatments and interventions. However, ensuring diverse participation in these trials is essential to truly understand how treatments work across different populations. By including individuals from diverse backgrounds, including various racial, ethnic, socioeconomic, and geographic groups, clinical trials can provide more comprehensive insights into how treatments may affect different demographics, leading to more inclusive and effective healthcare outcomes for all.

Historically, clinical trials have lacked diverse representation in their study populations (U.S. Department of Health and Human Services, 2023). Many studies, including Canadian ones, disproportionately over-represent Caucasians, despite the diverse population of Canada (Walker, 2021). Today, only 1%-3% of the eligible Canadian population participates in clinical trials (Silversides, 2009). For cancer trials, the reported rates of trial participants to new incident cancer cases are 4.7% overall, and as low as 1% in some Canadian provinces, as compared to 14% in the UK (Canadian Partnership Against Cancer, 2018; Sinha, 2007). This diversity is imperative for assessment of population specific risks, efficacy of interventions, and generalizability of the research (Government of Canada, 2023).

To address these inequities, efforts have increasingly focused on exploring barriers to inclusion and recruitment. Studies have highlighted how socioeconomic status impacts and creates barriers that are vital to address to improve recruitment (Corneli et al., 2023). For example, a 2021 study highlighted that lack of accessibility to the study location may pose as a barrier, resulting in recommendations for decentralized trials or allocation of additional funding for transportation (Skalicky & Hareendran, 2021). Additionally, another study recognized that language could be a barrier in the study process and strategies to bridge communication were shared (Palumbo et al., 2022). Adapting recruitment strategies for improving inclusion is a growing focus as well, including creation of comprehensive

“Today, only 1%-3% of the eligible Canadian population participates in clinical trials.”



recruitment materials and creating connections with local organizations that serve and work with these populations to establish trust and develop relationships (Walker, 2021; Government of Canada, 2023; Schapira & Smith, 2023).

Awareness of poor diversity in the clinical research field is improving. The Canadian Institute of Health Research (CIHR) has created specific policies to support diversity, inclusion, and equity within clinical trials (Canadian Institutes of Health Research, 2023). Natural Sciences and Engineering Research Council (NSERC) has also provided guidelines on diversity and inclusion practices within each aspect of the research process (Natural Sciences and Engineering

“Projections have determined that by 2041, immigrants will account for 34.0% of the total Canadian population.”

Research Council of Canada, 2023). While this is a step in the right direction, addressing disparities for specific minority groups, such as the immigrant population, is also necessary to consider due to varying barriers and lived experiences of communities.

The immigrant population is grossly underrepresented in the current Canadian research field. According to Statistics Canada, in 2021 almost a quarter of the population was composed of immigrants. Furthermore, recent population projections have determined that by 2041, immigrants will account for 34.0% of the total Canadian population (Statistics Canada, 2022). There are very limited studies focused on strategies to increase recruitment within this population, despite the understanding that immigrant populations have their own specific health concerns and disparities (Jindal, 2020). Studies show that visible minorities have significantly higher rates of untreated chronic and acute disease, poorer health outcomes, and higher mortality rates than the rest of the population (Jamal et al., 2021). A United States study on recruitment of immigrants and minority groups with

first-episode psychosis detailed how vital continuous communication was for the establishment of trust and engagement with this population (Hernandez et al., 2019). Another study, focused on recruitment of undocumented African immigrant women, highlighted that recruitment through trusted community members provided the most success (Olukotun & Mkandawire-Valhmu, 2020).

Various frameworks and approaches have been published to assess for equity and inclusion throughout development and clinical research process (Plamondon et al., 2023; Martin-Kerry et al., 2023). The Systematic Equity Action-Analysis (SEA) Framework, for example, allows for analysis through four elements: worldview, coherence, potential, and accountability. Questions are posed within each of the elements in a systematic approach to assess for equity integration within the appropriate setting. The process allows for reflection and dialogue surrounding various contexts, such as consideration towards diversity and inclusion within the research field (Plamondon et al., 2023). Assessment of various asset-based approaches, completed by Martin-Kerry et al. (2023), also provides a framework to characterize the research process. This is applicable in the context of bridging relationships and creating novel techniques to promote participation within the clinical research field with new immigrants. This approach highlights working with the population and communities to identify strengths and changes that can be made for an overall common agenda and utilizing these to make connections and implementations at the local or system level (Martin-Kerry et al., 2023).

