

# Leaving No One Behind in Long-Term Care: Enhancing Socio-Demographic Data Collection in Long-Term Care Settings



# National Institute on Ageing & Wellesley Institute

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## About the National Institute on Ageing

The National Institute on Ageing (NIA) is a public policy and research centre based at Ryerson University in Toronto. The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of perspectives, including those of financial, physical, psychological, and social well-being.

The NIA is focused on leading cross-disciplinary, evidence-based, and actionable research to provide a blueprint for better public policy and practices needed to address the multiple challenges and opportunities presented by Canada's ageing population. The NIA is committed to providing national leadership and public education to productively and collaboratively work with all levels of government, private and public sector partners, academic institutions, ageing-related organizations, and Canadians.

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Wellesley Institute is a non-profit and non-partisan research and policy institute that focuses on health and health equity in the Greater Toronto Area. Wellesley Institute's mission is to advance population health and reduce health inequities by driving change on the social determinants of health through applied research, effective policy solutions, knowledge mobilization, and innovation.

Wellesley Institute's recent work on seniors' care has focused on mitigating health inequities among older adults and enhancing long-term care and home and community care for older immigrants; as well as supports for family caregivers from diverse ethno-cultural communities.

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## Executive Summary

The COVID-19 pandemic has taken a disproportionate toll on Canada's most vulnerable populations. With growing evidence on the inequitable impacts of COVID-19 across Canada, it is reasonable to assume that similar impacts have occurred, and will continue to occur, amongst the diverse population groups of Canadians living and working in long-term care settings. Unfortunately, due to the long-standing failure to collect in-depth socio-demographic data in long-term care settings, it is currently not possible to understand the full scope of the pandemic's impact on residents and workers in Canada's long-term care settings.

Socio-demographic data is an important tool for measuring and reducing health disparities among people across different population groups and from different backgrounds. Evidence from Canadian literature clearly demonstrates that health outcomes differ based on social and demographic factors such as sexual orientation, gender identity, language, race, immigration status, and ethnicity, as well as access to affordable housing, adequate income, social inclusion and other factors. While limited, current research findings shed light on some of the existing inequities in Canadian long-term care settings, highlighting the importance of collecting and analyzing socio-demographic data, as well as the need for better data collection on diverse population groups living in long-term care settings. This report makes clear that without taking steps to enhance the collection of socio-demographic data in long-term care settings, the needs of

Canadians living in long-term care settings will continue to be misunderstood and preventable inequities in care and outcomes will persist.

Canada continues to lag behind other countries (e.g., United Kingdom, Australia, United States) in collecting population-based socio-demographic data—such as ethnicity, race, gender identity, and sexual orientation. There are, however, several sources of data which provide insight into Canada's older adult population, as well as the portion of the Canadian population currently residing in long-term care settings. These include: Canadian Institute for Health Information's (CIHI) Continuing Care Reporting System (CCRS) and Statistics Canada's Census of the Population, Canadian Community Health Survey, and Nursing and Residential Care Facility Survey. However, CIHI acknowledges that the CCRS, along with other CIHI and Statistics Canada health data repositories, fail to capture the information that can be effectively used to identify health inequities among people living and working in Canadian long-term care homes. By addressing this lack of socio-demographic data, we will begin to build a better understanding of the diverse populations living in long-term care settings, which will enable us to develop more targeted interventions to effectively address any existing health disparities. This report highlights that reliably collecting in-depth socio-demographic data across Canada would enable better policy and planning processes to address known gaps in care options for Canadians of all backgrounds.

In addition to the Census and sample surveys briefly mentioned above, some promising examples have been developed to collect enhanced socio-demographic data through administrative data in health and long-term care settings. These include: Toronto Central LHIN's *Measuring Health Equity*, CIHI's *Pan-Canadian Standards for Collecting Race-Based and Indigenous Identity in Health Systems*, and British Columbia's Office of Human Rights' *Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective*. Recently, there has been growing consensus on developing a standardized set of socio-demographic data that is comparable and linkable across jurisdictions and sectors. In particular, enhancing data collection in the domains of age, sex assigned at birth, gender identity, sexual orientation, race, ethnicity, language, and Indigenous identity. As each of the above initiatives seek to enhance the collection of socio-demographic data in the Canadian context, this report also offers reflections on the facilitators and barriers to the collection of such data.

As we turn to current initiatives for guidance on the collection of enhanced socio-demographic data, it is reasonable to ask why this data is not already being collected within Canada—especially as other countries are able to collect more in-depth socio-demographic data, which allows system-wide analysis of health inequities. As a result, numerous calls have been made to better collect socio-demographic data across Canada to identify disparities and promote health equity. This report echoes and amplifies calls that have identified the existing gap in collecting and utilizing health equity data in the Canadian long-term care sector as an important area for improvement.

To facilitate enhanced socio-demographic data collection in long-term care settings, lessons were drawn from existing initiatives. We have identified five key areas of consideration related to data collection and use. We conclude this report by offering the following key recommendations to move forward with planning and delivering long-term care that ensures health equity for older Canadians:

1. Ensure clarity exists amongst individuals living and working in long-term care settings about the purposes of socio-demographic data collection.
2. Build trust through community engagement in the design and implementation of socio-demographic data collection initiatives.
3. Ensure standardized socio-demographic data is collected across Canada's long-term care settings.
4. Ensure appropriate skills, training and understanding for those collecting socio-demographic data.
5. Ensure a commitment is developed to effectively and appropriately use the socio-demographic data being collected.

## Introduction

The COVID-19 pandemic has taken a disproportionate toll on Canada's most vulnerable populations. Across Canada, older adults, especially those living with dementia or Alzheimer's disease and residing in long-term care homes, have experienced the most devastating impacts of the COVID-19 pandemic.<sup>1,2,3</sup> In fact, COVID-19 deaths amongst adults 60 years of age and older have accounted for approximately 96 per cent of all deaths in Canada, and deaths amongst Canadians living in long-term care and retirement homes account for nearly 70 per cent of all deaths nationally.<sup>4</sup>

Beyond long-term care settings, it is becoming increasingly clear that COVID-19 has affected certain communities more than others. For example, Canadians from low-income, racialized, and 2SLGBTQIA+ communities have been reported to be at increased risk for COVID-19 infections and experience worsening mental health and greater financial impacts due to lay-offs and reduced work hours.<sup>5,6</sup> With this growing evidence on the inequitable impacts of COVID-19 across Canada, it is reasonable to assume that similar impacts have, and will continue to occur amongst the diverse population groups of

Canadians living and working in long-term care settings. However, due to the long-standing failure to collect in-depth socio-demographic data in long-term care settings, it is currently not possible to understand the full scope of the pandemic impacts on residents and workers in this sector.

**Without a new commitment to socio-demographic data collection, the needs of Canadians in long-term care will continue to be misunderstood, and preventable inequities in care and outcomes will persist throughout the duration of the COVID-19 pandemic and beyond.**

This paper calls for enhanced socio-demographic data collection to be considered as a core element of planning and delivering care in long-term care settings. Calls for the collection of enhanced socio-demographic data are not new. In Canada and internationally, researchers and clinicians

### 2SLGBTQIA+

An acronym representing the continually evolving array of sexual and gender identities. This specific acronym refers to the following identities: Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, asexual, and so many more.



have long advocated for the better collection and use of socio-demographic data to identify health disparities and promote health equity. Specifically, this data helps to achieve more responsive care while reducing needless inequities in treatment that end up driving poorer health outcomes and greater overall costs.

### **In fact, the assessment of quality in the provision of long-term care requires good data.**

However, as the Royal Society of Canada Working Group on Long-Term Care clearly noted, such data is something that Canada is embarrassingly short of in its long-term care sector.<sup>7</sup> Without this data, it will remain difficult to provide care that is responsive to individual needs, and potential gaps in equity will persist in long-term care settings.

In particular, this report has been developed to contribute to and support current and forthcoming discussions regarding the proposed development of new national long-term care standards. The federal government's commitment to supporting the establishment of new national long-term care standards, as first announced in the September 2020 Speech from the Throne, should be applauded.<sup>8</sup> The recent commencement of this work, led by Canada's Health Standards Organization (HSO), is mandated to engage deeply with Canadians of all ages and backgrounds. The HSO clearly states that the new National Long-Term Care Services Standard will adopt a "health equity lens" and a "culturally safe, culturally appropriate and mindful approach to care and service delivery across all long-term care interactions."<sup>9</sup>

### **This provides an immediate opportunity to consider, develop, and integrate data collection principles as a foundation for the creation of better national standards for long-term care.**

Good data not only plays an important role in helping to improve the quality of life and care for residents, their families, and care providers in long-term care settings, it is also a foundational component in achieving better outcomes.<sup>10,11</sup> Currently, only 69 per cent of Canadian long-term care homes are being accredited around the existing HSO National Long-Term Care Services Standard—which was last updated before the COVID-19 pandemic. The COVID-19 pandemic exposed a wide array of challenges in the provision of long-term care and it is clear that bold leadership and collaboration between federal, provincial, and territorial governments will be necessary to enable a more consistent approach, including universal implementation of the new National Long-Term Care Services Standard. While the focus of this paper is mainly on enhanced data collection in long-term care—in moving forward with the development of the national standards with a focus on improving quality of care and quality of work—we echo the growing call for taking immediate actions to significantly improve the working conditions of care providers and the quality of care services. This includes the physical spaces in which residents and care providers live and work.<sup>7,12,13</sup>

With this in mind, this paper reflects on the value of socio-demographic data in the context of planning and delivering long-term care and presents current challenges and opportunities for enhanced pan-Canadian socio-economic data collection in long-term care settings. It also identifies some principles of socio-demographic data collection that should not only be considered as a core

element of planning and delivering care in long-term care settings but could also inform the development of national long-term care standards. We conclude by offering key recommendations that will help advance health quality and health equity for all Canadians needing long-term care.

## Defining Long-Term Care

When thinking about long-term care, we use and advocate for the wide-scale uptake of the National Institute on Ageing's broad definition of long-term care as:

*A range of preventative and responsive care and supports, primarily for older adults, that may include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) provided by either not-for-profit and for-profit providers, or unpaid caregivers in settings that are not location specific and thus include designated buildings or in home and community-based settings.<sup>14</sup>*

We urge that the federal government use this broad understanding of long-term care when developing future policies and guidelines to enhance care for older Canadians.

While this paper mainly focuses on data collection on people living in long-term care homes, we hope that it will spark discussions around the need for enhancing socio-demographic data collection on older Canadians receiving care across a wide range of health care and social supports.

## Why Is Collecting Socio-Demographic Data Important?

Socio-demographic data is an important tool for measuring and reducing health disparities among people across different population groups and from different backgrounds.<sup>15</sup> Evidence from Canadian literature clearly demonstrates that health outcomes differ based on social and demographic factors such as sexual orientation, gender identity, language, race, immigration status, and ethnicity, as well as access to affordable housing, adequate income, social inclusion and other factors.<sup>16,17,18</sup> The emergence of COVID-19 may have exacerbated health inequities for some populations. For example, Egale Canada's *Impact of COVID-19 on the LGBTQI2S Community – Second National Report*<sup>6</sup> uncovered that COVID-19 has had an alarmingly disproportionate impact on LGBTQI2S people—particularly those from Black and racialized communities—in the areas of household finances, job loss, and mental and physical health.

