



# Share Your Story

Indigenous-Specific Racism in Health Care Across the Champlain Region: Full Report

Wabano Centre for Aboriginal Health in Partnership with the Ottawa Aboriginal Coalition

Funded by Ottawa Public Health



# In Deep Gratitude

Since time immemorial, the area in what is now known as the Champlain region, has been a gathering place for Indigenous people from many provinces. We came to this place to trade, to connect with kin, to work, and to share stories. Today, thousands of First Nations, Inuit, and Métis call this gathering place home.

The Ottawa Aboriginal Coalition (OAC) wishes to acknowledge the Indigenous people who live, work, and receive health care on the ancestral lands of the Algonquin/Anishnaabe and Ongwehonwe (the Champlain region). We know that in health care, many of you have not received the kind, competent care that is considered a human right in this country. Our hope is that the stories shared through this report are creating a new legacy for the generations yet to come. *Chi miigwetch.*

Both the OAC and the Champlain Indigenous Health Circle Forum (Circle) work to improve the health status of Indigenous peoples in Ottawa and throughout the Champlain region. The OAC and the Circle collaborated with this research to combine efforts to bring the stories of Indigenous people who experience racism while accessing health care across the Champlain region to light.

**This project is the result of work of many. We say chi miigwetch to:**

- **Indigenous community members** who courageously and generously came forward with their stories and provided valuable recommendations. We were honoured to bear witness to your stories and commit to carry them forward in a good way.
- **The research team** (comprised of community members, independent consultants, and service providers of the Wabano Centre for Aboriginal Health, Tungasuvvingat Inuit, and Minwaashin

Lodge - Indigenous Women's Support Centre) who bore witness to the stories. We give special thanks to Dr. Mohsen Haghbin for methodological consultation, training and data analysis and Marianna Shturman for research coordination and support.

- **The advisory committee** for your unwavering support and wise guidance.
  - Albert Dumont, Traditional Knowledge Keeper
  - Allison Fisher, Wabano Centre for Aboriginal Health
  - Amanda Kilabuk, Tungasuvvingat Inuit
  - Amber Montour, Health Department, Mohawk Council of Akwesasne
  - Chris Stewart, Tungasuvvingat Inuit
  - Christine Kouri, Children's Hospital of Eastern Ontario (CHEO)
  - Donna Lyons, Wabano Centre for Aboriginal Health
  - Kimberley Trotter, Ottawa Public Health
  - Late Jo MacQuarrie, Elder, Métis Nation of Ontario
  - Mary Daoust, Minwaashin Lodge – Indigenous Women's Support Centre
  - Peggy Dick, Algonquins of Pikwakanagan First Nation
  - Stephanie Mikki Adams, Inuuqatigiit Centre for Inuit Children, Youth & Families
- **The writing team** comprised of Allison Fisher, Donna Lyons, Marianna Shturman, Carlie Chase and Brenda Macdougall. With special thanks to **Madeleine Dion Stout** and **Marie Wilson** for thoughtful feedback and editing.
- **Ottawa Public Health** for providing funding for this study.

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# **Terms and Definitions**

# Terms and Definitions

## A Note on Terminology

In this report, “Indigenous” is used preferentially as the descriptor of the people who are the focus in this research report, which includes First Nations, Inuit and Métis. The *Declaration on the Rights of Indigenous Peoples Act* defines Indigenous with the same definition as Aboriginal in the Constitution Act, 1982.

The federal government continues to use the terminology “Registered or Treaty Indian,” “Indian reserves”, and “Status Indian”, all still included in the *Indian Act*. These terms are used in this report to identify a data’s original descriptors.

These terms and definitions are compiled from numerous reports and sources.

**ABORIGINAL** is the term used in the Constitution Act (1982) to identify the original peoples which in Canada are named as Indians (First Nations), Inuit and Métis. It is the term enshrined in section 35 of the *Constitution Act, 1982* and other pieces of Canadian law. Therefore, “Aboriginal” (like “Indian”) carries legal significance in Canada.

**ABORIGINAL RIGHTS** refers to the practices, traditions, and/or customs that are integral to Aboriginal societies. They arise out of prior occupation as well as social and cultural organization and they are protected in section 35.

**ANTI-INDIGENOUS RACISM OR INDIGENOUS-SPECIFIC RACISM** is the ongoing race-based discrimination, negative stereotyping, and injustice experienced by Indigenous peoples within Canada. It includes ideas and practices that establish, maintain and perpetuate power imbalances, systemic barriers, and inequitable outcomes that stem from the legacy of colonial policies and practices in Canada.

**BIAS** is a way of thinking or operating based explicitly or implicitly on a stereotype or fixed image of a group of people.

**CHAMPLAIN INDIGENOUS HEALTH CIRCLE FORUM (THE CIRCLE)** represents rural and urban First Nations, Inuit, and Métis communities across the Champlain region, and partners with the Champlain LHIN to address health and wellness issues, and health system improvement opportunities.

**CHAMPLAIN LOCAL HEALTH INTEGRATION NETWORK (CHAMPLAIN LHIN)** refers to the Ontario Crown Agency in the Champlain region that plans, funds, and coordinates health services. As of April 1st 2021, the Champlain LHIN was transferred to Ontario Health and along with South East and Central East LHIN are now part of the Ontario Health East region.

**COLONIALISM** is the policy or practice of acquiring full or partial political control over another country, occupying it with settlers, and exploiting it economically.

**COMMUNITY BASED PARTICIPATORY RESEARCH (CBPR)** is a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and what is practiced in communities to improve health.

**CULTURAL SAFETY** is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. Cultural safety can only be defined by the person receiving the care.<sup>1</sup>

**DEPARTMENT OF INDIAN/INDIGENOUS AFFAIRS (DIA)** is the government office with oversight for the Indian Act and responsibility for its implementation. Known by various names throughout its history, the department has always been closely aligned with resource and land development and hence its most recent incarnation as Indigenous and Northern Affairs Canada (INAC). Since the mid-20th century, the Department has been responsible for Inuit and more recently (post-1985) for the Métis. In 2016, the department was split into two areas: Indigenous Services Canada (ISC) and Crown-Indigenous Relations and Northern Affairs Canada (CIRNAC). ISC is responsible for programming and services, such as, First Nations and Inuit Health, Non-Insured Health Benefits, Jordan's Principle, and Education, among others. CIRNAC is responsible for treaties, agreements, and intergovernmental relations; northern affairs and the Arctic and Northern Policy Framework; implementing the TRC calls to action and the recommendation of the MMIWG inquiry.

**DISCRIMINATION** is the unfair or prejudicial treatment of people and groups based on characteristics such as race, gender, age or sexual orientation.

**FIRST NATIONS** is a term that became officially used beginning in 1980s by the first peoples previously known legally and colloquially as "Indian" while First Nation (without the "s") replaced the term "Indian band." No legal definition of the term exists but it is the preferred terminology today.

**HEALTH EQUITY** is the absence of avoidable, unfair or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification. "Health equity" implies that everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential.

**INDIAN** was used in Canada historically to refer to people now known as First Nations and, in some cases, it was used as a generic term to refer broadly to all Indigenous peoples before the 20th century. Indian is a legal identity that has been defined since 1876 by criteria set out in the *Indian Act*, and is similar to the term Aboriginal, in that it is enshrined in Canadian law and attempts to define specific groups of peoples.