Overall, there is a scarcity of information regarding the participation experiences of immigrants in clinical trials. It is crucial to develop strategies for enhancing and addressing the representation of diverse groups in Canadian clinical trials by comprehensively understanding their experiences and the obstacles they face in participating. This approach is essential for creating a study population that accurately reflects the diversity of the Canadian population, ultimately ensuring the effectiveness and relevance of clinical trial outcomes for all individuals. Raising awareness and providing education about clinical trials among immigrant populations is a crucial step toward achieving this goal.

METHODS

The Canadian Institutes of Health Research [CIHR], Canada's federal health research funding agency, granted an award to N2 Canada [www.n2canada.ca] to host a Café Scientifique. The Principal Investigator on the grant was Dr. Rachel Syme, University of Calgary.

Cafes are funded events designed to facilitate knowledge sharing and foster open, respectful dialogues between the public and health research experts. These gatherings focus on discussing health-related issues of public interest and are specifically customized to address the unique needs of the community they engage with.

The focus of this Café Scientifique, led by the N2 Public Engagement Committee, was to bring together people with lived experience as new immigrants to Canada, to explore the challenges and barriers they faced in accessing and participating in clinical trials. This community consultation was held at a public community centre in Toronto, Ontario on October 5th, 2023.

Recruitment posters were created and posted around the community inviting new immigrants to join in on a conversation about health research in Toronto. The language of the event flyer emphasized that the event was free of charge and provided refreshments and childcare services for attendees. The local community centre staff assisted with promoting the event and sharing information with interested individuals. recruitment materials and creating connections with local organizations that serve and work with these populations to establish trust and develop relationships (Walker, 2021; Government of Canada, 2023; Schapira & Smith, 2023).

The event was hosted at a local community centre within a neighborhood that has a high population of new immigrants. The community centre acts as a local hub, offering extra-curricular activities, after school programs, computer rooms, gym facilities, and a kitchen. The community centre is also physically accessible to the public.



OBJECTIVES

These were the stated objectives of the Café Scientifique:

- Increased awareness and understanding of clinical trials within new immigrant communities
- Enable the clinical trials community to develop effective materials to engage new immigrants in clinical trials
- Increased understanding of the barriers that newcomers experience to participating in clinical trials
- Create a model for future workshops to enable the clinical trial sector to host them within their community



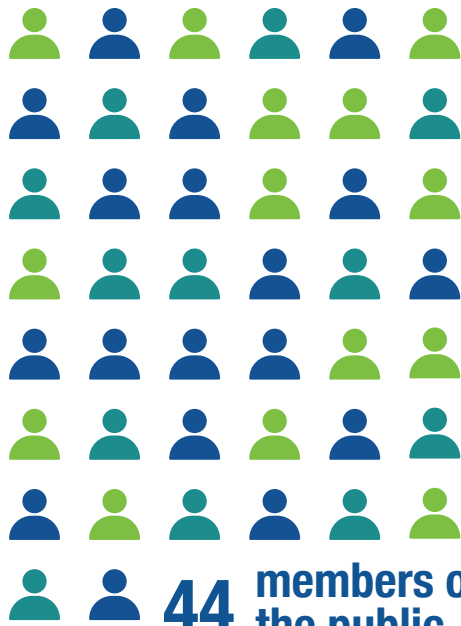
A total of 44 members of the public attended the event, all new immigrants, who had been residing in Canada less than five years. The group was composed of a diverse range of ethnicities and languages.

The program began with a couple of short presentations. The initial presentation concentrated on the basics of clinical research, offering the audience an introduction to the fundamentals and the nature of clinical research. The second presentation took a caregiver's standpoint, delving into the lived experience of an individual participating in a clinical trial.