Yet, Canada has long lagged behind other countries in collecting population-based socio-demographic data, such as ethnicity, race, gender identity, and sexual orientation.

**While it is now considered standard practice to report race and ethnic disparities in health in other countries, such as the United Kingdom, Australia, and the United States, race and ethnicity data is not routinely collected or reported at the federal, provincial, or local level in Canada.<sup>19</sup>**

For example, the Census of the Population<sup>20</sup> continues to fail to ask all Canadians about their race and ethnicity. Similarly, in Canada, gender identity and sexual orientation data has not been routinely collected. In fact, during the federal Standing Committee on Health 2019 consultation on the health of LGBTQIA2 communities in Canada, repeated calls were made by deputants for existing data collection processes to incorporate questions related to sexual orientation and gender identity and to attain sample sizes that enable intersectional analyses.<sup>21</sup> The 2021 Census includes a gender identity question for the first time.

## International Case: UK Census

In the U.K, a census has taken place every ten years, and it currently collects data across over 30 topics from residents in households and communal establishments such as care homes, hospitals, prisons, and boarding schools. Main uses of census data include funding formulae used to allocate central government resources to other organizations, local authorities and health bodies, policy development and planning by central, local, and regional government, and to conduct research within and outside government.<sup>22</sup> New topics have been added to the census over the years, while others have fallen away. The most recent census – the 2021 Census in England and Wales, for example, includes new questions about gender identity and sexual orientation for the first time. The Office for National Statistics (ONS) has identified user need for better data on gender identity and sexual orientation in order to support policy-making and monitor equality duties.<sup>23</sup> Previously, questions about ethnic group, religion, and main language were added into the census in 1991, 2001, and 2011, respectively.

The 2011 Census, linked with death records, provided an important data source for the ONS to examine health inequity impacts of COVID-19. The ONS's 2020 study<sup>24</sup> found that in England and Wales the risk of death involving the COVID-19 among some ethnic groups was significantly higher than that of those of White ethnicity: Black males and females were over 4 times more likely to die from a COVID-19 related death than White males and females. It also discovered that after taking into account age, measures of self-reported health and disability and other socio-demographic characteristics – all available in the 2011 Census – Black people were about twice as likely as White people to die from COVID-19. The study findings suggest that a substantial part of the difference in COVID-19 mortality between ethnic groups is explained by the different circumstances, in which members of those groups are known to live. These factors do not explain all of the differences, however, and require further exploration.

During COVID-19, inadequate socio-demographic data collection efforts emerged as a particular issue of concern when it became apparent that the disparities experienced by vulnerable populations, with respect to COVID-19 case counts and deaths, were not recognized or fully understood early enough to inform adequate public health measures (e.g., paid sick leave, targeted vaccination roll-outs).<sup>25,26</sup> Mounting pressure—fuelled by growing international

evidence on racial and ethnic disparities in COVID-19-related health outcomes<sup>27</sup>—has led a number of Canadian jurisdictions to gather race-based data to understand the equity impact of COVID-19. For example, Manitoba became the first province to track race-based inequities in COVID-19 cases.<sup>28</sup> Three public health units in Ontario started collecting race-based data in April 2020, followed by Ontario's Ministry of Health proposing all public health units collect enhanced socio-demographic

data, including race, income, household size, and language, from people who test positive for COVID-19 beginning in June 2020.<sup>29</sup>

The race-based and other socio-demographic data recently collected by Ontario's public health units has enhanced our understanding of how the COVID-19 pandemic differently impacted diverse population groups. For example, Toronto residents who identified as Arab, Middle Eastern, West Asian, Latin American, South East Asian, or Black were found to be six to nine times more likely to test positive for COVID-19 when compared to White respondents.<sup>30</sup> Further, data collected by Toronto Public Health has also shown that respondents with lower-income were more likely to test positive for COVID-19 than respondents with higher-income.<sup>31</sup> The Toronto Public Health data, however, does not include long-term care or retirement home residents. Because these public health units decided to collect enhanced socio-demographic data and publicly report their data, we now understand some of the existing gaps as a foundation for driving better equity-informed interventions and pandemic response plans.

While progress has been made to collect enhanced race-based and other socio-demographic data by some public health units,<sup>16</sup> the current data collection on COVID-19 still fails to collect information about gender identity and sexual orientation and there continues to be a particular paucity in the collection of socio-demographic data in long-term care settings. In Public Health Ontario's recent presentation on its progress on COVID-19 socio-demographic data collection, some public health units admitted that data collection was particularly poor in the long-term care settings.<sup>32</sup>

The enhanced socio-demographic data collection in long-term care settings is urgently required to identify and address health inequities among diverse population groups receiving long-term care.



## What Do We Currently Know About Health and Health Inequities in Long-Term Care Homes?

Across Canada, 415,530 older Canadians, aged 65 or older, live in 5,801 long-term care and retirement homes, representing 7 per cent of Canada’s total older adult population. Approximately 211,000 live specifically in publicly-funded long-term care homes, according to Statistics Canada’s 2016 Census data.<sup>33</sup> Further, about 46 per cent of Canada’s long-term care homes are publicly owned, while 54 per cent are privately owned (by a mix of for-profit or not-for-profit owners). These homes are almost always publicly-funded, either entirely or partially, regardless of their ownership type, and are governed

by the corresponding provincial or territorial governments, which have the jurisdictional responsibility in Canada for the provision of long-term care services.<sup>34</sup> To gain a deeper understanding of health and health inequity experienced in long-term care settings within Canada, there are several sources of data which provide insight into Canada’s older adult population, as well as the portion of the Canadian population currently residing in long-term care settings. The following discussion highlights the strengths and limitations of each data source.

**Table 1: Socio-Demographic Information Currently Collected on Long-Term Care Residents**

<b>CIHI’s Continuing Care Reporting System (CCRS)</b>	<b>Statistics Canada’s Census of Population (short-form Census)</b>	<b>Statistics Canada’s Nursing and Residential Care Facility Survey</b>
<ul style="list-style-type: none"> <li>• Age</li> <li>• Sex</li> <li>• Marital status</li> <li>• Indigenous identity</li> <li>• Education level</li> <li>• Primary language spoken at home</li> <li>• Resident’s prior primary residence neighbourhood income quintile</li> <li>• Geographic location</li> </ul>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Sex</li> <li>• Gender identity</li> <li>• Marital status</li> <li>• Knowledge of official languages</li> <li>• Language most often spoken at home</li> <li>• Mother tongue</li> <li>• History of attending French-language schools (for non-Quebec residents) or English-language schools (for Quebec residents)</li> </ul>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Sex</li> </ul>

## Existing Approaches to Collecting Socio-Demographic Data in Canada

Within Canada, there are a number of existing approaches to the collection of socio-demographic data—led by Canadian Institute for Health Information and Statistics Canada—that shed light on the health and health inequities experienced by Canadians.

### Canadian Institute for Health Information

The Canadian Institute for Health Information (CIHI) provides information on Canada's health system and population health across the continuum of care. It publishes publicly available reports annually on the profile of residents and hospital-based continuing care, based on data provided by the Continuing Care Reporting System (CCRS) and provides access to the CCRS data upon request.

#### *Continuing Care Reporting System*

The CCRS provides the main source of data about Canadians living in long-term care homes. The CCRS, launched in 2003-2004, contains socio-demographic, clinical, and functional information on long-term care residents, as well as other individuals receiving continuing care services in hospital-based facilities. The CCRS does not collect any staff information. The clinical standard for CCRS is the Resident Assessment Instrument-Minimum Data Set (RAI-MDS 2.0), which is a clinical assessment tool developed by interRAI, an international research network.

The RAI-MDS 2.0 has been modified for use in Canada by Canadian Institute for Health Information (CIHI), with permission from interRAI. The long-term care homes that have implemented the RAI-MDS 2.0 can submit data to the CCRS<sup>35</sup>—with participating provinces and territories submitting data to CIHI quarterly. From the submitted data, CIHI's annual reports present selected characteristics of long-term care residents, mostly related to health but also two socio-demographic indicators: age and sex.

Table 2 presents information about selected characteristics of residents living in long-term care homes who received services in 2019-2020 in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Newfoundland and Labrador, and the Yukon.<sup>36</sup> For example, about 65 percent of people living in long-term care homes are female, and the majority of long-term care residents, across the six jurisdictions, are living with some form of cognitive impairment, and/or other complex health condition. Overall, the residents living in long-term care homes today tend to be older, closer to the end of their lives, and experiencing more health challenges than residents in the past.<sup>37</sup> Consequently, more residents need extensive support with their activities of daily living.

**Table 2. Profile of Long-Term Care Residents on Selected Characteristics, 2019-2020**

Resident Profile	Total	Newfoundland and Labrador	Ontario	Manitoba	Saskatchewan	Alberta	British Columbia	Yukon
Average age	83	81	83	85	82	82	84	78
Younger than 65 (%)	6.7	7.6	6.4	4.3	10.4	9.1	5.4	13.8
85 and older (%)	54.3	41.8	54.6	58.1	55.2	51.2	55.6	36.3
Female (%)	65.2	63.7	66.8	68.9	62.5	60.7	63.4	52.3
Diagnosis of dementia (%)	61.6	55.2	63.2	59.8	47.7	56.8	64.1	51.9
Diagnosis of hypertension (%)	59.0	58.5	64.1	57.4	47.5	57.9	47.1	56.1
Diagnosis of cancer (%)	9.1	11.2	9.7	11.1	6.8	10.2	6.5	9.8
Diagnosis of diabetes (%)	25.8	29.8	28.0	23.1	21.9	25.3	20.6	23.0
Total dependence in Activities of Daily Living (ADLs) (%) <sup>§§</sup>	12.2	21.3	11.9	11.5	10.2	12.8	12.2	5.9
Severe cognitive impairment (%) <sup>***</sup>	32.7	48.1	33.6	27.0	29.7	32.3	30.7	25.4
Some indication of health instability (%) <sup>††</sup>	57.1	56.1	61.1	44.5	40.4	61.9	48.3	76.7
Signs of depression (%) <sup>†††</sup>	24.5	30.3	27.4	10.9	16.7	27.1	18.0	37.3
Limited or no social engagement (%) <sup>§§§</sup>	42.9	38.9	40.3	48.9	44.1	40.9	50.8	33.8
Daily pain (%) <sup>****</sup>	8.5	20.8	6.8	5.9	11.9	10.7	10.6	40.1
Some aggressive behaviour (%) <sup>††††</sup>	39.9	34.0	42.4	30.9	30.2	45.6	33.7	46.0
Some bladder incontinence (%) <sup>††††</sup>	76.7	70.6	80.4	67.3	62.0	78.3	70.6	59.2
Some bowel incontinence (%) <sup>††††</sup>	59.1	65.6	61.3	50.2	42.9	66.3	53.1	39.0

Data Source: CIHI (2020). Quick Stats: Profile of Residents in Residential and Hospital-based Continuing Care 2019-2020.