**INDIAN ACT** is the primary law the federal government uses to administer Indian status; First Nations governments; and the management of reserve land. It also outlines governmental obligations to First Nations peoples. The Indian Act pertains to people with Indian status; it does not directly reference Non-Status First Nations people, the Métis, or Inuit. First introduced in 1876, the Act subsumed a number of colonial laws that aimed to eliminate First Nations culture in favour of assimilation into Euro-Canadian society. The Act has been amended several times, most significantly in 1951 and 1985, with changes mainly focusing on the removal of discriminatory sections. It is an evolving, paradoxical document that has enabled trauma, human rights violations, and social and cultural disruption for generations of Indigenous peoples.

**INDIAN HEALTH SERVICES (IHS)** was established in 1945 under the auspices of the newly created federal Department of National Health and Welfare. The IHS branch was the new health care bureaucracy responsible for the health of Status Indian and Inuit specifically. IHS established the system of Indian Hospitals across Canada and managed the tuberculosis treatment for Status Indians and Inuit. With the implementation of national health care across Canada in the 1960s, the need for the IHS waned and the hospitals slowly closed. Today, programs and services such as First Nations and Inuit Health and Non-Insured Health Benefits are managed by Indigenous Services Canada (ISC).

**INDIAN HOSPITALS** were racially segregated health care facilities created in the early 20th century and therefore were only for the treatment of First Nation and Inuit patients. Canada owned and operated 22 hospitals with 2,200 beds across Canada (but mostly from Ontario eastward). These facilities were closed with the advent of Medicare at the end of the 1960s.

**INDIGENOUS** is a relatively new term adopted in Canada (and internationally) to refer to the original inhabitants. In Canada it encompasses the three groups of Peoples identified in the Constitution Act, 1982 as Aboriginal—Indian (First Nation), Inuit and Métis.

**INUIT** comprise a group of Indigenous Peoples from arctic Canada, northern Alaska, and Greenland. Within Canadian territory, the Inuit occupy Inuit Nunangat, the lands, waters, and ice of their homeland. Nunangat includes the territory of Nunavut, Nunavik (northern third of Quebec), Nunatsiavut and NunatuKavut (Labrador) and Inuvialuit (western Arctic, northernmost NWT).

**INTERGENERATIONAL TRAUMA** is historic and contemporary trauma that has compounded over time and has been passed from one generation to the next. The negative cumulative effects can impact individuals, families, communities and entire populations, resulting in a legacy of physical, psychological, and economic disparities that persist across generations. For Indigenous peoples, the historical trauma included trauma created as a result of the imposition of assimilative policies and laws aimed at attempted cultural genocide and continues to be built upon by contemporary forms of colonialism and discrimination.

**KIND AND COMPETENT CARE** is how both the Wabano Advisory Committee for the Wabano-Win: The Art of Seeing Clearly Indigenous Cultural Safety and the SYS focus group participants described how health and mental health care should be delivered.

**MÉTIS** are a distinct Indigenous People whose origins lie in the fur trade and the ensuing relationships between European (primarily, not exclusively, French, Scottish, and English) men employed in that economy and First Nations women (primarily, not exclusively, Cree, Assiniboine, Saukteaux/Anishinaabe, Dene). However, it is important to note that the Métis, while of mixed white and First Nations ancestry, were not then, and nor are they now, defined by this dual heritage (indeed, other Indigenous people have a history of mixed ancestry and are today mixed-blood people, not Métis, just as Canadians of Euro-First Nations ancestry are not Métis). This society emerged in the late eighteenth and early nineteenth centuries in the western interior of Canada between Lake Superior up to the Rocky Mountains and the northwestern United States between Minnesota and Montana and carved out for itself a new and distinct cultural identity.

**NON-INSURED HEALTH BENEFITS (NIHB)** is a program now administered by Indigenous Services Canada that provides medically necessary coverage (certain drugs, dental care, vision care, medical supplies & equipment, short-term crisis-based mental health support, and medical transportation) for eligible First Nation and Inuit individuals.

**OPPRESSION** refers to discrimination that occurs and is supported through the power of public systems or services, such as health care systems, educational systems, legal systems and/or other public systems or services; discrimination backed up by systemic power. Denying people access to kind, competent care or culturally safe care is a form of oppression.

**PREJUDICE** refers to a negative way of thinking and attitude toward a socially defined group and toward any person perceived to be a member of the group.

**RACISM** is the belief that a group of people are inferior based on the colour of their skin or due to the inferiority of their culture or spirituality. It leads to discriminatory behaviours and policies that oppress, ignore or treat racialized groups as 'less than' non-racialized groups.

**RESIDENTIAL SCHOOL SYSTEM** was a part of Canada's assimilative policy that removed and isolated Indigenous children from their families and communities so that they could be transformed into Canadians. The policy was founded on the notion that First Nation, Métis, and Inuit cultures and spiritual practices were inferior and uncivilized. It was an extensive system of schools funded by the federal government and administered by a variety of Christian churches including Catholic, Anglican, Methodist, Presbyterian, and United Church of Canada. There was, furthermore, a system of day schools and for some children, residential school facilities were in fact day schools. There were also missionary run boarding schools that functioned in the same capacity as residential schools but were not necessarily funded by the Canadian government.

**SIXTIES SCOOP (60S SCOOP)** refers to the practice of taking Indigenous children from their families by child welfare authorities and placing them either in foster care or up for adoption in the 1960s through to the late 1980s. However, this practice of mass removal began in the 1950s and in most cases, it was done without the consent of the families or knowledge of the communities.

**STATUS INDIANS** are people distinct from Métis and Inuit, are *recognized by the federal government as Indians under the Indian Act and have been added to the Indian Register*. Registered or Status Indians have certain rights recognized and benefits extended that are not recognized or extended to Non-Status Indians or Métis. Most members of First Nations that are signatories to treaties in Canada are Status Indians but status is not dependent on being in treaty.

**STEREOTYPE** is a fixed image. Refers to an exaggerated belief, image or distorted truth about a person or group; a generalization that allows for little or no individual differences or social variation.


**SYSTEMIC ANTI-INDIGENOUS RACISM** is evident in discriminatory federal policies such as the Indian Act and the residential school system. It is also manifested in the overrepresentation of Indigenous peoples in provincial criminal justice and child welfare systems, as well as inequitable outcomes in education, well-being, and health. Individual lived-experiences of anti-Indigenous racism can be seen in the rise in acts of hostility and violence directed at Indigenous people.

**SYSTEMIC RACISM** consists of organizational culture, policies, directives, practices or procedures that exclude, displace or marginalize some racialized groups or create unfair barriers for them to access valuable benefits and opportunities. This is often the result of institutional biases in organizational culture, policies, directives, practices, and procedures that may appear neutral but have the effect of privileging some groups and disadvantaging others.

**TREATY** is a formal agreement between two parties that create and solemnize a relationship. Each party has certain expectations and obligations, both explicit and implicit. Both the written and oral texts are considered to be reflective of the treaty text. A treaty adhesion was the extension of existing treaty terms and conditions to additional groups of First Nations who had not been present during the original negotiations. Accepting an *adhesion* involved complying with the treaty as it was originally drafted so that those who adhered to the existing treaties, First Nations and the crown, were subject to the same conditions and obligations as the original signatories.



# Executive Summary



We are all in this world together, and the only test  
of our character that matters is how we look after  
the least fortunate among us.

How we look after each other, not how we look  
after ourselves.