Following the presentations, the audience was organized into smaller groups of 5-6 individuals. Each group had two facilitators to guide discussions, using specific questions. The focus of these discussions was on the lived experiences of new immigrants, exploring how such experiences influence their access to clinical and research trials, and identifying any barriers they encounter.

The format of group discussions facilitated a thorough exploration of the challenges encountered by these communities, aiding in the identification of specific areas that could be targeted to improve recruitment and participation in clinical trials. After the event, attendees were invited to complete a satisfaction survey. The survey explored the impression of the event and solicited evaluation and feedback.





FACILITATOR QUESTIONS

The facilitators used the following questions for the discussion:

- What did you think about the presentations? Is there anything you are wondering about? Is there anything new you learned today?
- What do you know about clinical trials?
- What do you think about the role of clinical trials in the health system?
- What would you want to know about a trial before participating in it?
- Do you think immigrants to Canada should/can participate in trials?
- How and where would you like to be approached about a research study?
- Would you like to have someone discuss it with you verbally? Online? Written communication?
- Would you like to make decisions by yourself or have family with you?
- What would make it easier to participate in a clinical trial?
- What will prevent you from participating in a clinical trial?

KEY FINDINGS

Through the discussions, several significant insights emerged regarding the obstacles this community encounters in engaging with clinical trials.

Accessibility



Uncertainty of where to find reliable information about clinical trials

"In every family there is always someone touched by sickness, and we are always 'listening' for new treatments and new trials."

"When participants come from other countries, they have a different experience with research studies. They're understanding may include thinking that scientists are testing "new" drugs on them..."

Communication



Lack of diverse representation in clinical trials materials.

More information and awareness should be spread through in person, community based interactions

Family and caregivers should be involved in decision making, with permission from the patient.

"Parents and caregivers know best what they are going through. This should be given importance."

"Come to the community and hold events like these, with real people telling their story."

Cultural Competence



Researchers lack knowledge about cultural or religious constructs.

"Some individuals cannot give blood, so would this prevent them from participating? Are there exceptions?"

"Immigrants have pre-existing trauma; cultural / contextual sensitivity is needed when approaching these patients."

Language



Clinical trials related materials, not being accessible (ie language/ language level)..

"Language barriers can be addressed by incorporating more translators in clinical trials staff teams."

"Different people process information differently. For example, the word assessment. When I hear this, I think of a test"

Transparency



Hesitancy amongst individuals with regards to perceived risks of participating in a trial, some of them include: management of adverse events, being randomized to a placebo group, and fears of being 'experimented' on by researchers, motivated by financial gain.

"What are the side effects... This is my main concern."

"We are reluctant to try new drugs that are not in the market"

"They need to know what drug actually does"

"We have our reservations in trying a trial or new medicine whether it will be beneficial or not?"

"Will the new drug negatively impact our body?"

Trust



Level of trust in healthcare providers can be a barrier or facilitator

"Patient is already stressed. Imagine how it feels not having someone you can trust."

"Clinical trials help people, but we are concerned about trusting the doctor."

"I don't hide anything from my doctor but sometimes the barrier is that you can't have that open communication with your doctor. They can be dismissive."

DISCUSSION

Clinical trials have historically demonstrated poor representation of diversity in their study populations (U.S. Department of Health and Human Services, 2023). Immigrants are often underrepresented, particularly in Canadian studies, while they encompass almost a quarter of the total population (Statistics Canada, 2022).

The goal of the Café Scientifique was to educate and raise awareness about clinical trials, while examining the barriers to participation, within the immigrant population. The discussion at the Café, led to valuable insights that can be considered for implementation in clinical research projects, aiming to enhance engagement and participation among immigrant communities.

The discussion pinpointed key areas of concern expressed by immigrants and highlighted gaps in education and awareness. The identification of these critical areas will be beneficial for study teams to be aware of and develop strategies to address.

