



Marathon of Hope Cancer Centres Network Underserved and Underrepresented Populations Guideline_V1

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Introduction

The Marathon of Hope Cancer Centres Network (MOHCCN) aims to unite cancer researchers, clinicians, patients, administrators, and funders to accelerate precision medicine for cancer. The Network recognizes that there is a critical issue of diversity in cancer research and that this impacts the quality and accuracy of research findings and their applicability to the broader population. The MOHCCN aims to address this inequity by supporting and facilitating research that includes and benefits individuals of all backgrounds, creating a future in which precision cancer medicine can become a reality for all Canadians.

Part of this initiative is the creation of a well-annotated, uniformly generated and consistently quality-controlled dataset - composed of both clinical and genomic data - from a cohort of cancer patients that are representative of the Canadian population. In its first phase, the Network aims to include 15,000 cases in this dataset, called the MOHCCN Gold Cohort.

To help increase inclusion of underserved and underrepresented populations in MOHCCN research and create datasets that are representative of all Canadian populations, this guideline defines populations that are considered underserved and/or underrepresented for the purposes of Network activities.

The definitions and justifications for inclusion included in this guideline are largely based on the Canadian Cancer Society's [Advancing Health Equity Through Cancer Information and Support Services: Report on communities that are underserved](#), as indicated throughout the document. The Network recognizes that individuals may identify with more than one group or community listed in this guideline, and that this intersectionality will bring unique and valuable perspectives. Readers can refer to the report for more detailed information on the relevant groups, including considerations and recommendations for engagement and support.

Best practice recommendations and other guidance may be provided in a future revision of this guideline or in other Network documentation. Please note that the groups are not in any particular order.

Definitions of Underserved and Underrepresented Populations

Indigenous Communities¹

Indigenous peoples are descendants of the first inhabitants of what is now Canada. It is a collective noun for First Nations people, Inuit and Métis.

- First Nations: descendants of the original inhabitants of Canada. First Nations people identify themselves by the nation to which they belong.
- Inuit: original inhabitants of the northern regions of Canada.
- Métis: includes a person who self-identifies as Métis, is distinct from other Indigenous peoples, is of historic Métis Nation ancestry, and is accepted by the Métis Nation.
- Urban Indigenous people: refers primarily to First Nations people, Inuit and Métis currently residing in urban areas.

As of 2021, 5% of the Canadian population identify as Indigenous peoples, with the population expected to grow over the next 20 years.¹ Indigenous peoples have been significantly impacted by colonial structures and processes, resulting in health inequities and disparities that continue to this day. Limited data on cancer statistics exist for Indigenous communities, and mortality rates for certain cancers are higher in some Indigenous communities compared to the general Canadian population. Additionally, there are unmet needs of culturally appropriate treatment, education, support services, and continuity of care for Indigenous communities.

2SLGBTQI+ Communities¹

2SLGBTQI+ refers to people who identify as Two-Spirit, lesbian, gay, bisexual, trans, queer, questioning, and intersex. The "+" indicates other identities and experiences that fall outside the dominant heterosexual and cisgender (non-trans) identities (e.g. asexual, demisexual, and pansexual).

- Two-Spirit: encompasses a wide variety of Indigenous concepts of gender and sexual diversity. There are many understandings of the term Two-Spirit and the term does not resonate for everyone. People may identify with a term specific to their nation, as many Indigenous languages have words for gender and sexual diversity traditionally found in their communities. Two-Spirit is a cultural term reserved for those who identify as Indigenous.
- Lesbian: a woman who is attracted to women.
- Gay: a person who is attracted to people of the same gender. The word can refer to men or women, although some women prefer "lesbian."
- Bisexual: a person who is attracted to people of more than one gender.
- Trans: an umbrella term referring to people whose gender identities differ from the sex they were assigned at birth. "Trans" can mean transcending beyond, existing between, or crossing over the gender spectrum. It includes people who identify as transgender,

transsexual, non-binary or gender non-conforming (gender variant or gender queer).