That's all that really matters.

- Tommy Douglas, Founder of Medicare

# Executive Summary

Everything we do begins with a story. For that is what we all are: a bundle of stories. Our Elders tell us that stories are living things. Like plants in a garden, the stories that thrive are the ones we attend to.

One story that much of Canada attends to is that our universal health care is for everyone, regardless of income, age, gender, or race. The foundation of our health care system is that it is a human right. For many Indigenous people, however, this is not the story we share.

In early 2020, the BC government released a report entitled “In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in BC Health Care”. This report found that there was “widespread systemic racism against Indigenous peoples [and that] this stereotyping, discrimination and prejudice results in a range of negative impacts, harm and even death.”

While the BC report was being researched and written, Joyce Echaquan (a 37-year-old mother of seven from the Atikamekw Nation) was being racially abused by the nursing staff in Quebec who told her she had made bad choices, was stupid, only good for sex and that she was better off dead. She died videoing those words.

Ms. Echaquan’s story builds on the story of Hugh Papik, a 67-year-old Inuvialuit elder who died after elders’ home staff and nurses in the NWT reportedly thought he was drunk. He had actually suffered a stroke.

Mr. Papik’s story builds on the story of Brian Sinclair, a wheelchair-bound, double amputee, who was ignored to death in a Manitoba emergency waiting room because staff incorrectly assumed that he was just drunk and sleeping it off.

From every area of this country where health care is seen as a human right, Indigenous peoples are not seen and are dying because of it.

The Share Your Story (SYS) Project sought to uncover local stories of Indigenous-specific racism (also referred to as anti-Indigenous racism) in health care that occurred across the Champlain region. Our hope was that through these stories, health care organizations could begin generating local solutions that would build Indigenous confidence in the health care sector - a start to Indigenous peoples receiving the same level of care as all other Canadians.

The findings within this report were gleaned from more than two hundred individuals who engaged in the SYS project between November of 2018 and April of 2019. They reported 315 unique incidents of racism that occurred in health care institutions across the Champlain region.

Over half of these incidents, 59.4%, occurred within the last two years, and 84.4% within the last seven years. The stories shared in this project are not isolated incidents but, like the stories of BC, Quebec, NWT, and Manitoba, are part of a systemic, institutional failure of care. Incidents occurred so frequently that 78% of participants reported they regularly experience racism when accessing health services across the Champlain region.

## Specific key findings from the SYS project demonstrate the widespread failure of the health professionals across the Champlain region to meet the needs of Indigenous peoples:

1. Experience with racism and discrimination has been happening for years and continues to occur today;
2. Individuals with darker skin tones and who are easier to identify as Indigenous are more likely to experience racism;
3. Negative stereotypes about Indigenous peoples, including notions of Indigenous racial inferiority, are evident in the behaviours of health professionals responsible for treating Indigenous clients;
4. Reported behaviours of health care professionals range from overtly to covertly racist:
  - **Overt Racism:** name calling, inflicting pain, neglectful misdiagnosis, calling child welfare or security without just cause.
  - **Covert Racism:** ignoring, inequitable levels of care or attention, denying or withholding medications and/or treatment;
5. Hospitals have the highest frequency of reported racism;
6. Complaints about racist health professionals are often dismissed by administrators so racist misconduct is not properly addressed;
7. Anti-Indigenous racism negatively impacts the health and wellness of Indigenous people; 59% of participants believing their physical health has been negatively affected; 73% that their mental health has worsened; and
8. Collectively, these experiences have led to a lack of trust in, or willingness to access, health services in the region and caused Indigenous people to delay or avoid timely essential care. Three quarters of participants reported actively trying to reduce their interactions with health care institutions as much as possible, even at the risk of their own health, to avoid racist treatment.



## The data is unequivocal:

- It is supported by a substantive body of individual personal experiences and witnessed accounts.
- It is further cross-validated by participants' answers after they shared their stories and corroborated by interviewers' ratings.
- It is analyzed with reference to decades of national and international government-sponsored, independent, academic and media reports, all detailing context and examples of systemic racism, and the officially-sanctioned thinking behind it.

We know that ending racism against Indigenous people in health care is more than just *not being racist*. It requires us attending to a different story than the one we are currently telling ourselves through the unseeing eyes of privilege. It requires anti-racist action.

It requires a full commitment to eliminate anti-Indigenous racism and discrimination. In five years, it is expected that the recommendations be actioned with a ten year vision of the elimination of anti-Indigenous racism and discrimination in the health care system across the Champlain region.

The Share Your Story recommendations incorporate community voices with expertise from Indigenous-led organizations to target systemic racism on all levels - to begin to tell a better story than has been told, so far.

## Anti-racism:

**practice of identifying, challenging, preventing, eliminating and changing the values, structures, policies, programs, practices, profiles and behaviours that perpetuate racism.**

# Introduction

# Introduction

“This can’t keep happening!” The Indigenous Health Circle Forum (Circle) expressed their long-standing concerns about anti-Indigenous racism and discrimination in the health care system. The Circle was hearing multiple stories about the negative experiences of Indigenous people while accessing health care across the Champlain region.<sup>2</sup>

The Wabano Centre for Aboriginal Health is one of the ten members of the Circle that represents First Nations, Inuit, and Métis community members across the Champlain region.<sup>3</sup> The Circle had heard from community members who were denied service; treated as drunks; accused of drug seeking; ignored; put at the end of the line in emergency rooms; reported to the Children’s Aid Societies; subjected to negative and racist comments; and threatened with forcible eviction from health premises; among many others.

To address and end such discriminatory practices locally, the Circle partnered with the Champlain Local Health Integration Network (LHIN) to begin to:

- Document systemic Indigenous health and wellness issues;
- Improve the health care system through education and advocacy; and
- Ensure that the health needs of Indigenous people are considered in all future planning and decision-making processes.

The experiences shared informally with members of the Circle are not unique; nor are they a series of ‘unfortunate outcomes’; or ‘a few bad apples/employees’. They form part of a broader pattern of the Indigenous experience with health and health care systems nationally and internationally. This report is, however, limited to the local realities

and experiences of Indigenous people across the Champlain region, based on a focused research project — *Share Your Story*.

The *Share Your Story (SYS)* project was initiated by the Wabano Centre for Aboriginal Health, in partnership with the Ottawa Aboriginal Coalition, and funded by Ottawa Public Health. The project’s goal was to collect specific stories about racism and discrimination experienced by Indigenous people seeking medical care, with the following intentions:

- Situate local experiences within the broader, historical, colonial context;
- Record and examine incidents of racism reported by a wide range of Indigenous community members, health care personnel, and other witnesses;
- Identify possible “hot spots” of racism across the Champlain region;
- Study the impact of these experiences of racism on health and wellbeing;
- Probe a reconsideration of ‘kind and competent care’ from the perspective of Indigenous clients and service users;
- Select stories that can be videotaped and used for ongoing training and educational purposes (e.g., Indigenous Cultural Safety training modules); and
- Identify solutions intended to improve the health outcomes for the Indigenous communities across the Champlain region.

This report is a culmination of the above stated intentions and is a five-year strategy with the full expectation that in ten years anti-Indigenous racism and discrimination will be eliminated in the health care system across the Champlain region.