Note: Based on data from a total of 189,662 residents in 1,318 long-term care homes in Newfoundland and Labrador, Ontario, Manitoba, Saskatchewan, Alberta, British Columbia and Yukon.



While the CCRS offers standardized and comprehensive data on many Canadians living in long-term care homes, it has significant limitations in terms of offering a deeper understanding of the diverse populations living in long-term care settings across Canada beyond standard demographic indicators.

Currently, the CCRS includes several socio-demographic indicators: age, sex, marital status, Indigenous<sup>i</sup> identity, education level, primary language spoken at home, resident's prior primary residence neighbourhood income quintile, and geographic location (Table 1). Yet, the CCRS does not include many of the socio-demographic indicators that can be used to better measure health inequities, such as family or personal income, ethnicity, racial identity, immigration status, sexual orientation, and gender identity.<sup>38</sup> While CIHI calls such indicators an "equity identifier," referring to a "characteristic such as a demographic, social, economic, racial or geographic descriptor that can identify population subgroups for the purpose of measuring differences in health and health care that may be considered unfair or unjust,"<sup>39</sup> they have yet to be integrated into the CCRS.

Another challenge in current data collection considerations is the CCRS's limitations in providing pan-Canadian data, which captures information on long-term care residents across all of its provinces and territories. While it is widely used as a standard assessment tool for long-term care settings, participation in CCRS is currently not mandatory for all

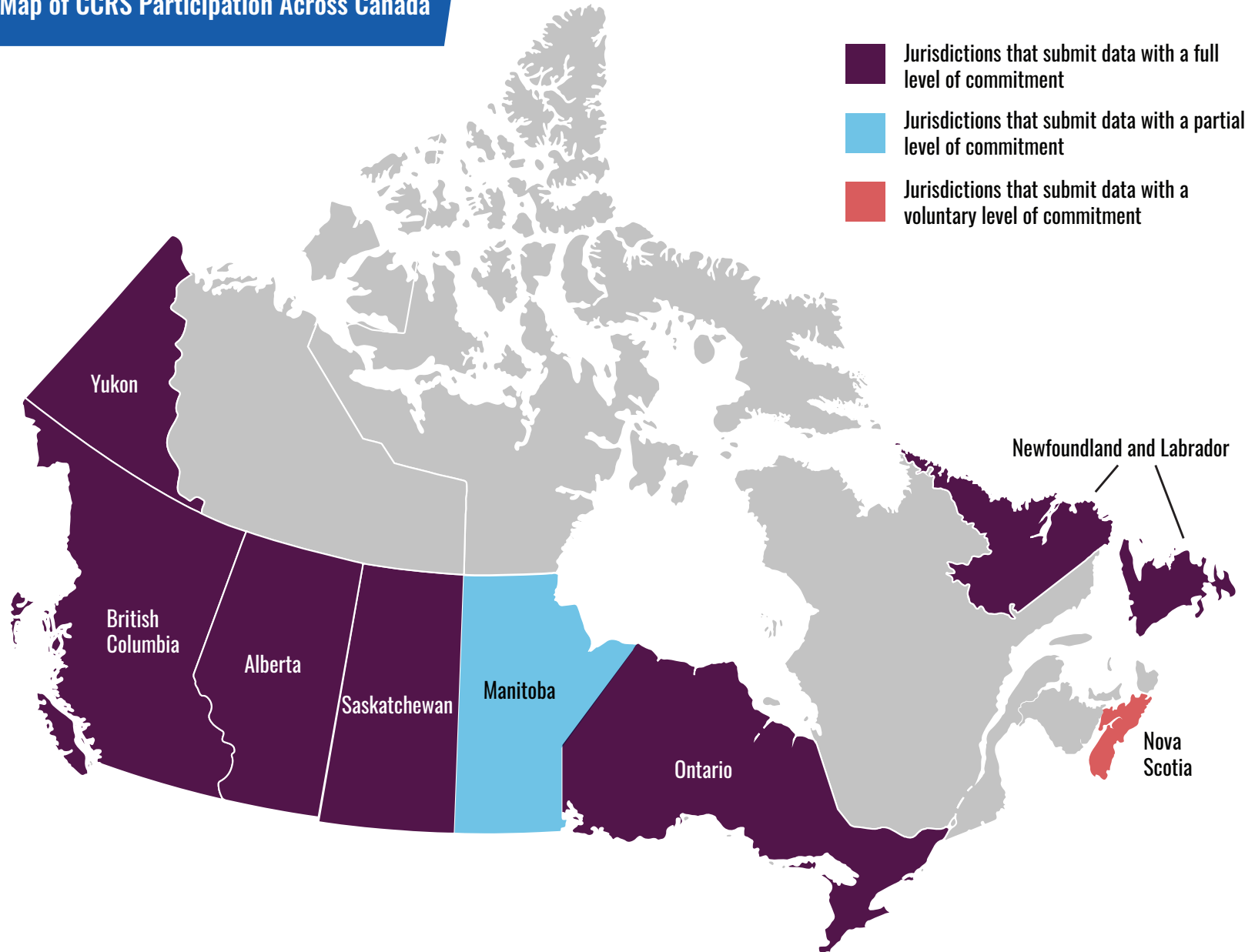
long-term care homes across Canada. As of 2020-2021, eight jurisdictions submit data to CCRS with a full level of commitment, a partial level of commitment, or a level of voluntary participation. Specifically, six jurisdictions are currently committed to fully submitting data for all of their long-term care homes: Newfoundland and Labrador, Ontario, Saskatchewan, Alberta, British Columbia and Yukon. Manitoba has a partial commitment, and Nova Scotia is participating on a voluntary basis (see Figure 1).<sup>35</sup>

The data provided by the CCRS is used for program planning, care monitoring, understanding populations and their needs, improving the quality of care, and allocating resources and research.<sup>35</sup> With a continued limited understanding of the diversity within Canada's residents living in long-term care settings, however, we not only remain ill-equipped to truly understand the scope of health inequities experienced among this population; planning and funding based on data that fails to capture the true diversity of needs may also be perpetuating and exacerbating the inequity experienced by residents living in long-term care settings. Collecting additional socio-demographic data in the CCRS could help to identify, develop, and implement effective interventions to address inequities and improve health and health equity for diverse resident groups Canadians living in long-term care homes.

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<sup>i</sup> While many documents referenced in this paper (e.g., CCRS) use the term *Aboriginal* (which for many years was the least contentious and most inclusive general term), we use the term *Indigenous* in reference to the larger collective of First Nations, Métis, and Inuit peoples throughout this report as a reflection of recent shifts in language and understanding.

**Figure 1: Map of CCRS Participation Across Canada**



## Statistics Canada

Another source of national-level data on older Canadians are Statistics Canada's national population-based surveys. Compared to the CCRS, the Statistics Canada's survey data provides a wider range of socio-demographic information, as well as health information, particularly on individuals from Canada's 2SLGBTQIA+, racialized, and/or immigrant communities. Statistics Canada currently collects data via a number of surveys, including the Census of the Population, Canadian Community Health Survey (CCHS), and the Nursing and Residential Care Facility Survey.

### *Census of the Population*

There are two versions of Statistics Canada's Census of the Population – short-form and long-form — which provide a crucial source of data on Canadians.<sup>40</sup> The short-form Census collects information from all Canadians, including those living in long-term care homes. However, the socio-demographic information currently collected by the short-form Census is limited to: age, sex assigned at birth, gender identity, marital status, knowledge of official languages, language most often spoken at home, mother tongue, and history of attending French-language schools (for non-Quebec residents) or English-language schools (for Quebec residents) (Table 1).<sup>41</sup> It is important to highlight that thanks to recent lobbying by health professionals and researchers, we are starting to see changes made to Census questionnaires. For example, while the 2016 Census only asked about sex assigned at birth, the 2021 Census now includes a new additional question about person's *current*

gender identity—recognizing that current gender "...may be different from sex assigned at birth and may be different from what is indicated on legal documents."<sup>42</sup> When linked with the CCRS data, the new short-form Census data could provide valuable information about health inequities by gender, as well as official language proficiency or mother tongue, among long-term care home residents. While this is a welcome addition to the 2021 Census, it still fails to include question(s) inquiring about sexual orientation and behaviour. However, Statistics Canada is currently conducting consultation on new standards proposed for sexual orientation.<sup>43</sup>

Compared to the short-form Census, data from the long-form Census is based on a representative sample (25 per cent of Canadians) and provides more comprehensive information about survey participants, including additional questions such as ethnicity, racial groups, religion, homelessness, immigration status, place of birth, and year of immigration. Unfortunately, the data generated under current practices will continue to be limited because the small sample sizes for certain sub-groups of the Canadian population, particularly those identify as 2SLGBTQIA+, continue to be an issue. This limits our capacity to conduct robust analyses of health inequities for marginalized population groups, as well as intersectional analyses to understand the health of queer and trans Black, Indigenous, and People of Colour (QTBIPOC) individuals and communities, for example.<sup>44</sup> Additionally, the long-form Census does not collect information from people living in institutionalized collective dwellings, including long-term care homes, retirement

homes, hospitals, and other settings. This exclusion, once again, limits our ability to understand the diversity within populations living in long-term care settings.

### *Canadian Community Health Survey*

The CCHS is a national cross-sectional survey aimed at providing health information at the national, provincial, and regional levels. It collects information related to health status, health care utilization and health determinants for the Canadian population. Approximately 65,000 Canadians aged 12 years and older are surveyed each year. The CCHS provides one of the most promising data sets to examine health inequities across diverse population groups in Canada. It collects socio-demographic information about age, sex assigned at birth, gender, sexual orientation, household income, immigration status, country of birth, length of time in Canada, ethnicity, racial groups, language mostly spoken at home, mother tongue, and knowledge of official languages. However, while the data generated by the CCHS is perhaps the most comprehensive population-based socio-demographic data available in Canada, it does not collect data on individuals living in institutionalized collective dwellings, including those living in long-term care and retirement homes. Further, the data regarding the health of Canada's 2SLGBTQIA+ communities is limited, as the CCHS has only recently begun to collect data on sexual orientation from respondents over the age of 59—previously limited to individuals aged 18 to 59.<sup>45</sup> The paucity of data available on 2SLGBTQIA+ older adults in Canada subsequently limits the possibility of intersectional analyses to understand the health of Indigenous or racialized 2SLGBTQIA+ older adults.<sup>21</sup>

### *Nursing and Residential Care Facility Survey*

Statistics Canada has also conducted surveys specifically on long-term care and retirement homes. Currently, the 2020 Nursing and Residential Care Facility Survey is collecting information from nursing and residential care facilities across Canada about operating revenues and expenses, personnel employed and hours worked, counts and characteristics of residents, and COVID-19 related questions. While this survey focuses mainly on information about facility characteristics and their operations, it also provides data on resident groups by age and sex (Table 1). Prior to being replaced by the Nursing and Residential Care Facility Survey, the Private Nursing and Residential Care Facilities Survey (2015 to 2018), Long-Term Care Facilities Survey (2011 to 2014), and Residential Care Facilities Survey (1996 to 2011) collected information about long-term care and retirement homes—and their residents. However, the resident information collected through these surveys was limited to age and sex only, not including gender identity and other information. No staff information has ever been collected.