ACCESSIBILITY

Accessibility to reliable sources on the purpose, nature and process of clinical trials was identified as a barrier that limited understanding and participation. Participants shared that they “don’t know much” about clinical trials.

Access to reliable information regarding the process of clinical research, and more awareness of these resources, would likely improve their willingness to partake. One member highlighted, “After getting more information, you are more comfortable.” They did note however, that as newcomers, sometimes it is difficult to trust online sources of information. Many believed that it would be more effective to connect with the immigrant community through



face-to-face discussions in locations where trust is higher, such as their community settings, which are also more accessible for them. These strategies have been discussed in other studies as well and have demonstrated success in recruitment efforts (Walker, 2021; Government of Canada, 2023; Schapira & Smith, 2023).

TRUST

Arriving to a new country is stressful and filled with novel experiences. Participants emphasized that along with trying to adapt to a new country, it was difficult to know who to trust. For many, the initial hurdle is navigating the healthcare system and locating a suitable healthcare provider. Creating a strong relationship with their doctor and trusting them to



Martin-Kerry et al. discuss in their approach the value of developing a common agenda that will allow for both sides to collaborate and lead to trust development over time (Martin-Kerry et al., 2023). Recognizing the significance of trusting relationships that participants have, be it with their doctor or family, is crucial to consider. Developing trust, through connections and relationships, can have long-lasting impacts on future participation and promotion of clinical trials within these minority communities (Wallington et al., 2012). Previous studies discussed within this paper also emphasized successful recruitment through establishment of trust and engagement with on-going communication, including collaboration with trusted community members (Schapira & Smith, 2023; Hernandez et al., 2019; Olukotun & Mkandawire-Valhmu, 2020).

In immigrant communities, where there might be a prevailing distrust of scientists and researchers due to perceived hidden agendas, incorporating patients with lived experiences can play a pivotal role in building trust. The presence of individuals who share similar life experiences fosters a sense of relatability and understanding. This relatability helps alleviate concerns about hidden motives, as community members see fellow individuals who have navigated similar challenges participating in research.

Patients with lived experiences serve as authentic ambassadors, bridging the gap between the scientific community and immigrant populations. Their firsthand knowledge and shared background make research endeavors more transparent and relatable, contributing to a greater sense of trust within these communities. This approach not only humanizes the research process but also demonstrates a commitment to understanding and addressing the unique needs and concerns of immigrant populations, thereby helping to overcome skepticism and foster a more inclusive and trusting relationship with researchers.

provide culturally sensitive care, was emphasized on multiple occasions during the evening. Given this context, although most participants acknowledged the value of clinical trials in benefiting others, some identified distrust in healthcare providers as a barrier.

Depending on an individual's status in Canada, the level of trust concerning the sharing of personal information may be particularly heightened, adding an extra layer of stress. This became evident even during the promotion of our Cafe event, as potential attendees expressed concerns about the collection of their personal information and were suspicious about the reasons behind it.

In some nations, where healthcare is privatized, citizens must pay for basic health services. This situation instills a fear that research might be viewed as a profit-driven venture for scientists and healthcare providers. To put it differently, there's concern that doctors, motivated by financial gain, might actively encourage patients to participate in clinical trials. This was also mentioned by some of the attendees.



CULTURAL COMPETENCE

The need of researchers to understand and address cultural and contextual sensitivities, including religious factors, was emphasized. One participant posed the question, “Some individuals cannot give blood, so would this prevent them from participating? Are there exceptions?” Another highlighted how pre-existing trauma and a lack of sensitivity consideration when approached by the clinical research team had implications. Through awareness and knowledge, researchers would be better equipped to understand and identify barriers faced by specific communities, with the ability to address them to increase involvement. This aspect is a key element of the SEA framework in assessing one’s understanding of worldview. It emphasizes a process of recognizing assumptions that shape beliefs and decisions (Plamondon et al., 2023). Accounting for, and understanding cultural context initiates a process to address barriers and develop solutions on immigrant inclusion and recruitment.