# Roots of Health Disparities in Indigenous Communities of Canada

Academic scholars, government and health services researchers, and policy makers, all agree that Indigenous people suffer from exceedingly high rates of chronic diseases and poor health.<sup>4</sup> Health scholars globally are now linking such poor health outcomes directly to issues of racism and calling for greater recognition that it is a significant determinant of Indigenous health and well-being.<sup>5</sup> What is only now being more fully explored, however, is the linkage between racism and colonialism in both global and local contexts. The SYS project very specifically comes about within the context of that broader research; focusing first on the role that Canada's colonial infrastructure has played in fostering this situation; then turning attention to localized experiences with racism across the Champlain region in health care institutions.

Consistently, and increasingly vocally, Indigenous peoples across Canada have identified colonialism as the root cause of inadequate nutrition and chronic food insecurity, substandard housing and sanitation, physical, emotional and psychological violence, and inappropriate, insufficient, or absent health and social services.

The largest and most comprehensive investigation into the impacts of colonialism on the security and well-being of Indigenous peoples in Canada was undertaken by the Royal Commission on Aboriginal Peoples

(RCAP) between 1991 and 1996. RCAP was established by an order-in-council in the immediate aftermath of a fatal armed confrontation between the Canadian military and the Indigenous people of Kanesatake and Kahnawake, following an attempted golf course expansion and encroachment onto traditional Mohawk lands by the Quebec community of Oka. The armed stand-off became known both as the Oka Crisis and the Oka Resistance.

In 1990, RCAP was mandated to investigate and propose solutions to the range of challenges experienced by Indigenous people in Canada.<sup>6</sup> Although not specifically focused on health and wellness, those who testified unequivocally stated that there was a clear relationship between their high rates of social, emotional, and physical illness and the structures of colonialism that define Canada's political, economic, and social institutions.<sup>7</sup>

The RCAP final report detailed the historic roots of colonialism in Canada and how its structures perpetuate ongoing inequities, violence, and marginalization of Indigenous peoples within a country proud of its international human rights record. It included excerpts from testimony such as that of Chief Edmund Metatawabin of Fort Albany First Nation who stated at a hearing in Timmins, ON in 1992 that:

Canadians enjoy homes with lots of rooms [complete] with full basements, water and sewer facilities, central heating, infrastructure to support the community. In Fort Albany, I have 80-year-old elders that struggle to get water from [outside] sources of water, standpipes as we call them. I have them struggling in 40-below weather to empty sewage pails in the places where they can empty them. I have them sitting in houses that are sitting on the ground without a proper foundation, subject to frost, cold, wind, made of plywood substandard housing ... they are not living like Canadians. We can only ask that we be allowed to live like Canadians.<sup>8</sup>

Based on thousands of hours of testimony such as this, and dozens of research reports submitted by a range of subject-matter experts, the Commission concluded that state institutions, while modern, had as their foundations colonial era law and policies that had never been designed to be either fair or equitable for Indigenous peoples.<sup>9</sup>

RCAP made over 400 recommendations with a conclusion that, if adopted, they would completely restructure the relationship between Indigenous people and Canada within twenty-years (by 2016). Though many of RCAP's recommendations remain unaddressed, one clear and positive outcome was the establishment in 1998 of its proposed Aboriginal Healing Foundation (AHF). This Indigenous-led agency was specifically tasked with responding to the legacy of the "Indian residential schools", particularly their impact on Indigenous health and well-being.

Simultaneously, significant effort was put into creating new structures for Indigenous health services generally, through increased funding for Indigenous health service providers. To this end, a number of Indigenous-controlled health agencies were created and funded.

Although the government never really gave up control over the process or provided equitable funding, the community health centres were created in rural, remote and urban communities that were Indigenous-led for the first time in Canadian history.

Another specific recommendation of RCAP that got action dealt directly with colonial damages to Indigenous health and wellbeing. RCAP called for the establishment of a Truth and Reconciliation Commission (TRC). The Commission moved from being an RCAP recommendation, to an obligation, because of a significant legal case that forced Canada to finally address the history of the residential school system. Some eighty thousand Indigenous residential school students brought a national class action against Canada and four national Churches for their respective roles in establishing and operating the schools as official government policy for more than a century.

The court-ordered TRC launched in 2008. Its 2015 final report, based in part on an unprecedented oral history collection of seven thousand statements from living survivors, included two volumes of history detailing Canada's stated aims to assimilate and Christianize Indigenous peoples. The TRC final report also included an entire volume devoted to Health and seven direct calls to action around health care, health-related professional development, and health systems management (see Appendix A).

Two recommendations specifically called on all levels of Canadian governments to acknowledge that the "current state of Aboriginal health in Canada is a direct result of previous Canadian government policies."<sup>10</sup> The TRC further called on Canada to establish measurable goals for identifying the reasons for the gaps in health outcomes between Indigenous peoples and non-Indigenous Canadians in a manner that is both collaborative and transparent and a new national mechanism for annual reporting on desired outcomes.<sup>11</sup>

**In a disturbing continuum, since 2015 three additional public inquiries have since released reports dealing specifically with:**

1. Violence against Indigenous women: National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG);
2. Violence and discrimination in the provision of certain public services to the Indigenous people of Quebec, including health and social services: Public Inquiry Commission on Relations Between Indigenous Peoples and Certain Public Services in Québec (the Viens Commission); and
3. Deplorable state of housing available to Indigenous Peoples globally: Report of the United Nations Special Rapporteur on Adequate Housing.<sup>12</sup>

All three reports identify systemic colonial structures of violence and racism as being at the heart of widespread Indigenous inequity and disadvantage within otherwise wealthy state systems. In their own ways, each inquiry concluded that anti-Indigenous racism and discrimination are deeply embedded in the existing state structures of colonialism.

While none of these reports were designed specifically to delve into issues of Indigenous health and well-being or even health care systems, they all clearly articulate that colonialism is responsible for the displacement, marginalization, and violence experienced by Indigenous peoples. Institutional structures, facilities, services and attitudes generate and reproduce oppression.

The MMIWG report, for instance, traced the everyday, interpersonal forms of violence as experienced through “institutions like the health care system and justice system”, institutions that are foundational to the

structures of Canadian society. Viens similarly concluded that it was, “impossible to deny the systemic discrimination experienced by First Nations and Inuit in relation to the public services” and that “existing structures and processes show a clear lack of sensitivity to the social, geographic, and cultural realities of Indigenous peoples.”<sup>13</sup>

Most recently, as a result of several disturbing incidents at health facilities in British Columbia, including the incident where emergency room health-care personnel played a “game” to guess the blood-alcohol level of Indigenous patients, Mary Ellen Turpel-Lafond was tasked with conducting a review of anti-Indigenous racism in the health system.<sup>14</sup>

The report, *In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care*, released November 2020, concluded that racism, stereotyping, and discrimination against First Nation, Métis, and Inuit people in the BC health care system was widespread and deadly. Outlining eleven key findings, the report states that current education and training for health workers is inadequate as are the numbers of Indigenous people in health leadership and decision-making positions within the provincial health system.<sup>15</sup>

At each successive inquiry since RCAP, Indigenous peoples have openly stated their belief that racism and discrimination stem from Canada’s colonial history and structures, and so do indifference, displacement, dispossession, marginalization, and violence. From that perspective, colonial thinking, racism, and poor health outcomes are inter-connected, deep-rooted, and originate from the same source. One thing is clear, despite advancements and changes in health delivery systems, and the myriad of recommendations from all of these and other international, national, and provincial reports, the reality of comparatively poor Indigenous health outcomes has remained stubbornly constant.