## International Case: Socio-demographic Data Collection in Long-Term Care

In the United States, the Long Term Care Minimum Data Set (MDS) collects data on residents living in nursing, or long-term care, homes. The Nursing Home Reform Act 1987 mandated the development of a standardized assessment system, and the MDS has been part of the federally mandated process for clinical assessment of all residents in Medicare and Medicaid certified nursing homes.<sup>46</sup> The MDS was implemented in all long-term care homes in 1996 and was developed by the InterRAI research network. The current version (MDS 3.0)<sup>47</sup> includes questions about a range of resident's socio-demographic information, including sex, age, race/ethnicity (e.g., American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian or Other Pacific Islander, and White), language (e.g., the need for an interpreter and preferred language), and marital status. US long-term care homes transmit MDS information electronically to the national MDS database at the Centres for Medicare & Medicaid Services (CMS). The CMS provides public access to regular reports summarizing socio-demographic and other clinical information for residents currently residing in long-term care homes.

In Australia, established in 2013, the National Aged Care Data Clearinghouse (NACDC) holds data for all clients of government-funded aged care, including residential aged care, home care, and transition care, from 1997 onwards. The data mostly relates to aged care programs operating under the Aged Care Act 1997. First introduced in the 1983-84 Federal Budget as the Geriatric Assessment Program, Aged Care Assessment Program Minimum Data Set (ACAP MDS)<sup>48</sup> collects aged care clients' socio-demographic information including age, sex, marital status, geographic location, Indigenous status, language, and country of birth. The Australian Institute of Health and Welfare and the Department of Health co-developed the GEN website ([www.gen-agedcaredata.gov.au](http://www.gen-agedcaredata.gov.au)), a comprehensive "one-stop shop" for data and information about aged care services in Australia. Currently, GEN provides access to the data and information from the NACDC. The key socio-demographic data on people using aged care, such as age, sex, Indigenous status, preferred language, and country of birth, are reported and updated annually on the GEN website.<sup>49</sup> The Royal Commission into Aged Care Quality and Safety's February 2021 report<sup>50</sup> acknowledged current limitations in Australia's aged care data—stating that it is not adequately integrated and analysed to guide how to achieve improvements in care. To inform assessment of how the aged care sector performs for the benefit of older people, the Royal Commission has recommended the Australian Institute of Health and Welfare curate and make publicly available a National Aged Care Data Asset, including information about people receiving aged care, the aged care workforce, and the performance of aged care providers.

**Ultimately, this report echoes and amplifies calls that have identified the existing gap in collecting and utilizing health equity data in the Canadian long-term care sector as an important area for improvement.**

In particular, CIHI acknowledges that the CCRS, along with other CIHI and Statistics Canada health data repositories, fails to capture the information that can be effectively used to identify health inequities among people living and working in Canadian long-term care homes.<sup>39</sup> Further, in the *Restoring Trust: COVID-19 and The Future of Long-Term Care* report, recently published by the Royal Society of Canada, the data gap—particularly on race, ethnicity, and language—was highlighted as a significant barrier to understand any existing disparities and making effective interventions to address the disparities in long-term care:

*Canada is multi-racial and that is reflected in our nursing homes, but data on race, language spoken and ethnic group are not routinely collected. This is particularly problematic because COVID-19 has differentially affected racialized populations. (p.16)<sup>7</sup>*

The Royal Society of Canada report strongly recommended that future federal support for the long-term care sector be tied to requirements for better data collection. It also urged that collected data must be used to address any “disparities and compounding vulnerabilities among both residents and staff, such as race, ethnicity, language, gender identity, guardianship status, socioeconomic status, religion, physical or

intellectual disability status, and trauma history screening” (p.29). While we remain focused on the need for better data collection among residents living in long-term care in this paper, we acknowledge and echo calls for enhanced socio-demographic data collection among workers—as well as residents—since such data will shed light more broadly on the organizational culture within a long-term care home. Further research is needed to identify the gaps in the current socio-demographic data collection on people working in long-term care settings across Canada, and the ways to enhance standardized data collection on this population group.

## Health Inequities in Long-Term Care: Evidence from Canadian and International Literature

As we join researchers and advocates in calling for enhanced collection and analysis of socio-demographic data in long-term care settings, this section explores the current evidence from Canadian and international studies on health disparities, as well as inequities in access to care experienced by people needing long-term care. While limited, current research findings shed light on some of the existing inequities in Canadian long-term care systems, highlighting the importance of collecting and analyzing socio-demographic data, as well as the need for better data collection on diverse population groups living in long-term care settings.

A few Canadian studies have used existing long-term care assessment and admission data to examine health disparities among residents living in long-term care homes. Jeong and colleagues<sup>51</sup> examined the RAI-MDS data, linked with other administrative databases such as Immigration, Refugees and Citizenship Canada's Permanent Resident database, to look at the differences in hospitalizations, emergency department visits, and mortality rates between immigrants and long-term residents (who arrived before 1985 or are Canadian-born) living in Ontario's long-term care homes. Using the linked data, this study was able to identify that 4.4 per cent of newly admitted long-term care home residents were immigrants, significantly less than the 13.9 per cent of Ontarians, aged 65 years or older, who were immigrants. More than half of the

immigrants in this study had no knowledge of either English or French at the time of arrival in Canada, and less than 30 per cent identified English as their primary language on admission to a long-term care home. The study found that immigrants as a group were less likely to die during the one-year follow-up period after moving into a long-term care home, but they were more likely to be hospitalized when compared to other groups. Accounting for the primary language of the resident, however, reduced any difference in one-year hospitalization rates between immigrants and long-term residents. Furthermore, speaking a non-English language as primary language was associated with increased risk of hospitalization. The authors highlighted the need for strategies to overcome communication barriers to reduce disparities in access and health outcomes.

When it comes to understanding the health inequities experienced by long-term care home residents from 2SLGBTQIA+ communities, the lack of standardized data collection on resident's sexual orientation and gender identity has created a significant knowledge gap. Despite the limited understanding of 2SLGBTQIA+ communities living in long-term care homes, existing literature within and beyond Canada has noted fears of needing to "go back into the closet" and/or receiving lower quality of care in long-term care settings because of their sexual orientation or gender identity.<sup>52</sup> While the 2021 Census now includes questions regarding gender identity—while continuing to omit sexual orientation—in response to the Committee's recommendation that data collection be improved, it is not possible to address the fear and inequity experienced



by 2SLGBTQIA+ individuals within long-term care settings without a more complete picture of the health of 2SLGBTQIA+ communities in Canada (as noted earlier).<sup>53</sup>

Other studies have examined the inequities in accessing long-term care homes. The Wellesley Institute's 2016 study, *The Cost of Waiting for Care: Delivering Equitable Long-term Care for Toronto's Diverse Population*,<sup>54</sup> investigated differences in long-term care home wait times, using publicly-available wait time data from the Toronto Central Community Care Access Centre (TC-CCAC), which managed admissions to 36 long-term care homes in central Toronto. This study found that those who applied for basic accommodation (i.e., two to four beds per room) waited about three months longer than those who applied for private accommodation (i.e., one bed per room). This disparity may be linked to the financial costs of long-term care accommodations since, in Ontario, residents in basic accommodation are eligible for government subsidies, but not those in private accommodation. The study also found that people who applied for ethno-cultural specific homes waited about six months longer than those who applied for homes that were not designated as ethno-cultural specific homes. This suggests that more culturally specific homes are needed to meet current demand. The research findings suggested that lower-income Torontonians who needed government subsidies and those from ethnic and linguistic minority populations, might face longer waits than English-speaking Canadians with financial means in accessing a long-term care home bed.

The Wellesley Institute's 2020 study, *Waiting for Long-Term Care in the GTA: Trends and*

*Persistent Disparities*,<sup>55</sup> further examined the inequities in long-term care home wait times, using the Modernized Client Profile Database, an administrative dataset that contains information on people waiting to be placed in a long-term care home in Ontario. The study found that while the median wait time was not much different between male and female residents, the wait time varied widely across different population groups. Overall, older residents (i.e., 85 years or older) waited longer than younger residents; people who reported neither English nor French as their first language experienced longer wait times for placement; those waiting for a home serving those of a particular religion, ethnic origin, or culture reported significantly longer wait times than those waiting for a home with no specific cultural or religious designation, with the same level of care needs.

## **Reliably collecting in-depth socio-demographic data across Canada would enable better policy and planning processes to address known gaps in care options for Canadians of all backgrounds.**

The lack of data regarding 2SLGBTQIA+ experience in LTC, taken alongside the limited data on the experiences of ethnic and linguistic minority populations, underscores the need for more attention in this area. Ultimately, it is clear that without taking steps to enhance the collection of socio-demographic data in long-term care settings, current and ongoing fears and inequities experienced by diverse communities with respect to access to care within long-term care settings will continue.



## The COVID-19 Context

In the context of the COVID-19 pandemic, to our knowledge, no Canadian research has yet investigated the intersection of health equity impacts and socio-demographic characteristics among long-term care residents or staff. While the National Institute on Ageing (NIA) has been tracking reported case counts and outbreak in Canadian long-term care and retirement homes, this data does not provide a deeper analysis of the actual populations residing and/or working within each long-term care and retirement homes, as its data sources related to resident and staff cases and deaths are not reported even at the level of age or gender.<sup>4</sup> Building from this data, researchers have explored

the impact of some home-level factors on the COVID-19 outbreaks and mortality in Ontario long-term care and retirement homes. Findings indicated more negative impacts on those living in for-profit homes, especially those under chain-ownership and with a higher share of multi-bed rooms.<sup>56,57,58</sup> CIHI has also reported that shortages in personal support workers (e.g., 25% short at least once between March and June 2020), and use of PSWs provided by external agency on 7 or more days in any month from March to June 2020, contributed to higher severity of outbreaks and resident mortality during the first-wave of the COVID-19 pandemic.<sup>59</sup>

### NIA's LTC COVID-19 Outbreak Tracker

The NIA made a significant contribution to the lack of data infrastructure noted in the federal government's Budget 2021 through its [LTC COVID-19 Outbreak Tracker](#). The tracker has been widely cited throughout the COVID-19 pandemic, most notably contributing to the recent NIA/Canadian Institute for Health Information (CIHI) report: [The Impact of COVID-19 on LTC in Canada Focus on the First 6 Months](#). Using NIA LTC Tracker data, this report illustrated the disproportionate impact that COVID-19 has had on LTC residents, staff, and family members.

