Canadian
Cancer Clinical
Trials Network

Improving Trial Access for Indigenous Peoples

Indigenous Sovereignty, Truth and Reconciliation

A guide to support sites, clinical research staff, sponsors, and funders for accessing additional recommendations and best practices for engaging First Nations, Inuit and Métis Peoples in clinical trials.

Improving Trial Participation

Fostering Trust and Improving Communication

Recommendations

- Prioritize building relationships with Indigenous (First Nations, Inuit and Métis) communities. Community representatives can lead and guide the process - level of engagement and action should be determined by the members, not by the researchers.
- Engage with Indigenous communities, organizations, and governing bodies early in the trial planning process.
- Establish a community advisory board to provide guidance on cultural safety, historical barriers and how to provide trauma informed care.
- Provide trial documents in Indigenous languages and ensure trial information is clear and concise. Use interpreters if translation is not available.

Improving Trial Awareness

Recommendations

- Disseminate information about trials through trusted channels (e.g. First Nations, Inuit, Métis community organizations, Indigenous health services, and Indigenous Leaders)
- Organize knowledge sharing events and sessions - community member can educate trial staff about cultural and historical barriers and research/trial staff can inform community members about trials.
- Co-develop trial materials with input from Indigenous community members to ensure they are culturally appropriate (e.g., testimonial videos of Indigenous trial participants sharing their experience).

Improving Trial Access

Recommendations

- Provide fair compensation for transportation, childcare services and any other costs associated with participation.
- Establish satellite sites or mobile clinics in accessible locations within or near Indigenous (First Nations, Inuit and Métis) communities or organizations to minimize travel burdens.

Developing Inclusive Trial Design

Recommendations

- Ensure a pan-Indigenous approach is not taken and differences across First Nations, Inuit, Métis peoples are considered
- Consult with Indigenous community members to guide the development of culturally appropriate interventions and outcome measures.
- Eliminate bias from eligibility criteria.
- Incorporate Indigenous perspectives, values, and traditional healing practices into the trial design, where appropriate and acceptable to the community.

Education and Training for Clinical Research Staff

Recommendations

- Ensure staff undergo comprehensive training and education, including but not limited to Indigenous (First Nations, Inuit and Métis) health, trauma informed care, cultural competency, and cultural safety.
- Promote respect for and understanding of traditional knowledge, medicines, practices, healers and spaces.

Increasing Diversity of Clinical Research Teams and Inclusive Hiring Practices

Recommendations

- Recruit Indigenous (First Nations, Inuit and Métis) researchers, clinicians, and staff members to reflect the diversity of the communities being served.
- Offer training and professional development opportunities for Indigenous individuals interested in pursuing careers in clinical research.
- Establish mentorship programs and support networks to foster career advancement and retention among Indigenous research professionals.

Collection of Trial Participant Data

Race, Ethnicity and Social Demographic Data

Recommendations

- Consult with Indigenous members (First Nations, Inuit and Métis) before implementation to ensure data collection is performed safely and appropriately. Ensure data collection processes are culturally sensitive, confidential, and respectful of Indigenous participants' autonomy and self-identification. Follow Indigenous guidelines for appropriate data collection.
- Include questions about Indigenous identity in trial enrollment forms and electronic health records, where appropriate and acceptable to the community.
- Regularly review and analyze demographic data to monitor representation, identify disparities, and inform targeted outreach and recruitment strategies.

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References

1. Ahmed, S., Shahid, R.K., & Episkenew, J.A. (2015). Disparity in Cancer Prevention and Screening in Aboriginal Populations: Recommendations for Action. *Current Oncology, 22(6), 417-426.* https://doi.org/10.3747/co.22.2599

2. Bell, J.AH., Kelly, M.T., Gelmon, K., Chi, K., Ho, A., Rodney, P., & Balneaves, L.G. (2020). Gatekeeping in cancer clinical trials in Canada: The ethics of recruiting the "ideal" patient. *Cancer Medicine, 9(12),4107-13.* https://doi.org/10.1002/cam4.3031.

3. Dickmann, L. J., & Schutzman, J. L. (2018). Racial and Ethnic Composition of Cancer Clinical Drug Trials: How Diverse Are We? *The Oncologist*, *23(2), 243–246.* https://doi.org/10.1634/theoncologist.2017-0237

4. El-Deiry, W.S & Giaccone, G. (2021). Challenges in Diversity, Equity, and Inclusion in Research and Clinical Oncology. *Front Oncology, 24(11), 642112.* doi: 10.3389/fonc.2021.642112

5. Fienkeng, M., Croker, A., Recinos-Vasquez, Z., & Carter, M. (2022). Enhancing diversity in clinical trial populations: An agency-industry perspective. *Regulatory Focus*. https://www.raps.org/news-and-articles/news-articles/2022/12/enhancing-diversity-in-clinical-trial-populations

6. Lauren M. Hamel, Louis A. Penner, Terrance L. Albrecht, Elisabeth Heath, Clement K. Gwede, and Susan Eggly. (2016). Barriers to Clinical Trial Enrollment in Racial and Ethnic Minority Patients with Cancer. *Cancer Control, 23(4), 327-337.* doi.org/10.1177/107327481602300

7. LaVallie, D. L., Wolf, F. M., Jacobsen, C., & Buchwald, D. (2008). Barriers to Cancer Clinical Trial Participation among Native Elders. *Ethnicity & Disease*, *18*(2), 210–217. https://www.jstor.org/stable/48667335

8. Letendre, A., Garvey, G., King, A., King, M., Crowshoe, R., Bill, L., Caron, N. R., & Elias, B. (2020). Creating a Canadian Indigenous Research Network Against Cancer to Address Indigenous Cancer Disparities. *JCO global oncology, 6, 92–98.* https://doi.org/10.1200/JGO.19.00049

9. Mainous, A.G., Kelliher, A., & Warne, D. (2023). Recruiting Indigenous Patients Into Clinical Trials: A Circle of Trust. *The Annals of Family Medicine*, 21(1), 54-56. https://doi.org/10.1370/afm.2901

10. Oyer, R. A., Hurley, P., Boehmer, L., Bruinooge, S. S., Levit, K., Barrett, N., et al. (2022). Increasing Racial and Ethnic Diversity in Cancer Clinical Trials: An American Society of Clinical Oncology and Association of Community Cancer Centers Joint Research Statement. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*, *40(19), 2163–2171.* https://doi.org/10.1200/JCO.22.00754

11. Williams, J.S., Walker, R.J., & Egede, L.E. (2016). Achieving Equity in an Evolving Healthcare System: Opportunities and Challenges. *Am J Med Sci, 351, 33–43.* 10.1016/j.amjms.2015.10.012

12. Canadian Institute for Health Information. (2022) *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada.* Ottawa, ON. https://www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf

13. The First Nations Information Governance Centre. (2014). *Ownership, Control, Access and Possession (OCAP™); The Path to First Nations Information Governance*. Ottawa, ON. https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389_ocap_path_to_fn_information_governance_en_final.pdf

14. Cancer Care Ontario. (2019). *First Nations, Inuit, Métis and Urban Indigenous Cancer Strategy 2019–2023.* *https://www.cancercareontario.ca/sites/ccocancercare/files/assets/PCC_4114_FNIMuI_ExecSummary.pdf*
15. Ontario Health. (2023). *First Nations, Inuit, Métis and Urban Indigenous Health Framework.* *https://www.ontariohealth.ca/sites/ontariohealth/files/FNIMUI-HealthFrameworkReport.pdf*