# Canada's Colonial Health Infrastructure

Such a well-documented national fact begs a national question. How open is this country and its people, to grasping its own history and understanding the heavy weight it bears on the present? Some have called it a lack of historical literacy. Others, a national blind-spot. It thrives at any level or sector of Canadian society that is quick to blame Indigenous peoples for their realities rather than looking at circumstances or systems that privileged, and continue to privilege the relative wellbeing of some, at the expense of others.

At times, it is at the very top level of society. In 2009, for instance, then Prime Minister Stephen Harper during a G20 press conference declared that Canada, in comparison to other countries present, had “one of the most stable regimes in history. There are very few countries that can say, for nearly 150 years, they’ve had the same political system without any social breakdown, political upheaval, or invasion. We are unique in that regard. We also have no history of colonialism.”<sup>16</sup> When questioned about this de-contextualization of Canada’s colonial past, the PMO explained that he was responding to a question about Canada’s role in the international financial market and meant Canada had no history of colonialism within that specific context.

Both statements, however, are fundamental denials of Canada’s history—both the history the nation inherited from the colonial exploits of Great Britain and France, as well as Canada’s own long tradition of internal settler-colonialism. This history includes the occupation of Indigenous lands, exploitation of resources, displacement of peoples, imposition of laws to dismantle Indigenous spiritual and socio-political systems, and a century-long assimilation policy that systematically marginalized and segregated Indigenous peoples apart from Canadian society.

True, the Canadian state did not go out and colonize other nation states in the modern era, or wage protracted military wars against Indigenous peoples. However, Canada has continued to engage in the *domestic* colonization of Indigenous nations, lands, and resources, through the geographic expansion of the settler state, the imposition of European laws and legal systems, and the self-approved extraction of its economic wealth.

Political scientist Phil Henderson concluded that *settlers* to Canada have deep, and often unacknowledged investments in the reproduction of systems of oppression that provide for their own material and physical position of privilege.<sup>17</sup> As a result, Canadians have been conditioned to believe that their history is benevolent and that the construction of Canada is rooted in principles of peace, order, and good government. Based on this reasoning, Canada is a just and fair nation state with a stellar international reputation and equitable universal Medicare system, and the poor health, living conditions, and lack of educational attainment must be the fault of Indigenous people themselves.

In Canada, there is only an appearance of universality and equal access to health services.<sup>18</sup> The availability of resources and access to health care services differ significantly for Indigenous clients and communities, in comparison to non-Indigenous Canadians. Historians Mary Jane McCallum and Adele Perry argue that the roots of inequity lay in Canada’s colonial history which governed First Nations, Inuit, and Métis Peoples in ways that took away their ability to control their health and their own lives personally, culturally, and structurally.<sup>19</sup> Successive versions of assimilationist policies were imposed. When they seemed to fail, Indigenous peoples, not the imposed systems, were blamed for being inadequate, incapable, and otherwise deficient.

Social justice scholars Gordon Pon, Kevin Gosin, and Doret Phillips argue that today the older and often discredited racialized logics continue to legitimize unequal social relations based on the exploitation, domination, and annihilation of non-Western people.<sup>20</sup>

Since the 19<sup>th</sup> century a great deal of meaning has been given to the *race* as a biological fact, a natural law, as opposed to a socially constructed idea. It was believed that humans could be defined and ranked from inferior to superior based on quantifiable categories of racial traits including cranial size, skin colour, or the shape and prominence of particular facial features.

Scientific racial theories built a system of classification based on identifying racial groupings, and then socially legitimizing white people from Western Europe as the pinnacle of the evolutionary ladder with their civilization representing *man's* ascent to perfection. These beliefs were reinforced intellectually through the fields of archeology, comparative anatomy, biology, and genetics, and then rationalized through social science and humanistic pursuits such as anthropology and history.<sup>21</sup>

Twentieth century medical interventions were justified by a system of beliefs about Indigenous peoples being more susceptible to disease. That belief continues to inform 21<sup>st</sup> century biomedical research. Modern medicine remains fixated on locating biological explanations for often excessively high rates of chronic diseases among Indigenous Peoples, instead of exploring colonial and racist roots of modern medicine and general inequities across all systems. In a country that envisions itself as free, multicultural, open-minded, tolerant, and democratic—inequality, racism, and discrimination flourishes.<sup>22</sup>

In short, scientific racism legitimized and justified imperialism and colonialism as well as the subjugation of 'lesser' races. This logic legitimized the removal of Indigenous children from their families and communities by federal authorities and placement of children in governmentally sponsored and church ran residential schools. This logic continued to legitimize the removal of Indigenous children by provincial child welfare authorities in the early 1950s and well into the 1960s when residential schools started to close, during an era known as the Sixties Scoop. Current realities, policies, and legislation have also resulted in the continued removal and relocation of Indigenous children as well as chronic funding shortfalls and jurisdictional disputes that underserve them.

Intended to control, the removal of Indigenous children and sterilization<sup>23</sup> of Indigenous women was justified by public health concerns rooted in racist assumptions about the ability of Indigenous parents to raise their own children, and colonial beliefs that the Indigenous family structure was culturally flawed, unhealthy, and socio-economically damaging to everyone, most especially children.<sup>24</sup> These policies and practices led to today's continuing legacy of individual and collective harms, with accompanying social disruption and health crises throughout Canada.

In Canada pernicious ideas of race remain with us because they remain written into the very fabric of Canada's national infrastructure, particularly in laws such as the Indian Act, and in health, education, and social services; fuelling anti-Indigenous racism and discrimination. First Nations, Inuit, and Métis may experience these structures differently because of their distinct historical and legal relationships to the state. However, despite these distinctions between and among Indigenous peoples, the experience of racism is largely paralleled and so are many of the health outcomes.

## First Nations:

**First Nations Status** – For First Nations — Status under the Indian Act anchors and defines their relationship to the state, rendering them as a person subject to a different set of laws. The colonial government’s goal was, and is, to reduce the numbers of *Indians* through policies of assimilation. This began with the state assuming the right to legally define who was, and therefore who was *not*, an Indian. After defining the *Indian* in law, the state then defined that population of people as *wards* of the State. This was also the mechanism through which Canada claimed a legal right to manage the affairs of *Indians* (now generally known as First Nations) as well as their resources and lands.

The federal bureaucracy of Indian Affairs was established to manage and enforce the Act with the support of the Justice Department and the Northwest Mounted Police (now RCMP). The Indian Act governed all aspects of life. Until the late 1950s, federal policy ensured that status First Nations people were confined to designated Indian Reserves. (These still serve as the basis of First Nation communities today). A pass system requiring prior authorization by designated Indian Agents served to manage and monitor any movements off Reserve. Economic activities such as farming were also regulated, restricted, and monitored by officials of the Department of Indian Affairs (DIA), preventing unwanted market competition with non-Indigenous neighbours.<sup>25</sup>

The federal department also controlled all issues related to health and medical care for Status Indians, and directly supported the growth of medical services in church-run hospitals and care facilities until the 1930s-40s.<sup>26</sup> It was a criminal offence for a Status Indian to refuse to see a doctor, go to the hospital, or leave the hospital before being discharged. By law, the RCMP could and did arrest First Nations patients who refused medical attention, returning them to hospital, or taking them to prison if they refused to comply.<sup>27</sup>

The history of racially segregated health care in Canada is rooted in reactive government policies concerning tuberculosis (TB). In the early 20<sup>th</sup> century, TB was believed to survive on unclean surfaces and then “seep” into people through dark, damp, dirty, or otherwise immoral environments.<sup>28</sup> Because Indigenous peoples were believed to be more susceptible to disease, the issue was regarded as unsolvable. As such, little was done to help First Nations communities before 1948.