Emerging evidence and studies from the United States and the United Kingdom show significant disparities among long-term care home residents in COVID-19-related health outcomes. Particularly, the routinely collected race and ethnicity data on long-term care home residents in these countries allowed researchers to explore race-based health disparities in the context of COVID-19. Overall, evidence suggested that individual-level factors such as racial/ethnic minority status, living with dementia, older age, male sex, and receipt of Medicaid or Medicare, were found to be associated with poorer COVID-19-related health outcomes.<sup>27,60</sup> For example, Li and colleagues<sup>61</sup> examined racial/ethnic disparities in weekly counts of new COVID-19 cases and deaths among US long-term care home residents and staff. Their study found that the likelihood of having at least one new resident case was 76 per cent higher for the high-proportion group (with 30.17 per cent or higher) than for the low-proportion group (with lower than 2.92 per cent). Similar across-home disparities were found for the weekly count of new COVID-19 deaths among residents during the week of May 25, 2020. The study found no substantial disparities in self-reported shortages of staff or PPE across the homes. Another study by Kaiser Family Foundation<sup>62</sup> found that US long-term care homes with a relatively higher share of Black or Hispanic residents were disproportionately affected by COVID-19, compared to those with a lower share of Black or Hispanic residents as well as a higher share of White residents—as measured by the share reporting deaths, share reporting cases, and the severity of outbreak. Further, current evidence within and beyond Canada suggests that incidence of COVID-19 infections in the surrounding community was found to have the strongest association with

the number of infections and/or outbreaks in long-term care settings.<sup>65</sup>

While we do not yet have clear evidence of the health equity impact of COVID-19 on diverse population groups living in long-term care homes, we do know from Canadian and international evidence that low-income groups and racialized populations are experiencing disproportionately higher rates of COVID-19 infections and related deaths.<sup>31</sup> Based on current understandings of the impact of higher community transmission in Canada's lower-income and racialized communities, it is fathomable that these impacts could lead—and, arguably, have led—to disproportionately negative outcomes for older adults living and staff working in long-term care homes. Yet, without data, we do not know the full scope of the health equity impact of the pandemic on diverse population groups living and working in long-term care settings.

# Current Initiatives to Enhance Socio-demographic Data Collection in Health and Long-term Care Settings

Across Canada, some promising examples have been developed to collect enhanced socio-demographic data through administrative data in health and long-term care settings, in addition to the Census and sample surveys briefly mentioned above. More recently, there has been growing consensus on developing a standardized set of socio-demographic data that is comparable and linkable across jurisdictions and sectors. To advance health equity, a standard approach is important to ensure harmonized collection, measurement and reporting of health inequities across Canada.<sup>63</sup> The following highlights selected promising initiatives, as well as their set of socio-demographic questions.

## Measuring Health Equity in Toronto Central LHIN

In 2013, the Toronto Central LHIN (TC-LHIN) became Canada's first regional health organization to mandate routine collection of standardized, patient-level socio-demographic data in 16 hospitals and 16 community health centres. TC-LHIN adopted an evidence-based demographic data tool that came out of a research project led by Mount Sinai Hospital, Centre for Addiction and Mental Health (CAMH), St. Michael's Hospital, and Toronto Public Health.<sup>64</sup> This tool includes a set of standardized socio-demographic questions focused on eight variables: spoken language, Canadian-born,

ethnicity/race, disability, gender, sexual orientation, income, and number of people income support (see Table 3 for an example of questions asked). In 2019, a pilot was conducted to collect socio-demographic data from selected home and community care clients, with the purpose of exploring the feasibility of expanding such data collection into the home and community care sector.<sup>65</sup> The collection of equity data continues to be a high priority for Toronto Central LHIN (now known as Ontario Health-Toronto Region), with an aim to record demographic data on 75 per cent of patients and clients in the system.<sup>66</sup>



**Table 3. We Ask Because We Care – TC LHIN Hospitals Demographic Questions**

<p><b>1. What language would you feel most comfortable speaking in with your health care provider? Check ONE only</b></p>				
<input type="checkbox"/> 1. Amharic <input type="checkbox"/> 2. Arabic <input type="checkbox"/> 3. ASL <input type="checkbox"/> 4. Bengali <input type="checkbox"/> 5. Chinese (Cantonese) <input type="checkbox"/> 6. Chinese (Mandarin) <input type="checkbox"/> 7. Czech <input type="checkbox"/> 8. Dari	<input type="checkbox"/> 9. English <input type="checkbox"/> 10. Farsi <input type="checkbox"/> 11. French <input type="checkbox"/> 12. Greek <input type="checkbox"/> 13. Hindi <input type="checkbox"/> 14. Hungarian <input type="checkbox"/> 15. Italian <input type="checkbox"/> 16. Karen	<input type="checkbox"/> 17. Korean <input type="checkbox"/> 18. Nepali <input type="checkbox"/> 19. Polish <input type="checkbox"/> 20. Portuguese <input type="checkbox"/> 21. Punjabi <input type="checkbox"/> 22. Russian <input type="checkbox"/> 23. Serbian <input type="checkbox"/> 24. Slovak	<input type="checkbox"/> 25. Somali <input type="checkbox"/> 26. Spanish <input type="checkbox"/> 27. Tagalog <input type="checkbox"/> 28. Tamil <input type="checkbox"/> 29. Tigrinya <input type="checkbox"/> 30. Turkish <input type="checkbox"/> 31. Twi <input type="checkbox"/> 32. Ukrainian	<input type="checkbox"/> 33. Urdu <input type="checkbox"/> 34. Vietnamese <input type="checkbox"/> 35. Other (please specify): _____ <input type="checkbox"/> 88. Prefer not to answer <input type="checkbox"/> 99. Do not know
<p><b>2. Were you born in Canada?</b>   <input type="checkbox"/> 1. Yes   <input type="checkbox"/> 2. No   <input type="checkbox"/> 88. Prefer not to Answer   <input type="checkbox"/> 99. Do not know            If <b>NO</b>, what year did you arrive in Canada? _____</p>				
<p><b>3. Which of the following best describes your racial or ethnic group? Check ONE only</b></p>				
<input type="checkbox"/> 1. Asian – East (e.g. Chinese, Japanese, Korean) <input type="checkbox"/> 2. Asian- South (e.g. Indian, Pakistani, Sri Lankan) <input type="checkbox"/> 3. Asian-South East (e.g. Malaysian, Filipino, Vietnamese) <input type="checkbox"/> 4. Black-African (e.g. Ghanaian, Kenyan, Somali) <input type="checkbox"/> 5. Black-Caribbean (e.g. Barbadian, Jamaican) <input type="checkbox"/> 6. Black-North American (e.g. Canadian, American) <input type="checkbox"/> 7. First Nations <input type="checkbox"/> 8. Indian-Caribbean (e.g. Guyanese with origins in India) <input type="checkbox"/> 9. Indigenous/Aboriginal – not included elsewhere <input type="checkbox"/> 10. Inuit	<input type="checkbox"/> 11. Latin American (e.g. Argentinean, Chilean, Salvadoran) <input type="checkbox"/> 12. Metis <input type="checkbox"/> 13. Middle Eastern (e.g., Egyptian, Iranian, Lebanese) <input type="checkbox"/> 14. White-European (e.g. English, Italian, Portuguese, Russian) <input type="checkbox"/> 15. White - North American (e.g. Canadian, American) <input type="checkbox"/> 16. Mixed heritage (e.g. Black - African & White – North American) Please specify: _____ <input type="checkbox"/> 17. Other(s): Please specify: _____ <input type="checkbox"/> 88. Prefer not to answer <input type="checkbox"/> 99. Do not know			
<p><b>4. Do you have any of the following? Check ALL that apply</b></p>				
<input type="checkbox"/> 1. Chronic illness <input type="checkbox"/> 2. Developmental disability <input type="checkbox"/> 3. Drug or Alcohol dependence <input type="checkbox"/> 4. Learning disability <input type="checkbox"/> 5. Mental illness <input type="checkbox"/> 6. Physical disability <input type="checkbox"/> 7. Sensory disability (i.e. hearing or vision loss) <input type="checkbox"/> 8. Other (Please specify): _____	<input type="checkbox"/> 9. None <input type="checkbox"/> 88. Prefer not to answer <input type="checkbox"/> 99. Do not know			

**5. What is your gender? Check ONE only**

<input type="checkbox"/> 1. Female	<input type="checkbox"/> 6. Other (Please specify):_____
<input type="checkbox"/> 2. Intersex	<input type="checkbox"/> 88. Prefer not to answer
<input type="checkbox"/> 3. Male	<input type="checkbox"/> 99. Do not know
<input type="checkbox"/> 4. Trans-Female to Male	
<input type="checkbox"/> 5. Trans-Male to Female	

**6. What is your sexual orientation? Check ONE only**

<input type="checkbox"/> 1. Bisexual	<input type="checkbox"/> 6. Other (Please specify):_____
<input type="checkbox"/> 2. Gay	<input type="checkbox"/> 88. Prefer not to answer
<input type="checkbox"/> 3. Heterosexual	<input type="checkbox"/> 99. Do not know
<input type="checkbox"/> 4. Lesbian	
<input type="checkbox"/> 5. Queer (a term used by people who do not follow common sexual orientations)	
<input type="checkbox"/> 6. Two-Spirit (a term used by Aboriginal people)	

**7. What was your total family income before taxes last year? Check ONE only**

<input type="checkbox"/> 1. \$0-\$29,999	<input type="checkbox"/> 88. Prefer not to answer
<input type="checkbox"/> 2. \$30,000-\$59,999	<input type="checkbox"/> 99. Do not know
<input type="checkbox"/> 3. \$60,000-\$89,999	
<input type="checkbox"/> 4. \$90,000-\$119,999	
<input type="checkbox"/> 5. \$120,000-\$149,999	
<input type="checkbox"/> 6. \$150,000 or more	

**8. How many people does this income support?**

\_\_\_\_\_person(s)       88. Prefer not to answer       99. Do not know

Hospitals and community health centres are using the collected data in a variety of ways: to profile who is being served, to stratify health service utilization and outcome data, to build into quality improvement plans, and to inform clinical care.<sup>67</sup> For example, the collected data from hospitals and community health centres have enabled health equity researchers to link the data with other health administrative databases, in order to identify existing inequities in health outcomes and health service use. A 2016 ICES study<sup>68</sup> found considerable differences across racial/ethnic groups in many of the examined measures for health care utilization and comorbidities. For example, Black patients had the highest average length of hospital stay, 1.4 times that of Latin American patients. Black patients had the lowest rates of post-discharge follow-up visits to primary care physician. Another study by Smith et al.<sup>69</sup> investigated whether and to what degree patient-level socio-demographic factors, including the eight variables plus education, influence the incidence of hospital re-admission over a 30-day time frame in a Toronto hospital. This study found that patient-level socio-demographic factors in fact did not substantially influence risk of unplanned re-admission. Other factors, such as frequency of previous hospitalizations, were however associated with re-admission. With the data, service providers and health system administrators can better identify any existing gaps, track health inequities, and develop programs and services to address the needs of disadvantaged population groups.

With the increasing recognition of need for enhanced socio-demographic data collection across Canada, resources developed by the Measuring Health Equity initiative have been shared widely. In recent years, several organizations, as well as municipal and

regional health units— such as Mississauga Halton LHIN, Central West LHIN, Toronto Public Health, Saskatoon Public Health, Algoma Public Health (Sudbury region)—have adopted or begun planning for patient-level socio-demographic data collection, using some or all of the eight socio-demographic questions.<sup>75</sup>



## Pan-Canadian Standards for Collecting Race-Based and Indigenous Identity in Health Systems by Canadian Institute for Health Information

Acknowledging the lack of consistency in the approaches used to measure health equity across Canada, CIHI convened a pan-Canadian stakeholder dialogue in 2016 to build consensus and help develop standards for equity stratifiers that will enable comparisons across health system levels and jurisdictions.<sup>70</sup> As a result of a series of consensus-building exercises, a set of seven core equity stratifiers was identified as highest priority for measuring equity in health care: age, sex, geographic location, income, education, Indigenous identity and ethnicity/racial groups. Additionally, seven stratifiers were identified as important but requiring further consideration: housing, disability, language, health insurance, immigrant status, sexual orientation and gender identity.