COMMUNICATION

Diverse representation in clinical trials significantly influences recruitment and participation. When asked about factors that would facilitate participation in a clinical trial, participants emphasized the “importance of representation” and the value of “seeing people more like you.” This representation should extend to recruitment materials and other public-facing documents. The Café Scientifique program, featuring a caregiver who is also

an immigrant, sharing their lived experiences while addressing concerns and questions from the audience, proved to be a reassuring experience for the attendees. Many participants expressed that hearing about other immigrant’s experiences within clinical research would alleviate their hesitancy and have a more significant impact.

Participants recommended organizing monthly educational meetings specifically aimed at informing new immigrants about clinical trials, to bridge the recruitment gap. These sessions would facilitate open dialogues where concerns about clinical trials could be addressed by individuals from the same cultural background who have firsthand experiences with the clinical trial and research processes.

Participants emphasized the abundance of emails and mail received when immigrating to a new country. Recruitment from “real people”, either in community centres or religious centres, carries a sense of trust and more willingness to consider participation. Continuous communication in-person, thereby also establishing trust, has proved successful in other studies (Schapira & Smith, 2023; Hernandez et al., 2019; Olukotun & Mkandawire-Valhmu, 2020). In clinical settings, individuals frequently expressed feeling overwhelmed and unprepared to learn about research studies. This underscores the importance of providing a comfortable and safe environment for them.

Moreover, participants stressed that the decision to participate in a clinical trial often involves discussions with their family. They emphasized the value



of involving family members in communication and recruitment efforts, expressing the sentiment that “there should be space for family members to voice their opinions” and noting that “patients place more trust in their family members.” While the role of family in the health decision making process varies across cultures, it was emphasized that these options should be in place.

Various studies on asset-based approaches detail the value of supportive networks within communities, and how these connections facilitate empowering individuals (Martin-Kerry et al., 2023; Wallington et al., 2012; McLean et al., 2017; Foot & Hopkins, 2010). Utilizing these connections while strengthening and acknowledging them have aided in both initiating and bridging relationships. Martin-Kerry et al. (2023) emphasize this in their approach discussing shifting control towards individuals and communities. Based on the feedback gathered from participants, it is crucial to support and leverage trust and communication within their cultural communities and families for effective inclusion efforts.



TRANSPARENCY

Many participants in the Café Scientifique session highlighted the importance of transparency in discussions about clinical trial participation. A recurring theme was the concern over perceived risks associated with the experimental clinical interventions,

leading to hesitancy among participants to engage in the trials. The discussion included the following statements, “They need to know what the drug actually does”, “We have our reservations in trying a trial or new medicine [on] whether it will be beneficial or not,” and, “What are the side effects - this is my main concern.” Participants expressed concern about the use of placebos in clinical trials, and whether the process of ‘randomization’ in clinical trials was indeed authentic. Many emphasized that they would like to be well informed about the mechanism of the agents being utilized, and whether it would be safe or worsen their condition. Many also had concerns about whether researchers would discontinue the interventions if no improvement was seen. Additionally, if an adverse event took place, they were unfamiliar with reporting and how it was ensured that their health was protected. Transparency surrounding these topics, many felt, would alleviate concerns surrounding participation in clinical trials.

The SEA framework highlights the importance of accountability, with the framework focusing on analysis of how it is carried out within the clinical process (Plamondon et al., 2023). Strategies to increase dialogue and open communication should be utilized throughout the research process so that concerns, misinformation, and mistrust can be identified and addressed.



LANGUAGE

Many participants stressed that language barriers can hinder understanding and participation in research trials, with several attendees expressing, “Language is important.” To overcome this challenge, recommendations included incorporating captions in presentations delivered to the audience, and providing translated clinical trials materials. Additionally, discussions focused on the importance of integrating more translators into the clinical team to address not only language barriers but also incorporate cultural sensitivity. Consideration for language allows for a more welcoming and accommodating environment that participants feel would increase consideration to participate, demonstrated by success in other studies with the immigrant population (Schapira & Smith, 2023; Hernandez et al., 2019; Olukotun & Mkandawire-Valhmu, 2020).