The circumstances directly attributable to Canada’s colonial systems - dislocation, poverty, stress, malnutrition, inadequate housing - were not factored into the thinking. Instead, medical experts racialized the experience of disease, declaring First Nations people a threat to public health. As a result, by 1944 the infection rate in the Status Indian population was ten times the national average and remained high well into the 1960s.<sup>29</sup>

Through the process of dealing with tuberculosis, Indian Health Policy<sup>30</sup> was developed and administered in Ottawa by white urbanites with no real knowledge or lived experience in First Nations communities. Their perspective, therefore, was to solve “the problems” of Status Indians by “promoting health, assimilation, eradication of traditional practices, and removing the threat of spreading epidemics to non-Aboriginal populations.”<sup>31</sup>

These perspectives were foundational in the creation of the Indian Health Services (IHS) Branch in 1945, with separate Indian Hospitals specifically designated for Indigenous patients. Historian Maureen Lux argued that a segregated and unequal health system was created for First Nations people based on notions of their evolutionary racial inferiority, with particular illness and disease attributed to them.<sup>32</sup>

The Canadian medical system, as a part of a global system of medical knowledge, instruction, training, and care, constructed the *Indian* body as one so deficient in design that it was weak, more susceptible to diseases, inherently pathological, and, in turn, required fixing because they threatened the well-being of Canada and Canadians.<sup>33</sup> Based on this belief system, hospitals, foster homes and residential schools acted

by removing and isolating people diagnosed as ill, confining them in separate, racially segregated hospitals, sanatoria, and/or designated wards within mainstream institutions.

Today, the faulty logic of the diseased Indigenous body is engrained in service provision and the belief system is perpetuated by the health care professionals.

“I had this family doctor. I probably got her when I was 15... I had been for a blood workup every year... I have always been extremely healthy, never on any medications... in fact, my brother and my dad also saw her and she knows more than just me in a family setting... we [my wife and I] were talking about how we were going to start trying to conceive a child, and that my wife would be the first one to carry and that the hope was that I would carry our second child. And during that conversation the doctor’s comment was *oh it’s a good thing...* my wife, who is not Indigenous, was the one who was carrying first, because I would be deemed a high risk pregnancy because of my heritage, and that she would follow me closely because I would be at high risk for diabetes and, I can’t fully remember because she listed off basically anything that could go wrong in a pregnancy. She said that I was at high risk because I was Indigenous... I was shocked, and I said... ‘We are a year apart... and we are in the same bracket of fitness, BMI...’ And she said, ‘Well, you are native.’”

-SYS First Nations Two-Spirit Participant

With the separate medical system in place, First Nation people were often refused access to municipal and provincial hospitals. If they were admitted, they received uneven care. Why? Because the DIA refused to compensate the facility at the same rate for care as specified for other Canadians, justifying DIA responsibility to ensure Canadian tax dollars were used in the most cost-effective way. Some significant numbers were never factored into the cost calculations; that First Nations themselves were already paying for their own medical care via the resource revenues the federal government took from Indigenous lands, to be managed on behalf of their wards.<sup>34</sup>

After years of underfunding, and with the introduction of universal Medicare in 1968, the federal government gutted the Indian Health Services (IHS) budget with the rationale that it had created a new equitable health care plan for everyone. The federal plan was to socially and legally integrate status First Nations into provincial and territorial health care systems by the end of the 20<sup>th</sup> century.

While each province and territory deliver health services that can now be accessed by First Nations, there are health-related goods and services provided for in Treaties and other legal instruments that are not covered by Medicare. As a result, Health Canada administers the Non-Insured Health Benefits (NIHB) program. It covers certain drugs, vision and dental care, medical supplies and equipment, short-term crisis intervention, mental health counselling, and transportation for medical purposes.<sup>35</sup> It is important to note that the Government of Canada does not formally recognize health as a Treaty Right and that their delivery of services and programs is a 'policy-based' decision.

Still, provincial health service systems too often regard all Indigenous, but especially First Nations patients as a burden on their limited resources, arguing they are a federal responsibility. This has led to jurisdictional disputes over costs and service delays, often compounded by geographic isolation, and racist attitudes, leaving Indigenous patients at risk.<sup>36</sup>

*“I was in distress and I wasn’t feeling well mentally. I ended up self-harming pretty badly. I needed medical attention... an ambulance was called I was brought to... hospital... the doctor then took out his stapler and stapled my wounds when I asked specifically for removable sutures so that they’ll remove on their own after 10 days and he said, ‘No, I don’t have time for this’... and what really upset me... telling me that I should seek support at my reserve and asking why I left... Now my scarring is 10 times worse...”*

-SYS First Nations Female Participant

What Canadians accept as the minimum in their state-provided social programming, including access to hospitals, doctors, and associated health care services, are not universally or equitably available to First Nations people. The appearance of universality and equality within Canada’s universal health care structure is not a reality for many of them.

**First Nations (Non-Status Indians)** – Not all First Nations people are recognized as Status Indians under the Indian Act. There exists a population of Indigenous people who are culturally First Nations but who, are designated by the federal government as *Non-Status Indians*. Their recognition has been displaced by a broad range of imposed federal laws and policies.

Throughout the 19<sup>th</sup> and 20<sup>th</sup> century, the goal of successive waves of Canadian governments was to reduce the numbers of *Indians* and, therefore, reduce the financial burden on the Canadian purse. Assimilation policies that violated Indigenous rights and personhood were the tools to manage that reduction, and several devastating initiatives were imposed in law. People were paid to ‘voluntarily’ give up their Indian Status in exchange for rights that other Canadians took for granted: to vote, join the army, go to university, start a business, enter into a contract, hire a lawyer, purchase and drink alcohol, and so on.

Involuntary enfranchisement, another way to lose Indian Status, most often happened through marriage, but only for women marrying a non-native man. Prior to 1985, a non-native woman who married a non-native man became a Status Indian simply by marriage and carried all the rights of a Status Indian – a glaring example of gender inequality within the Indian Act and Canadian law. The apprehension and adopting out of children to non-native families also led to loss of Indian Status. Whether voluntary or involuntary, all loss of Indian Status transferred to the next and future generations of children throughout the 20th century, until successful court challenges reversed some of these decisions.

Historically, such Non-Status Indians acutely felt the weight of the Indian Act. It legally excluded many of them from the right to live in their communities of origin, isolating them as culturally First Nations, but non-Indians under the policies and legislation of Canada. While this category of people may self-identify as First Nations, and be perceived as such by others, they are not entitled to Non-Insured Health Benefits (NIHB), were denied access to the Indian Health Services (HIS), and are therefore considered of similar legal and policy status as the Métis in Canada’s health, education, and legal systems.

## Inuit:

While the Inuit have several centuries of contact with non-Inuit people—initially fur traders and whalers and eventually missionaries and the Northwest Mounted Police (now RCMP)—the impact of colonial law and policy has been more widely felt throughout Inuit Nunangat (the Inuit homeland also known as the Arctic or high north) since the early-to-mid-20th century. In 1924, the first Legislative Bill regulating the place of Inuit in Canadian law was created, and the Indian Act was amended to also assign responsibility for Inuit to the Department of Indian Affairs (DIA). Notably, the Bill clearly stated that Inuit were Canadian citizens and therefore *not* wards of the state, unlike status First Nations. This Bill was repealed in 1930.