Building on the initial work from the pan-Canadian dialogue, CIHI has supported standards for health equity measurement through offering online resources and publishing a series of reports. *Measuring Health Inequalities: A Toolkit*<sup>71</sup> was developed to assist analysts and researchers with measuring and reporting on health inequalities, with a focus on stratifying health indicators. Among a variety of guidelines and resources in this online toolkit, the Equity Stratifiers Inventory<sup>39</sup> is particularly useful; it lists the availability of 19 selected equity stratifiers, in addition to residential postal code, in each of CIHI and Statistics Canada

data sources. For example, out of 20 measures included in the Inventory, the Continuing Care Reporting System (CCRS)—which was profiled above as it contains information on long-term care home residents and hospital patients—incorporates only five stratifiers (i.e., age, sex, disability, homeless, and language). Six are partially available (i.e., income, education, geographic location—urban vs rural/remote, Indigenous identity, marital status, and residential postal code) and nine are not available (i.e., gender, ethnicity, racial groups, employment status, occupation, immigration status, sexual orientation, social support, and health insurance).



**Table 4: Summary of Equity Stratifier Definitions (CIHI)<sup>39</sup>**

Equity Stratifier	Construct	Measure
Age	Age in years	Age categories should be determined on an indicator-by-indicator basis for measuring health inequality
Sex	Sex assigned at birth	2 categories: <ul style="list-style-type: none"> <li>• Female</li> <li>• Male</li> </ul>
Gender	Lived gender	3 categories: <ul style="list-style-type: none"> <li>• Female gender</li> <li>• Male gender</li> <li>• Gender diverse</li> </ul>
Income	Relative income	Income quintiles
Education	Educational attainment	Highest self-reported household educational attainment using 5 categories: <ul style="list-style-type: none"> <li>• Less than high school</li> <li>• High school completion</li> <li>• Post-secondary school completion below bachelor’s degree</li> <li>• Bachelor’s degree completion</li> <li>• Post-secondary school completion above bachelor’s degree</li> </ul>
Geographic location	Urban and rural/remote place of residence*	Statistical Area Classification type (SACtype) defined as <ul style="list-style-type: none"> <li>• Urban (SACtypes 1,2,3)</li> <li>• Rural/remote (SACtypes 4,5,6,7,8)</li> </ul>

Note: \*Consider a measure of travel burden for complementary analyses.

CIHI’s 2018 report, *In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality*, provided recommended definitions for selected equity stratifiers: age, sex, gender, geographic location, income, and education (Table 4: Summary of equity stratifier definitions). With the support of pan-Canadian expert working groups, these definitions were developed in collaboration with Statistics Canada. CIHI’s 2020 report, *Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada* (Table 5), presented standardized race-

based and Indigenous identity questions and response categories. These standards were adapted from the Government of Ontario’s Anti-Racism Directorate race data standards and The Upstream Lab’s SPARK study (Screening for Poverty and Related social determinants and intervening to improve Knowledge of and links to resources).<sup>71</sup> This report also offered some guidance of mapping CIHI’s proposed standards to Statistics Canada’s data standards, while acknowledging Statistics Canada’s<sup>39</sup> on-going work of reviewing its ethno-cultural data standards.



As part of a broader program of work underway at CIHI to harmonize and strengthen health equity measurement, the goal of these documents and resources has been to facilitate and encourage the use of standard equity stratifiers in data collection, performance

measurement and reporting initiatives, eventually enabling comparisons across Canada.<sup>40</sup> CIHI is currently in the process of gathering feedback regarding the collecting, analysis and reporting of proposed standards.

**Table 5: Proposed Race-Based and Indigenous Identity Data Collection Standards<sup>63</sup>**

<b>Proposed race-based question</b>	
We know that people of different races do not have significantly different genetics. But our race still has important consequences, including how we are treated by different individuals and institutions. Which race category best describes you? Check all that apply:	
<b>Proposed response categories</b>	<b>Examples</b>
Black	African, Afro-Caribbean, African Canadian descent
East/Southeast Asian (optional: may collect as 2 separate categories — East Asian and South-east Asian)	Chinese, Korean, Japanese, Taiwanese descent or Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent
Indigenous (First Nations, Métis, Inuk/Inuit)*	First Nations, Métis, Inuk/Inuit descent
Latino	Latin American, Hispanic descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)
South Asian	South Asian descent (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)
White	European descent
Another race category	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable
<b>Proposed Indigenous identity question*</b>	
Do you identify as First Nations, Métis and/or Inuk/Inuit?	
<b>Proposed response categories (select all that apply)</b>	
Yes, First Nations	
Yes, Métis	
Yes, Inuk/Inuit	
No	
Prefer not to answer	

Note: \*It is recommended that reporting on Indigenous identity data and communities be informed through engagement with Indigenous communities in the jurisdiction of data collection. Distinctions-based approaches — that is, identifying First Nations, Inuk/Inuit and Métis communities and/or other Indigenous populations such as nations or clans — may be preferred.

## Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective by British Columbia's Office of the Human Rights Commissioner

In September 2020, the B.C. Human Rights Commissioner published a Special Report, *Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective*<sup>72</sup>, which both answered and echoed the calls to collect disaggregated data to advance human rights and to develop policy that effectively addresses systemic inequalities. The report presented a framework for disaggregated data collection that is grounded in “the grandmother perspective” offered by Gwen Phillips of the Ktunaxa Nation, a B.C. First Nations Data Governance Initiative Champion, highlighting the importance of relationship:

*“First Nations governments are not wanting to operate with the Big Brother mentality that we’ve all been groomed into believing in relation to what data does to us – it’s more like we want to come from the grandmother perspective. **We need to know because we care.**”*

The report also highlighted the important role of a well-defined and articulated process and purpose, while applying a framework that defines the important difference between tools, process, and purpose:

*“Disaggregated data is merely a tool (to be utilized depending on the context and aim) and it must be accompanied by a process*

*that supports the purpose of reducing systemic racism and oppression and achieving equity.”*

The report recommended the development of the Anti-Discrimination Data Act (ADDA), that is focused on building respectful relationships with marginalized communities to ensure that community needs and voices are meaningfully included in the collection, use, and disclosure of disaggregated data. Also recommended for the B.C. government was to develop the ADDA in consultation with the province’s Office of the Human Rights Commissioner and Office of the Information and Privacy Commissioner. A set of specific recommendations were made for the ADDA to include provisions that outline:

- Privacy protections in line with principles of B.C.’s Data Innovation Program including the FiveSafes model, the protection for de-identified data and personal identifiable data and the completion of privacy impact assessments with full consideration of potential individual and community harms.
- The development of a data governance model with Indigenous institutions and governments (based on nation-to-nation relationships) in support of self-determination and sovereignty.
- The establishment of a Community Governance Board to make collaborative decisions with government, whose membership shall include members of systemically oppressed communities for which data—such as race-based, Indigenous, gender, and disability data—will be collected.

- A Community Data Secretariat to provide backbone support to this Board, including additional, individual supports where necessary for meaningful participation to address financial, logistical and technological barriers.
- The establishment of data standards as defined by the Community Governance Board and broad engagement with communities.
- The extension of the mandate of the Office of the Information and Privacy Commissioner to include the evaluation of complaints or concerns about the collection, use or disclosure of data covered by this legislation.

In November 2020, the B.C. government appointed the province's first Parliamentary Secretary for Anti-Racism Initiatives to work on key initiatives to address discrimination through collaborating with B.C.'s Human Rights Commissioner, and other stakeholders, to introduce legislation that will help reduce systemic discrimination and pave the way for race-based data collection essential to modernizing sectors like policing, health care, and education.<sup>73</sup> Based on the advice of stakeholders from various racialized and Indigenous communities, the province will conduct broader public engagement on race-based data collection starting in summer 2021. Public consultation on the anti-racism legislation is expected to begin in fall 2022.

## Race and Ethnicity Data Collection During the COVID-19 Pandemic

In what follows, we present two promising examples of provincial efforts to collect race and ethnicity data to better understand the differential impact of COVID-19 within Black, Indigenous, and People of Colour (BIPOC) communities.

### Manitoba's Data Collection on Race, Ethnicity and Indigeneity

In May 2020, Manitoba became Canada's first province to collect race, ethnicity and Indigeneity (REI) information from people who test positive for COVID-19. The province set the guideline that supports the data collection process in collaboration with an Advisory Working Group, consisting primarily of Black, Indigenous, and People of Colour. Regional public health staff are required to ask every person who tests positive for COVID-19 to self-declare which REI group they belong to (while responding is voluntary). To facilitate the collection of this data, public health staff were given a letter explaining the rationale for such data collection and a detailed script to be used when collecting information from clients. For example, the script for collection of REI identifiers<sup>74</sup> includes the following introduction about the data collection:

*"Public Health has been directed to collect information about Racial/ Ethnic/ Indigenous identity in people who test positive for COVID-19. This will help us monitor how COVID-19 is impacting different communities. With this information we are able to respond to specific community needs and better plan*

*for your healthcare, public health, and other services. We are asking all people who test positive for COVID-19 in Manitoba to answer this question."*

The script then asks a question about a person's REI information by: "We recognize this list of racial or ethnic identifiers may not exactly match how you would describe yourself. Keeping that in mind, which of the following best describes the racial or ethnic community that you belong to?" Response categories include African, Black, Chinese, Filipino, Latin American, North American Indigenous - that is, First Nations, Metis or Inuit, South Asian, Southeast Asian, White, Other. It also offers a list of examples of possible countries/regions of origin for each REI identifier (Table 6) to help public health staff assist clients to select the right category. These REI identifiers were developed based on census categories and population sizes within Manitoba. Clients' responses are then entered into the Public Health Information Management System used by the province to track reportable illness.

In March 2021, the Manitoba government published a report focusing on the REI data collected, *COVID-19 Infections in Manitoba*.<sup>75</sup> This report found that 51 per cent of people who tested positive for COVID-19 from May 1 to December 31 self-identified as BIPOC, while they represented just 35 per cent of the population in Manitoba. In particular, African, Filipino, North American Indigenous, and South Asian groups were over-represented in COVID-19 case counts, while White people were under-represented by 16 per cent points. The report highlighted the impact of "systemic racism, that is the differential access by race to the goods, opportunities and services of society", such as occupation, income, housing,

**Table 6. Race, Ethnicity, and Indigeneity Identifiers (Manitoba)<sup>75</sup>**

REI Identifiers	Examples of Possible Countries/Regions of Origin
African	Algeria, Cameroon, Cote d'Ivoire, Democratic Republic of the Congo, Egypt, Eritrea, Ethiopia, Kenya, Morocco, Nigeria, Somalia, South Africa, Tunisia
Black	Canada, United States, Caribbean, Africa
Chinese	
Filipino	
South Asian	India, Pakistan, Bangladesh, Sri Lanka, Bhutan, Nepal, Maldives
Southeast Asian	Vietnam, Cambodia, Laos, Thailand, Singapore, Malaysia, Indonesia, Timor-Leste, Myanmar (Burma), Brunei
Latin American	Mexico, Brazil, Colombia, El Salvador, Guyana, Peru, Argentina, Venezuela, Cuba, other countries in Central and South America
North American Indigenous	
White	Canada, United States, Britain, France, other European countries, Australia, New Zealand
Other	

and health care and other supports, as major contributing factors for such disparities. According to a recent statement by Health and Seniors Care Minister, the REI data will be used to help inform the government determine what needs to be done to address the identified disparities in its future planning.