BURDEN OF COST AND TIME


During the Cafe Scientifique, there was no discussion on the practical burdens associated with trial participation, such as the time and costs associated with attending study visits. In a survey of 1000 Canadians who were approached to participate in a clinical trial, the costs of participation were described as a barrier and significantly increased the likelihood they would decline to enroll in a trial (Orth & Trytten, 2015). A similar survey in cardiometabolic trials to understand minority participation in clinical trials found that time and resource constraints (financial burden, time commitment, transportation and compensation and logistics) were one of five critical barriers (Clark et al., 2019). We believe that these burdens would also impact the Cafe participant’s decision to participate if they were asked to enroll in a specific clinical trial.





CONCLUSION

Every participant at the Café Scientifique event unanimously agreed that immigrants to Canada should actively engage in clinical trials. The hesitancy faced by many immigrants in engaging with clinical research and the strategies to address these concerns were highlighted, focusing on six key areas: accessibility, trust, cultural values, communication, transparency, and language. Overall, event attendees found the sessions highly valuable in introducing and enhancing their understanding of clinical and research trials.



Based on completed feedback forms, there is a strong desire for more frequent events similar to these, where members of the public can engage with researchers and peers, establish connections, and engage in open dialogue. Attendees inquired about the schedule for the next event, expressing their willingness to participate in future research initiatives.

Implementing the six key findings outlined in this paper should be taken into consideration in the clinical research process to enhance the recruitment of a diverse and representative study population in Canadian studies. This not only enhances the generalizability of study results but also fosters relationships and trust, facilitating more targeted research for the immigrant population. This paper contributes to the limited literature on considerations for diversity and inclusion in clinical research studies, particularly focusing on the immigrant population. We anticipate that this contribution will be valuable in future clinical research endeavors and look forward to its practical application by research teams across Canada.

The table below lists our six key findings, along with recommendations on how to address them:

FINDING	RECOMMENDATION
<p>Accessibility</p> 	<ul style="list-style-type: none"> • Access to reliable resources providing education on the clinical trials process • Face-to-face discussions in a group, community setting to discuss concerns and address misconceptions
<p>Trust</p> 	<ul style="list-style-type: none"> • Open communication & relationship with healthcare providers can facilitate discussions surrounding participation in clinical trials • Conduct discussions focused on fiscal relationships between Sponsors, Investigators and 'compensation' for participants, to improve awareness and knowledge, and dispel misconceptions in this area. • Involve patients with lived experiences as part of recruitment and education process
<p>Cultural Competence</p> 	<ul style="list-style-type: none"> • Research teams need to complete cultural competence/sensitivity training, in order to interact with diverse populations in a culturally safe manner.
<p>Communication</p> 	<ul style="list-style-type: none"> • Utilize recruitment material with diverse representations • Engage people with lived experiences as immigrants to promote education and awareness about clinical trials. • Organize events to promote awareness on clinical trials in community settings • Involve trusted family members in discussions and recruitment efforts
<p>Transparency</p> 	<ul style="list-style-type: none"> • More awareness is needed regarding the use and purpose of placebo's • Provide information on any novel agents being utilized within the study and potential risks associated with their use • Share process of adverse event reporting and follow-up
<p>Language</p> 	<ul style="list-style-type: none"> • Translated materials in various languages • Communicating in a culturally sensitive manner • Having diverse staff on study teams, who can translate for participants, in a culturally sensitive manner • Diverse representation in patient facing materials in clinical trials

FUTURE DIRECTIONS

The six key findings from the Café Scientifique should be incorporated into the standard practices of research teams. It's important to recognize that new immigrant communities across Canada may encounter specific barriers in their local contexts. Therefore, it is crucial to actively involve local communities in adopting these findings to effectively address their unique needs and challenges.