Next, the governing body for the Arctic at the time was then made responsible for Inuit affairs. That body was the Northwest Territories Council, though based not in the north but in Ottawa. That Council, in turn, gave responsibility to the RCMP because of their sustained physical presence in the North, to administer relief for Inuit (food, health care, and ammunition).

Finally, in 1939, the Supreme Court of Canada pronounced, in *R. v. Eskimo*, that the Inuit were “legally” Indians and therefore the jurisdictional responsibility of the federal government. However, they were not subject to the Indian Act. Concurrently, with the collapse of the world fur economy in the 1930s, the Canadian government initiated relief programs for Inuit, while at the same time asserting greater control over Inuit life in much the same way that it had with status First Nations.<sup>37</sup>

Until the end of World War II, responsibility for the Inuit including northern health and social assistance was left to traders, police officers, military personnel, and missionaries.<sup>38</sup> In some Arctic locations, Canadian medical services had been offered in limited capacity. The first government physician serving eastern Arctic Inuit travelled annually to Baffin Island. In the western Arctic, a physician was stationed in the

northern community of Aklavik during the 1930s. Furthermore, health care services were administered in the Arctic by southern doctors who annually travelled north by ship, taking x-rays to screen for tuberculosis, a practice that continued until the 1970s. Others worked out of, or more often rotated through, a network of health aid posts, nursing stations, and regional hospitals.

By the 1950s, the pace of change in the Arctic intensified because of the Cold War military tensions between Russia and the United States and its allies. This fuelled the construction of radar stations, airstrips, and the Distant Early Warning communications transmission system (known as the DEW-Line) along the 70<sup>th</sup> parallel. This was also a time of growing mining activity.

These incursions into Inuit territory by Canada led to the federal government coercing Inuit to settle in permanent village locations, with promises of housing, health, education, and welfare services on par with the rest of Canada. Throughout the Arctic, southern-styled prefabricated houses, store-bought food, and wage labour employment became new norms, while Inuit children were taken away to far distant residential schools in unprecedented numbers. By the 1970s the decline in Inuit individual and family health and well-being were apparent.<sup>39</sup>

Although Canada was supplying medicines, paying the salaries of medical staff, and sometimes providing the funds for relief services, in 1945 the Inuit were administered under the newly created Indian Health Services (IHS) branch. Inuit who needed treatment for tuberculosis or other complex medical care were routinely evacuated thousands of kilometres south to hospitals in the IHS system, such as the Charles Camsell Hospital in Edmonton, Alberta.<sup>40</sup> Before antibiotic treatments were administered in the late 1950s, the “cure” for tuberculosis was rest at state run sanatoria or hospitals within the IHS branch, and a range of medical interventions.

These treatments were only available in southern Canada and therefore it became routine to evacuate Inuit from the Arctic—first for tuberculosis treatments, and eventually for other forms of medical intervention, including childbirth. These health-related evacuations often resulted in lengthy separations from families, who received little or no information on the health status of relatives being treated in the south. Inuit tuberculosis patients stayed at southern hospitals or sanatoria for, on average, two and a half years. Some stayed longer. Others died and were buried in the south, far from home and family, who were often never notified.<sup>41</sup>

Canada's disease management regime devalued Inuit humanity. Bodies were medicalized while overall human well-being was disregarded. Paternalism and cultural disrespect within the IHS system were elements of the same colonialism that had dehumanized all Indigenous People, considering them first and foremost as problems to be solved, not fellow human beings with shared needs. Inuit, like Status Indians, were integrated into the Canadian Medicare services in the late 1960s, so they are also covered by the Non-Insured Health Benefits (NIHB) program if deemed eligible.

“My mom... was taken away by the doctors thinking that she had TB and she was gone for two years... my grandfather used to work for RCMP, but I think they really had not much control over the doctors and priests taking the kids away from my grandparents. I am sure that was traumatizing for my grandparents... my mom was just a baby... when she came back... my mom was not the same.”

-Inuk Female Participant

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“This involves the Ottawa Doctor because if you live in Baffin, we go to Ottawa for hospital... I slipped and fell and dislocated my wrist, so I went to the hospital in Iqaluit and the Doctor there was very good. He x-rayed it. He said you have a dislocation. The bone is out, and my finger bones were also out of place. So, the Doctor sent the x-ray to the specialist down here because that’s how it works... the specialist down here, bone specialist [communicated with] the Doctor in Iqaluit, ‘She was born that way. She has a rare deformity’ and the Doctor didn’t have any authority over the specialist down here in Ottawa... and I said... ‘This is my normal hand and this is my normal hand too, but I dislocated it because I fell on the steps’. He said ‘We’re operating on you tomorrow morning’... [The specialist] said ‘She was born with a rare deformity’ and they didn’t believe me and they ended up cutting my bone.”

-SYS Inuk Female Participant

Today, while claiming sovereignty over all of Inuit Nunangat, Canada continues to provide services for Inuit in ways that make them victims of their own geography. Medical services, though improved in a few larger centres like Iqaluit, remain limited. Both Inuit, and their First Nations neighbours continue to be sent thousands of kilometres south

for any complex, specialized, or urgent care. The lengthy separation of families, little support and accommodation in southern cities and facilities, and racism during times of health risk and medical stress are ongoing features of the Inuit experience with universal Medicare.

## Métis:

Unlike Status Indians and Inuit, the Government of Canada recognized no formal legal relationship with the Métis until 1982 when they were identified as Aboriginal people in the Canadian Constitution. As a result, the Métis were never legally classified as wards of the state and the federal government never accepted any responsibility for this Indigenous population. Since the early-20th century, the Métis have been a jurisdictional football between federal and provincial governments, each denying responsibility for ensuring their access to basic services, particularly health, education, and poverty reduction programs.

Nevertheless, because of the prevailing pseudo-scientific notions of race, the Métis were also treated as racially inferior based on the same criteria attributed to both First Nations and Inuit. They were pushed further and further to the margins of Canadian society and ignored until health and poverty related issues within their communities threatened the well-being of white Canadians.

By the 1920s and 30s, as a consequence of how the western prairie regions were settled, the majority of Métis were landless, poor, and living in isolated villages or on the edges of cities and towns. By the 1930s and 1940s, state agents (particularly in Alberta and Saskatchewan) deemed them a problem to be fixed. In this era there was no social welfare system to help the economically disadvantaged overcome poverty. Rather than being considered in this light, Métis were instead regarded as, and treated like, a public health crisis that threatened the physical well-being of settlers.<sup>42</sup>

In 1939, for instance, George Dulmage, Reeve of Orkney, Saskatchewan, circulated a petition about the issue of Métis poverty, demanding the province deal with this problem of indigent people draining municipal resources in the region. Three years later, Dulmage appeared at a local

Board of Trade meeting demanding that something be done about the approximately 150 homeless Métis families congregating south of Yorkton who were, in his words, *disease-ridden*.

In the same year, an RCMP officer stationed in the Qu'Appelle Valley reviewed the living conditions of a small Métis community and observed that it was comprised of itinerant labourers, squatting on Crown lands, and living in makeshift shacks and tents. Poorly dressed and malnourished, many of the adults required medical treatment for conditions like trachoma, tuberculosis, and other communicable diseases.