**Ontario’s Collection of Socio-Demographic Data (Race, Income, Household Size, and Language) during COVID-19**

In June 2020, the Ontario government introduced a regulatory change to mandate the reporting of data on race, language, income, and household size for individuals who have tested positive for COVID-19, within all public health units in Ontario. While some of Ontario’s public health units—such as Toronto, Ottawa, Middlesex-London and Sudbury—had begun collecting race-based data voluntarily prior to this, the province-wide data collection aimed to provide a more

complete picture of outbreaks across the province and inform the government’s work with local public health units and other health care partners to implement effective policies to respond to the COVID-19 pandemic.<sup>76</sup>

Public Health Ontario has developed resources and training materials to help public health staff be better informed and equipped with the knowledge and tools needed for effective data collection. For example, Public Health Ontario’s June 2020 Webinar covered topics around health equity principles, the new standardized set of socio-demographic questions, and the value of asking socio-demographic questions.<sup>77</sup> Another resource, *Introducing Race, Income, Household Size, and Language Data Collection: A Resource for Care Managers*,<sup>29</sup> was developed to provide information to support the collection of socio-demographic data, with a sample script, tips for case managers, frequently asked questions, as well as background information.

## Guiding Practices Exemplar #1: Questions from *Introducing Race, Income, Household Size, and Language Data Collection - A Resource for Care Managers*<sup>29</sup>

Race: In our society, people are often described by their race or racial background. For example, some people are considered “White” or “Black” or “South Asian.” Which race category best describes you? Select all that apply from the options I will read out:

Race categories	Description/examples
Black	African, Afro-Caribbean, African-Canadian descent
East/Southeast Asian	Chinese, Korean, Japanese, Taiwanese descent Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent
Latino	Latin American, Hispanic descent
Middle Eastern	Arab, Persian, West Asian descent, e.g. Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, etc.
South Asian	South Asian descent, e.g. East Indian, Pakistani, Bangladeshi, Sri Lankan, IndoCaribbean, etc.
White	European descent
Another race category	Another race category (Optional: allow write-in response)
Do not know	
Prefer not to answer	

Income: Income can come from various sources such as from work, investments, pensions or government. Examples of income include your pay, Employment Insurance, Social Assistance, Child Tax Benefit and other income such as child support, spousal support (alimony) and rental income.

- 1) What was your total household income before taxes in 2019? Select one from the list of income ranges I will read out:
  - 0 - \$29,999;
  - \$30,000-\$49,999;
  - \$50,000-\$69,999;
  - \$70,000-\$99,999;
  - \$100,000-149,999;
  - \$150,000 or more;
  - Do not know;
  - Prefer not to answer

We also know that income is impacted by the number of people supported by that income. The more people, the more stretched the income will be. So as part of asking about your income, can you let us know.

- 2) Including yourself, how many family members live in your household?
  - \_\_\_(people);
  - Do not know;
  - Prefer not to answer

Language: We know that language barriers can impact people's experiences when accessing health services and other programs. In order to understand language profiles of our clients/patients, we are going to ask you two questions on language.

- 1) What is the language that you first learned at home in childhood and still understand?
  - Drop down list of languages already in iPHIS
  - Do not know
  - Prefer not to answer
- 2) In which of Canada's official languages, English or French, are you most comfortable?
  - English
  - French
  - Both English and French
  - Neither
  - Do not know
  - Prefer not to answer

Published reports by Toronto Public Health<sup>31</sup> and Peel Public Health<sup>78</sup> clearly presented that people from racialized communities, particularly those from Black, South Asian, and Southeast Asian communities, and lower-income households were disproportionately affected by COVID-19. With the collected data, Toronto Public Health's plan includes publishing monthly reports on the COVID-19 infection rates by different socio-demographic groups. Toronto Public Health also aims to use

this data to reduce inequities in how COVID-19 is affecting the population through various initiatives. These include consulting and collaborating with community agencies that serve groups of people over-represented in the COVID-19 infection rates, focused health promotion messaging, recommending areas for focused testing, and longer-term planning and advocacy for a more equitable system of health and social services.<sup>79</sup>

## Challenges and Opportunities to Enhance Socio-demographic Data Collection

While we turn to current initiatives for guidance on the collection of enhanced socio-demographic data, it is reasonable to ask why this data has not already been collected within Canada—especially as other countries (e.g., United Kingdom, United States, Australia) are able to collect more in-depth socio-demographic data, which allows system-wide analysis of health inequities. For decades, numerous calls have been made to better collect socio-demographic data across Canada to identify disparities and promote health equity.

**Yet, Canadian governments' persistent decision not to collect such data have kept us from tackling inequities by shielding us from the existing disparities which stem from systemic discrimination and racism.<sup>80</sup>**

In fact, collecting socio-demographic data has never been on the government's priority list. Canada's failure to collect such data, particularly race-based data on COVID-19 infections, was described as discrimination by "neglect."<sup>81</sup>

As each of the above initiatives seek to enhance the collection of socio-demographic data in the Canadian context, they also offer reflections on the facilitators and barriers to the collection of such data. For example, in its efforts to establish pan-

Canadian standards for collecting race-based and Indigenous identity data, CIHI pointed out that the limited collection of socio-demographic data in Canada's health care settings was in part because of a lack of consensus on standards for collection.<sup>71</sup> *The Guide to Demographic Data Collection in Healthcare Settings*<sup>72</sup> developed by the Human Rights & Health Equity Office at Sinai Health provided particularly useful lessons for the long-term care sector, based on the experience of leading the Measuring Health Equity in Toronto Central LHIN project. The Guide highlighted staff resistance as one of the most commonly cited barriers to socio-demographic data collection efforts. It elaborated that resistance was often rooted in poor or inconsistent training on *how* to ask questions, alongside general discomfort with the questions being asked (e.g., race, sexual orientation, gender identity), failure to clearly communicate *why* the data is being collected, and patient concerns regarding *what* will be done with the data once it is collected (e.g., implications for quality of care). This guide presented four key strategies for successful demographic data collection: i) define goals for data collection; ii) engage senior leadership; iii) engage staff and patients/clients; and iv) commit to ongoing evaluation.

The *COVID-19 Infections in Manitoba* report also highlighted that while the collection of REI data increased over time, a wide variance among regional health authorities still exists in how often the question is being asked,



from 47 per cent to 81 per cent of the time. Although REI data collection is mandatory, the REI information has been recorded in 67 per cent of cases and the province is aiming to have it collected 90 per cent of the time.<sup>82</sup> The report identified some of the potential limitations to collecting REI identifier data, such as system factors and reluctance to ask because of discomfort with the topic. It also acknowledged the lack of concurrent collection of language information and inconsistent language supports available for those with limited English proficiency.

A recent progress update from Ontario Public Health<sup>32</sup> also shared challenges in collecting socio-demographic data from those who test positive for COVID-19. As of December 2020, the response rates on socio-demographic questions ranged from 46.8 per cent on mother tongue, 47.2 per cent on income, 48.3 per cent on official language, 65.8 per cent on household size, to 67 per cent on race/ethnicity question. The experiences of one public health unit highlighted that data completeness and accuracy continued to be a challenge. Barriers include the limited capacity for case management as a result of surge in cases, increased resistance from clients to engage, continued discomfort asking the question with concerns around impact on rapport with clients, and limited training capacity for new staff.

In addition to considerations of the challenges and barriers encountered in endeavouring to *ask* questions for the collection of enhanced socio-demographic data, it is important to consider the possible reasons for hesitancy, resistance, and/or avoidance in respondents.

**Specifically, long-standing histories of discrimination, harassment, and victimization within Canadian society—including within long-term care settings—rooted in systemic racism, homophobia, transphobia, ageism, and ableism (to name only a few), have resulted in distrust and skepticism with respect to data collection.**

For example, 2SLGBTQIA+ older adults may be hesitant to disclose information related to their social identities since hiding—or invisibility—has historically been a self-protection measure to avoid mistreatment and harassment.<sup>83</sup> Understanding the implications of these challenges and barriers is necessary to collecting enhanced socio-demographic data. It is also vital for gaining a better understanding of the diverse populations that live within long-term care settings and how data can be used to improve quality and responsiveness of care.

Ultimately, by addressing this lack of socio-demographic data, we will begin to build a better understanding of the diverse populations living in long-term care settings, which allows us to develop more targeted interventions and effectively address any existing health disparities. Overall, when collected properly and consistently, socio-demographic data will form an essential component in improving the health and health equity of Canadians living and working in long-term care settings, through:

- i) developing a comprehensive profile of all Canadian long-term care home residents and staff;
- ii) examining differences in health outcomes along the variables of age, race, ethnicity, language, income, sexual orientation, gender identity, and others;
- iii) identifying and tracking gaps in care services and quality;
- iv) enhancing relationship-centred care and addressing individual care needs related to ability, religion, culture, ethnicity, language, gender identity, and other factors;
- v) developing programming, policies, and services to reduce and eliminate health inequities based in socio-demographic population differences.<sup>72</sup>



## Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities in Ontario<sup>84</sup>

The Black Health Equity Working Group, made up of Black health sector leaders and health equity experts, began meeting early in the COVID-19 pandemic to develop a governance framework for health data collected from Black communities in Ontario. The working group aimed to address concerns from Black communities about the process of race-based data collection, for COVID-19 cases, and the continued extraction of data from the communities without the return of tangible benefits. The framework development was informed by a series of stakeholder consultations with Black community members, researchers and academics, public health professionals, and health system organizations in Ontario. The working group's 2021 report introduces the EGAP framework, which outlines guiding principles in four areas of focus:

- **ENGAGEMENT:** Genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis, and use.
- **GOVERNANCE:** Community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables.
- **ACCESS:** The right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right.
- **PROTECTION:** The safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

The EGAP Framework envisages Black communities gaining control over their collective data, through the establishment of Community Governance Tables, representative of local communities, in various locations across the province. The Community Government Tables, as decision-making bodies, will review and approve or reject external parties' plans for community engagement, data collection, data management, data analysis, and data. Only with approval can the external party proceed with the work. Thus, data stewards and users will be answerable to Black communities through the Community Governance Tables, which can be developed and adapted for different circumstances and organizations.

The report also presents seven-step recommendation for realizing the EGAP framework: 1) education; 2) community engagement; 3) Community Governance Tables; 4) stakeholder engagement; 5) community engagement; 6) community data management and data sharing agreements; and 7) data stewardship.