Groups and individuals organizing community engagement events can utilize similar approaches to those employed in this Café Scientifique. Many national and provincial clinical trial-enabling organizations and networks currently aim to strengthen Canada's ability to conduct clinical trials that are representative and inclusive of our population. The framework developed for the Cafe event presents an opportunity for these groups to build on the Cafe methods and hold similar events in their community or province. People from racial and ethnic minorities

and other diverse groups are underrepresented in clinical trials (Office of the Commissioner, 2022). Research teams can enhance diversity in trial participation by deepening their comprehension of the culture and history of the people and communities involved in the trials, particularly concerning their experiences with healthcare and research. There are several ways to advance the diversity practices of a clinical trial site, including providing opportunities for staff to take cultural competency and safety training, employing staff who are racially, ethnically and culturally diverse and more representative of their local community, and involving patients or community members as part of a research team.

Advancing our understanding of the immigrant population and other equity seeking groups, both generally and specific to various local contexts across Canada, is vital to designing trials that are more inclusive and accessible to them.



REFERENCES

1. U.S. Department of Health and Human Services. (2023, April 24). Diversity and Inclusion in Clinical Trials. National Institute of Minority Health and Health Disparities. <https://www.nimhd.nih.gov/resources/understanding-health-disparities/diversity-and-inclusion-in-clinical-trials.html>
2. Walker, R. (2021). White Paper: Achieving Diversity in Clinical Trials. https://javararesearch.com/wp-content/uploads/2021/05/White-Paper_Achieving-Diversity-in-Clinical-Trials-1.pdf
3. Silversides A. (2009). Clinical trials: the muddled Canadian landscape. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne*, 180(1), 20-22. <https://doi.org/10.1503/cmaj.081897>
4. Canadian Partnership Against Cancer. (2018). The 2018 Cancer System Performance Report. <https://www.partnershipagaincancer.ca/topics/2018-cancer-system-performance-report/>
5. Sinha G. (2007). United Kingdom becomes the cancer clinical trials recruitment capital of the world. *Journal of the National Cancer Institute*, 99(6), 420-422. <https://doi.org/10.1093/jnci/djk140>
6. Government of Canada. (2023, July 7). Best practices in equity, diversity and inclusion in research practice and design. Best Practices in Equity, Diversity and Inclusion in Research. <https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/edi-eng.aspx>
7. Corneli, A., Hanlen-Rosado, E., McKenna, K., Araujo, R., Corbett, D., Vasisht, K., Siddiqi, B., Johnson, T., Clark, L. T., & Calvert, S. B. (2023). Enhancing Diversity and Inclusion in Clinical Trials. *Clinical Pharmacology & Therapeutics*, 113(3), 489-499. <https://doi.org/10.1002/cpt.2819>
8. Skalicky, A., & Hareendran, A. (2021). Enhancing Clinical Trial Diversity in the Era of Decentralized Trials: The Value of Patient Insights. *The Evidence Forum*. <https://www.evidera.com/white-paper-enhancing-clinical-trial-diversity-in-the-era-of-decentralized-trials/>
9. Palumbo, P., Hong, P., Marsh, M., O'Brien, S., Poopat, C., Toal, C., Andrews, M., & Sanchez, H. (2022). WHITE PAPER: Diversity in Clinical Trials Participation: A Life Sciences Perspective. <https://trinitylifesciences.com/wp-content/uploads/2022/05/Trinity-Whitepaper-Diversity-in-Clinical-Trials-Participation.pdf>
10. Schapira, L., & Smith, S. M. (2023). Crucial Role of Effective Communication in Recruiting Immigrant Patients Into Cancer Clinical Trials. *JCO oncology practice*, 19(11), 948-950. <https://doi.org/10.1200/OP.23.00522>
11. Canadian Institutes of Health Research. (2023). What We Heard Report: Future of Clinical Trials. <https://cihr-irsc.gc.ca/e/53429.html>
12. Natural Sciences and Engineering Research Council of Canada. (2023, June 6). NSERC guide on integrating equity, diversity and Inclusion Considerations in Research. NSERC. https://www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/EDI_guidance-Conseils_EDI_eng.asp
13. Statistics Canada. (2022, October 26). Immigrants make up the largest share of the population in over 150 years and continue to shape who we are as Canadians. *The Daily*. <https://www150.statcan.gc.ca/n1/daily-quotidien/221026/dq221026a-eng.htm>
14. Jindal, R. M. (2020). Refugees, asylum seekers, and immigrants in clinical trials. *The Lancet*, 395(10217), 30-31. [https://doi.org/10.1016/s0140-6736\(19\)32529-2](https://doi.org/10.1016/s0140-6736(19)32529-2)
15. Jamal, S., Jones, C., Walker, J., Mazereeuw, M., Sheppard, A. J., Henry, D., & Marrett, L. D. (2021). Cancer in First Nations people in Ontario, Canada: Incidence and mortality, 1991 to 2010. *Health reports*, 32(6), 14-28. <https://doi.org/10.25318/82-003-x202100600002-eng>