- **Queer:** an umbrella term used and reclaimed by some whose sexual orientations or gender identities fall outside the dominant heterosexual and cisgender identities.
- **Questioning:** a period where a person explores their own sexual or gender identity. The person may not be certain if they are gay, lesbian, bisexual or trans and may be trying to figure out how to identify themselves.
- **Intersex:** an umbrella term referring to people born with sex characteristics (external or internal sex organs, chromosomes or sex hormones) that fall outside of the strict binary of male or female. Being intersex is a naturally occurring variation in people. Typically, intersex people are assigned one sex, male or female, at birth. As with everyone, people who are intersex have a range of gender identities.

As of 2018, about 1 million Canadians identify as 2SLGBTQI+, equating to about 4% of the population over age 15.¹ Limited data on cancer statistics exists for 2SLGBTQI+ communities, and physical health and health problems are understudied in the population. 2SLGBTQI+ communities experience inequities in health care because of the stigmatization and discrimination they face, leading to barriers to access, experience and outcomes.

Children with Cancer

The age range for children with cancer may vary by location as per clinical standards. Please refer to local standards. For example, this may be from 0 to 14 years of age or 0 to 18 years of age.

Research for children is unique as it warrants special attention to reducing the intensity of treatments, incorporating patient and caregiver perspectives, and long-term healthcare needs.³

Adolescents and Young Adults (AYAs) with Cancer¹

AYAs refers to people who are aged 15 to 39 years when diagnosed with cancer. AYAs are further defined by the following subgroups.

- Early adulthood: 15 to 19 years
- Young adulthood: 20 to 24 years
- Late young adulthood: 25 to 39 years

In 2021, 12.5 million AYAs lived in Canada, making up 32.7% of the total population.¹ AYAs have unique developmental, psychosocial and self-management needs, which vary depending on the subgroup to which they belong.

Older Adults¹

Older adults are people aged 65 years and older. Subcategories are as follows.

- Youngest-old: 65 to 74 years
- Middle-old: 75 to 84 years
- Oldest-old: 85+ years

The older adult population is growing as Canadians live longer and healthier. As of 2022, over 7 million Canadians are over the age of 65, making up 18.8% of the total population.¹ Although older adults make up the largest proportion of new cancer diagnoses, many are not receiving the same information and treatment options as younger individuals. Older adults face challenges with ageism in health care, which may result in over-treatment or under-treatment and poorer outcomes.

Individuals with Advanced Cancers¹

An advanced cancer is a cancer that is unlikely to be cured, and the focuses of care change in physical, emotional and practical ways. Advanced cancer is also known as metastatic, terminal, end-stage, or stage 4 cancer. For some people, the cancer may already be advanced when it is diagnosed. For others, the cancer may not become advanced until years after it was first diagnosed.

Cancer stage is not consistently recorded for all cancer types in Canada in surveillance data. When it is recorded, it is only at the time of diagnosis. Surveillance data may therefore not include progression of a cancer to advanced stages after diagnosis. Individuals with advanced cancer may encounter challenges and barriers to receiving appropriate emotional and practical support.

Individuals with Rare Cancers¹

A rare cancer is defined as cancer that is diagnosed in less than 6 of every 100,000 people in Canada each year.

Rare cancers make up 20% of new cases in Canada, with survival rates being lower than those for common cancers.¹ Individuals with rare cancers experience inequities in treatment and care due to a lack of familiarity and clinical knowledge with rare cancers.

Non-English or French Speaking Communities¹

This group refers to people living in Canada who are not able to communicate in either official language, English or French, which might be used to deliver their care. Individuals are from various ethnicities and cultural backgrounds.