# Moving Forward: Recommendations for Enhanced Socio-Demographic Data Collection in LTC Settings

To facilitate enhanced socio-demographic data collection in long-term care settings, lessons could be drawn from existing initiatives, such as the *Measuring Health Equity* project, and the race-based and other socio-demographic data collection implemented in Manitoba and Ontario during the pandemic. Informed by these initiatives, we offer a number of key recommendations to move forward with improving socio-demographic data collection and its use in long-term care in Canada. The recommendations presented in this paper build upon the key considerations presented in the NIA's 2019 report, *Enabling the Future Provision of Long-term Care in Canada*,<sup>14</sup> and the Wellesley Institute's 2017 paper, *Socio-Demographic Data and Equity in Health Services in Ontario: Building on Strong Foundations*,<sup>15</sup> which identified nine guiding principles and best practices for implementing initiatives to strengthen socio-demographic data collection in Ontario:

- Collecting data for appropriate purposes,
- Privacy and protection of data,
- Informed consent,
- Transparent data collection,
- Opt-in/opt-out framework,
- High-quality data,
- Standardized data,
- Self-reported data, and
- Trained staff

Inspired by the aforementioned work and the discussion presented in this paper, we have identified six key areas of consideration

related to data collection and use that can inform efforts to plan and deliver long-term care that ensures health equity for older Canadians.

## **1. Ensure clarity exists amongst individuals living and working in long-term care settings about the purposes of socio-demographic data collection.**

Enhanced socio-demographic data collection from individuals living and working in long-term care settings must be collected and used for appropriate purposes, consistent with Canada's human rights framework. The socio-demographic data cannot be gathered for any purpose, or used in any way, that would lead to discrimination in service provision or employment in long-term care settings or elsewhere. The purposes for which socio-demographic data is collected should be clearly defined and communicated to those who are being asked the questions, as well as those who are asking. Experience in Canadian health care settings suggests that people are open to answering socio-demographic questions if they understand *why* the data is being collected and that answering these questions will not negatively impact treatment or access to services.<sup>85,86</sup>

## **2. Build trust through community engagement design and implementation of socio-demographic data collection initiatives.**

An important component in designing and implementing enhanced collection of socio-demographic data is engagement and consultation with members of communities which are directly impacted by the lack of such data collection. For example, when collecting, analyzing, reporting, and interpreting data on Indigenous identity (as proposed in our next recommendation), the process must ensure the application of First Nations principles of Ownership, Control, Access and Possession (OCAP), Inuit Qaujimajatuqangit, or other community-based ethics codes. That is, the question and response categories for Indigenous identity should be decided in consultation and collaboration with Indigenous communities in the jurisdiction where data is being collected and respect fundamental principles of Indigenous data sovereignty.<sup>71</sup>

By engaging with diverse communities in the design of socio-demographic data collection initiatives, such initiatives are better positioned to address their needs and implement data collection strategies that are respectful by taking into account lived experiences and perspectives.<sup>75,87</sup> In so doing, these engagement and consultation efforts will bolster the trust in processes of socio-demographic data collection within long-term care settings across Canada.

## **3. Ensure standardized socio-demographic data is collected across Canada's long-term care settings.**

Standardized data collection is crucial to improve data consistency and accuracy and reduces variations across jurisdictions and settings that may impact data quality.<sup>88</sup> To enhance socio-demographic data collection on Canadians living and working in long-term care settings, we propose that a set of standardized socio-demographic questions be implemented within long-term care settings across Canada. This standardized set of questions will include considerations of:

- Age
- Sex assigned at birth
- Gender identity
- Sexual orientation
- Race/ethnicity
- Language (preferred language – which language residents feel comfortable speaking in with their care providers, and/or official language proficiency)
- Citizenship and immigration status (and year of arrival)
- Annual income (and household size)
- Marital status
- Education level
- Disability
- Indigenous identity\*

The selection of this proposed set was informed by the socio-demographic data collection standards adopted by Canada's promising initiatives presented above. The selection rationale for each socio-demographic identifier has been well documented in these initiatives, such as the

CIHI's proposed standards for health equity measurement and the Measuring Health Equity project. Development of specific questions and response categories for each identifier could be informed by the existing and proposed socio-demographic data collection standards by these initiatives.

As a main source of data about Canadians living in long-term care homes, the CCRS is well positioned to facilitate the enhanced socio-demographic data collection on long-term care residents. Currently, a standardized data set on some of the socio-demographic information as well as extensive health and clinical information is already being collected and entered into the CCRS on long-term care residents across the majority of Canadian provinces and territories. Enhancing socio-demographic data collection in the CCRS, through incorporating additional variables (i.e., gender identity, sexual orientation, preferred language, citizenship and immigration status, race/ethnicity, and annual income) can leverage on-going efforts to improve equity data collection in various health administrative datasets, led by CIHI in collaboration with Statistics Canada and other key stakeholders across the country. Another pathway to enhanced socio-demographic data collection in long-term care settings could be developing a new standardized socio-demographic questionnaire and mandating all long-term care and retirement homes across the country to collect this new data from each resident and care provider.

#### **4. Ensure appropriate skills, training and understanding are established for those collecting socio-demographic data.**

Properly trained and educated staff are essential to maintain quality in data collection and security.<sup>89</sup> High-quality staff training can improve understanding and acceptance of the rationale and significance of data collection, which contribute to staff buy-in, comfort in answering resident questions, and overall trust in the data collection process.<sup>15</sup> As described earlier, the level of response rates is largely dependent on the staff understanding of the importance of data collection and their skill-level in asking the questions. Staff reluctance to ask socio-demographic questions because of discomfort was also identified as one of the contributing factors to low compliance in some of these jurisdictions. The Measuring Health Equity project identified that the training of data collectors was the key step in successful implementation of data collection initiatives. Education on health equity more broadly was found particularly important in moving attitudes and acceptance toward staff buy-in and interest.<sup>88</sup> Socio-demographic data collection experiences in Canadian health care settings also emphasize that *how* we ask questions is as important as *what* we ask.<sup>10</sup> Building on the promising practices within existing initiatives, effective staff training materials and clear data collection guidelines could be developed and offered to all staff collecting resident-level data in long-term care settings.

**5. Ensure a commitment is developed to effectively and appropriately use the socio-demographic data being collected.**

The standardized collection of enhanced socio-demographic data across Canada must be paired with a commitment to effective and appropriate use of the data at the local (home), provincial, and federal levels. At the local level, enhanced socio-demographic data collection will provide long-term care homes with a better understanding of individual resident needs which will better enable the provision of equitable and affirming care and support. At the provincial level, the collection of enhanced socio-demographic data has the power to highlight gaps in care and support experienced by diverse population groups (e.g., long wait time experienced by certain population groups) and to address identified gaps by effective measures to improve cultural competency across the LTC sector. This could include enhanced funding towards cultural programming across the sector, language supports, hiring initiatives, and the development of culturally specific long-term care homes. Any policy decisions on funding allocations should include rationales for how they align with the population needs identified by the analysis of enhanced socio-demographic data. At a federal level, data-driven strategies for improving the health equity of diverse communities should be a priority of long-term care settings and governing bodies. To ensure the effective and appropriate use of socio-demographic data, processes must be implemented for monitoring and evaluating the usage of data in care planning, system improvement, and accountability, as well as updating

accreditation processes (based on the performance of health equity outcomes).<sup>83,90</sup>



## Guiding Practices Exemplar #2: Ontario Centres for Learning, Research, and Innovation's Embracing Diversity Toolkit

For specific guidance on how to enhance equity, diversity, and inclusion efforts within the long-term care sector, the Ontario Centres for Learning, Research, and Innovation (CLRI) have created an *Embracing Diversity* toolkit<sup>91</sup> which offers guidance and suggestions for enhancing cultural safe and appropriate care that acknowledges diversity amongst residents and care workers within all aspects of LTC homes. Acknowledging that LTC homes are at varying points along their journeys towards equity and inclusion, this interactive toolkit combines print and online components to provide practical steps for improving equity, diversity, and inclusion practices in the following seven impact areas within LTC homes: Planning and Policy; Organizational Culture; Education and Training; Human Resources; Community Capacity Building; Resident and Family Engagement; and Service Provision.

By modelling a series of Promising Practices within each impact area, the assessment tool was designed to help individuals and teams within LTC settings identify and assess what they are doing well, areas for improvement, guide the development of quality improvement plans, and inform organizational strategic planning to incorporate equity, diversity and inclusion. Following the assessment tool, the toolkit provides strategies and suggestions for supporting LTC homes in beginning or deepening conversations about equity, diversity and inclusion in their organizations. An example from related to Impact Area 1: Planning and Policy is provided below.

On page 34 of the toolkit, Ontario CLRI offers a number of suggestions for *Finding Inspiration and Taking Action* related to “Promising Practice 1.9: Our home collects and uses resident demographic data to plan services and activities”:

### Incorporating Demographics Into Planning

The goal is to create a diverse and healthy environment that is representative of the demographics, languages and cultures of the current (and emerging) residents in your home. Does your leadership team and team members reflect the populations and communities you serve?

Many reports are available online from municipalities that have conducted needs assessments on local community demographics (e.g., Vital Signs reports). This data can give a picture of the needs of potential workforce and residents and can be incorporated into planning for the future of your LTC home.

Demonstrating a commitment to diversity can be complicated. Several parties may have a stake in changes (e.g., unions, management, professional groups, in-house diversity committee, residents, families, volunteers, and community agencies). Collaboration with these parties is crucial—they can facilitate and affirm diversity improvements. They can play a key role in preventing, recognizing and addressing cultural conflicts in a thoughtful and courteous manner.



## Conclusion

In moving forward with establishing enhanced socio-demographic data collection standards across Canada, we recognize the complexities of developing and enforcing a pan-Canadian solution given the current systems of long-term care that each province and territory is primarily responsible for.<sup>92</sup> Enhancing socio-demographic data collection in long-term care settings, requires strong commitment from and collaboration between federal, provincial, and territorial governments. Supportive federal leadership can play a vital role in collaboratively establishing stronger national long-term care standards and ensuring all provincial and territorial governments are able to embrace them, with a shared vision of achieving health and health equity for all Canadians needing long-term care.

As the federal government leads this initiative, Statistics Canada—in light of its recently announced investment in improving the way that it captures data on race, gender, and sexual orientation<sup>93</sup>—is well-positioned to take a lead on improving socio-demographic data collection. For example, ensuring that national surveys, such as the short-form Census, include additional socio-demographic questions such as sexual orientation and race/ethnicity will generate a more comprehensive understanding of the Canadian population, including those living in long-term care settings. Further, each province and territory could also take immediate action on mandating all long-term care and retirement homes within their jurisdiction to routinely collect enhanced socio-demographic data on

their residents and staff and report on their progress. Such data initiative could also be adopted to collect and utilize data on people needing and providing care across a wide range of health care and social supports including home and community care.

Ultimately, when used effectively, socio-demographic data can be a powerful tool to improve health and health equity for all Canadians living and working in long-term care settings. With a more complete picture of *who* is living and working in long-term care settings through enhanced collection and use of socio-demographic data, we will be better positioned to fully identify, understand, and address inequities in health and care experienced by diverse populations who live in long-term care settings.

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