CANADIAN SPECTRUM WORKING GROUP (CSWG)

<u>BRIEFING NOTE</u>

September 6, 2023

Subject: Ensuring optimal data representation and applicability through participant diversity.

Dear Consortia Leads of the Marathon of Hope Cancer Centres Network (MOHCCN),

This letter is to bring to your attention the critical issue of diversity in cancer research and its impact on the accuracy and applicability of research findings to the broader population. Under our contribution agreement with Health Canada, MOHCCN is addressing this issue to ensure that our Network's future research includes and benefits all populations equally, leading to a path forward in which personalized cancer genomic medicine can become a reality for all of Canada's populations.

We acknowledge that local and regional differences exist in opportunities to contribute to our vision of diversity and recognize that different contributions from different sites are important and relevant. It is vital for the MOHCCN efforts to include the Canadian Spectrum of our populations so that this exciting project, and the lifesaving research that it spawns, benefits us all; a vision that Terry Fox was clear about from his very first step in his Marathon of Hope.

1. **Underrepresentation of Historically Disenfranchised Populations**: There is increasing awareness that historically disenfranchised populations, including racial and ethnic minorities, women, elderly individuals, rural and remote populations, and individuals with certain health conditions have been substantially under-represented in research projects. This under-representation creates a significant disparity in access to, and participation in, cancer research, leading to inadequate representation of diverse populations.

2. **Indigenous Populations**: It's important to recognize that Indigenous populations have distinct cultural, historical, and political contexts that warrant special constitutional/legal protections and different data access standards. These protections may include land rights, self-governance, cultural preservation, and the right to maintain traditional practices and customs. Separate data access standards or classifications may be necessary to accurately capture the unique circumstances and challenges faced by Indigenous communities. Indigenous data sovereignty must be part of this discussion.

3. **Lack of Representation**: A concerning issue that has emerged is the discrepancy between the selection of research participants and the populations that are impacted by the implementation of the results. Even when the research includes diverse populations, the numbers often do not reflect the demographic composition of the intended target population. This lack of representation undermines the ability to generalize research findings to the broader population.

4. **Relevance of Findings**: When research participants do not mirror the composition of Canadian populations, there is a risk that the data obtained from these research projects may not be broadly relevant. This leads to a skewed and biased body of knowledge that is further propagated in downstream research that uses the data, as we envision the use of MOHCCN datasets. This propagation of bias compromises the generalizability of research findings to the national population.

5. **Potential Missed Diagnosis and Treatment Opportunities**: The lack of diversity in research can also result in the absence of genomic data that could otherwise greatly benefit historically disenfranchised populations. Health conditions, treatments, and interventions may have different effects or effectiveness in various demographic groups. Our commitment to include these populations in MOHCCN cancer research can improve the discovery of potential breakthroughs or eventually optimal treatments for them.

We agree that addressing the issue of diversity in the context of the MOHCCN is essential to ensure the accuracy and applicability of cancer research findings. By actively promoting diversity and inclusivity, we should commit to enhancing the representation of historically disenfranchised populations and Indigenous communities and mitigate bias in research results and disparities in healthcare that result from them, thus fostering a more equitable and effective healthcare system. Specifically, The Canadian Spectrum Working Group:

- is committed to exploring strategies to promote diversity in cancer research and increase the inclusion of underrepresented populations in the MOHCCN gold cohort dataset.

- will develop a Network-wide strategy to support the inclusion of core data elements in the MOHCCN gold cohort data standard. This work will require collaboration among research institutions, regulatory bodies, Indigenous leadership, and industry stakeholders to facilitate data sharing and access to diverse populations.

- will work collaboratively through a "road show" with every region/Consortia to support local initiatives that enhance diversity and inclusion within the Network. In these partnerships, we can identify gaps, and provide the Network's support to work together and achieve these goals.

Thank you for your commitment to this important endeavor. If you could provide us with the names and contacts of the individuals at your institution/consortia who should be part of this effort, we would greatly appreciate it.

Sincerely,

Nadine Caron, co-chair CSWG   Gina Ogilvie, co-chair CSWG