In Canada, 4.6 million people predominantly speak a language other than English or French at home, with about 580,000 or 1.6% of the population not speaking either official language.¹ If people are unable to communicate in English or French, they may experience barriers throughout their cancer experience. There is limited data on the challenges these communities face, and unmet needs include quality online cancer information, culturally tailored

programs, and resources in multiple languages.

Newcomers to Canada¹

A newcomer is someone who has been in Canada for less than 5 years. A newcomer can be an immigrant or a refugee who moved from their country of origin to Canada.

In 2021, 8.3 million people were or had been a landed immigrant or permanent resident in Canada, accounting for about 23% of the total population.¹ There is limited cancer statistic data available on newcomers.

Racialized Communities¹

Racialized communities refers to people who have racial meanings attributed to them as a group in ways that negatively affect their social, political and economic lives. Race is a social construct that can change over time and place. The term may include but is not limited to: Black ethnicity (including African or Caribbean ancestry), South Asian, Chinese, Arab/West Asian, Southeast Asian, Filipino, Latin American, African, Caribbean, Korean, Japanese and Pacific Islander.

As of 2021, about 9.6 million people from over 450 ethnic origins and ancestries reported being a part of a racialized community, making up 26.5% of the total population.¹ Canada is behind in recording race-based data; therefore, the impact on these communities is not well understood. Racialized communities experience inequities in health care due to racism, lack of access to culturally relevant information, and lack of appropriate supports.

Rural and Remote Communities¹

A community is considered rural or remote when it has a population of 10,000 or less or because geography has limited people's access to healthcare facilities and services.

About 6 million Canadians, or 16% of the population, live in rural and remote areas.¹ Living in rural and remote areas can negatively impact socioeconomic, environmental and occupational health determinants, which may lead to poor health outcomes. These communities have unmet psychosocial and informational needs, and there are higher cancer mortality rates than urban centres.

People with Low Socioeconomic Status

The definition of low socioeconomic status may vary by location. Please refer to local standards, where available. For example, the Government of Canada describes low-income cut-offs as relative income thresholds where a household devotes 20% more on necessities (food, shelter and clothing) than the average household.⁴

Individuals with a Disability

A disability includes a wide range and degree of conditions that may be present at birth, caused by an accident or developed over time.⁵ Individuals with a disability refers to persons whose daily activities are limited as a result of an impairment or difficulty with particular tasks.⁶ This may include a physical impairment, mental disorder, learning disability or dysfunction, developmental disability, or mental impairment.⁵

References

1. Canadian Cancer Society. Advancing Health Equity Through Cancer Information and Support Services: Report on communities that are underserved. 2023 Oct. Available: https://cdn.cancer.ca/-/media/files/about-us/our-health-equity-work/underserved-communities-report_2023_en.pdf
2. Public Health Agency of Canada. Childhood Cancer Counts in Canada. 14 Feb 2022 [accessed 11 Sep 2024]. Available: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/childhood-cancer-counts-canada.html>
3. Pediatric Oncology Group of Ontario. 2020 POGO Surveillance Report. 2020. Available: <https://www.pogo.ca/wp-content/uploads/2020/10/2020-POGO-Surveillance-Report.xlsm>
4. Government of Canada. A Backgrounder on Poverty in Canada. 2016 Oct. Available: <https://www.canada.ca/content/dam/canada/employment-social-development/programs/poverty-reduction/backgrounder/backgrounder-toward-poverty-reduction-EN.pdf>
5. Ontario Human Rights Commission. Policy on ableism and discrimination based on disability. 2016. Available: https://www.ohrc.on.ca/sites/default/files/Policy%20on%20ableism%20and%20discrimination%20based%20on%20disability_accessible_2016.pdf
6. Statistics Canada. Classification of Status of Disability. 8 Sep 2015 [accessed 11 Sep 2024]. Available: <https://www23.statcan.gc.ca/imdb/p3VD.pl?Function=getVD&TVD=247841&CVD=247841&CLV=0&MLV=1&D=1>

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