16. Hernandez, M., Franco, R., Kopelowicz, A., Hernandez, M. Y., Mejia, Y., Barrio, C., & López, S. R. (2019). Lessons Learned in Clinical Research Recruitment of Immigrants and Minority Group Members with First-Episode Psychosis. *Journal of immigrant and minority health*, 21(1), 123-128. <https://doi.org/10.1007/s10903-018-0704-y>
17. Olukotun, O., & Mkandawire-Valhmu, L. (2020). Lessons Learned From the Recruitment of Undocumented African Immigrant Women for a Qualitative Study. *International Journal of Qualitative Methods*, 19. <https://doi.org/10.1177/1609406920904575>
18. Plamondon, K. M., Dixon, J., Brisbois, B., Pereira, R. C., Bisung, E., Elliott, S. J., Graham, I. D., Ndumbe-Eyoh, S., Nixon, S., & Shahram, S. (2023). Turning the tide on inequity through systematic equity action-analysis. *BMC public health*, 23(1), 890. <https://doi.org/10.1186/s12889-023-15709-5>
19. Martin-Kerry, J., McLean, J., Hopkins, T., Morgan, A., Dunn, L., Walton, R., Golder, S., Allison, T., Cooper, D., Wohland, P., & Prady, S. L. (2023). Characterizing asset-based studies in public health: development of a framework. *Health promotion international*, 38(2), daad015. <https://doi.org/10.1093/heapro/daad015>
20. Wallington, S. F., Luta, G., Noone, A. M., Caicedo, L., Lopez-Class, M., Sheppard, V., Spencer, C., & Mandelblatt, J. (2012). Assessing the awareness of and willingness to participate in cancer clinical trials among immigrant Latinos. *Journal of community health*, 37(2), 335-343. <https://doi.org/10.1007/s10900-011-9450-y>
21. McLean, J., McNeice, V. and Mitchell, C. (2017) *Asset-based Approaches in Service Settings: Striking a Balance*. Glasgow Centre for Population Health, Glasgow.
22. Foot, J. and Hopkins, T. (2010) *A Glass Half Full: How an Asset Approach can Improve Community Health and Wellbeing*. IDEa, London.
23. Orth, A., Trytten. C. (2015) Learning from the Participant Experience - The BC Clinical Trial Participation Survey Presentation, ACRP 2015 Global Conference. <http://dx.doi.org/10.13140/RG.2.2.10008.16640>
24. Clark, L. T., Watkins, L., Piña, I. L., Elmer, M., Akinboboye, O., Gorham, M., Jamerson, B., McCullough, C., Pierre, C., Polis, A. B., Puckrein, G., & Regnante, J. M. (2019). Increasing Diversity in Clinical Trials: Overcoming Critical Barriers. *Current problems in cardiology*, 44(5), 148-172. <https://doi.org/10.1016/j.cpcardiol.2018.11.002>
25. Office of the Commissioner. (2022, November 4). Clinical Trial Diversity. U.S. Food and Drug Administration. <https://www.fda.gov/consumers/minority-health-and-health-equity/clinical-trial-diversity>