Although the Saskatchewan Department of Public Health was legally required to act on this report, it had no immediate solution and was unprepared to mobilize because they could not be seen to waste public money, given a general and pervasive anti-Métis sentiment within the province.

Some Métis children were kept out of school because local parents believed Métis *might* be carrying communicable diseases, and feared their own children would be put at risk. The same sentiment existed about medical facilities. As a result, the provincial government deemed the Métis to be a federal responsibility. The federal government disagreed. As a result, no services were provided by either government.<sup>43</sup>

In the late 1960s, with the extension of universal Medicare, Métis gained better access to health care, but they still experienced unequal access based on ancestry, language, and background. Like First Nations and Inuit, although distinctly defined in and by colonial laws, Métis have also experienced systemic racism, including a generalized stereotype of inferiority, the apprehension and removal of children from homes, and forced or coerced sterilization of women.

# Impacts of Settler-Colonialism and Racism

Many Indigenous and non-Indigenous health experts agree on the root causes of poor health among Indigenous peoples. Public health scholar Charlotte Reading explored issues of disparity and inequality in health systems focusing on structural determinants — historical, political, societal, and economic. Reading specifically sought to address why the diabetes rates among the Indigenous population was three to five times higher than the non-Indigenous population.

Reading argued that bio-medical analysis and treatment tends to be limited to the physical body, with focus on obesity, poor diet, and inactive lifestyle. However, consideration of socio-economic determinants beyond the body may reveal a lack of money to buy healthy food, the lack of healthy food in remote locations, and the lack of access to recreational facilities, equipment, or natural spaces for safe physical activity.

Crowding, remote isolation, and insufficient public and private sector job creation all become further contributing factors to poor health. Centralized colonial structures designed for the ease of administrative processes have directly contributed to chronic food insecurity, limited educational and training opportunities, and a market economy that undervalues the skills possessed by Indigenous peoples. Reading concludes that this lack of investment in Indigenous Peoples by the colonial state is responsible for the poor health and negative outcomes experienced by Indigenous peoples in Canada.<sup>44</sup>

Taking Reading's approach further, McCallum and Perry argue the need to explore the ideological roots of racism asking why Indigenous bodies are constructed as comparatively inferior and/or fragile and why health policies and biomedical practices prefer to treat pathological conditions of the body rather than the colonial construction of the *Indian*.<sup>45</sup>

Nursing scholars Josephine Etowa and Elizabeth McGibbon note that while knowledge in the health field is thought to be data-informed and research-based, it is filtered through an ideological sensibility that defines marginalized people as irrational and primitive. When such racism is deeply embedded, health professionals may not consciously notice that the underlying racist assumptions about Indigenous people are influencing their interactions and decisions.<sup>46</sup>

“I was a student and I was assigned to this lady, she was 23 years old and she was [Indigenous]. I remember, she was from Moosonee... and she was flown to an Ottawa hospital to give birth. It was a high risk pregnancy, she had a C-section... she had not been eating because she didn't like the food here... so it's a big concern because it's a new mother and so I told the teacher and I was shocked; the teacher told me 'Don't worry about these people, they are like that because they think that they own the country when we are the ones that own this country...' I told her 'But I heard that... Indigenous people were here before the European and the British people came'; she told me 'Don't be political with me, you are to do what I'm saying, don't ask me questions because if you keep asking me these kind of question I will make you fail... I will make you fail and you will never become a nurse'.

Then I asked the teacher 'Can I have [the umbilical cord] put in an envelope so that [the client] can take it back home?'... She said 'What is the point, you know these people are junk?' I said 'It's important to her, there is a reason for her to take it, to take the clip home'; and then she said 'Okay, you can give it to her because you are paying so much attention to her which is unnecessary.'

[Nursing student advised the client] 'don't sign anything unless you have an interpreter because... they might take your baby' And [the client] said 'Thank you' because that is what they wanted to do and then the teacher had the guts to tell me 'Even if she doesn't need us, they will die, the baby will die, who cares?'"

-Witness Nursing Student

Pon et al argue that within helping professions such as social work, medical services, and education, the idea that Canada as fair and tolerant prevails, despite evidence of pervasive racism and sexism. The evidence of other realities is then dismissed or rationalized as the fault of *those* who are deemed to possess personal and/or cultural deficiencies.<sup>47</sup>

McCallum and Perry's book, *Structures of Indifference: An Indigenous Life and Death in a Canadian City*, explores the relationship between belief, thought, and practice in the health care systems. The book addresses the 2008 death of Brian Sinclair in the waiting area of the Winnipeg Health Science Centre's emergency room, arguing that settler colonialism generated individual and collective structures of indifference among hospital staff.<sup>48</sup>

Sinclair, a wheelchair-bound, double amputee, was referred to the Health Sciences Centre by his doctor to get immediate attention for a relatively minor medical problem. He died thirty-four hours later still sitting in the waiting area, never having been registered, triaged, or attended to by emergency room personnel despite speaking twice to the desk clerk and security personnel, and having two other patients attempt to advocate for him.

At the inquest, health care workers gave a number of excuses for ignoring Sinclair during those thirty-four hours: they assumed he was drunk and sleeping it off; had been discharged earlier in the day and had nowhere to go; was homeless and had come into the emergency room to get out of the cold.

The tragic case of Brian Sinclair is not an isolated incident. A more recent example is the September 2020 death of Joyce Echaquan at the hospital in Joliette, Quebec. Seeking treatment for a stomach issue, the thirty-seven-year-old mother of seven from the Atikamekw Nation was racially abused and berated for her medical condition. Nursing staff told her she had made bad choices, was stupid, only good for sex and that she was better off dead. Despite her obvious state of distress,

Echaquan managed to record and live-stream the abusive behaviour she was experiencing on Facebook, leaving a public record of how she was treated by individuals in a system responsible for her life.<sup>49</sup>

Countless similar incidents are playing out daily in Canadian health service institutions. But they receive little or no attention unless and until a patient dies. According to the Echaquan family, Joyce was reluctant to seek further medical help. She'd already had several appointments at the Joliette hospital for a series of health issues. In the fall of 2020, before her final hospitalization and death, she said she felt that the nursing staff were "fed up with her" and would not provide the adequate care."<sup>50</sup>

Many Indigenous people across the Champlain region have reported similar feelings about accessing health care to those expressed by Echaquan.

**"The [hospital staff] would send her [the client] home and say 'There is nothing wrong with you' and she was really frustrated. She had said, 'I really think it is because I am Indigenous, they're not doing anything.' I was really upset. That was traumatic for me to know that she could have died. And that doctor just wanted to send her home... the good thing is she got service, but she almost died to get the service."**

-Witness Health Professional

The 2010 Urban Aboriginal People's Study (UAPS) captured the range of anti-Indigenous attitudes and behaviours experienced by urban First Nations, Métis, and Inuit people within the health sector.<sup>51</sup> In the study 43% reported a belief that poor treatment from non-Indigenous health care professionals was rooted in racism, with 50% of First Nations, 48% of Inuit, and 36% of Métis stating that they faced discrimination in a variety of forms. Overall, 18% of respondents felt these negative experiences with the health sector led to their feelings of shame, lowered self-esteem, and diminished self-confidence.<sup>52</sup> They reported that they had been treated unfairly or disrespectfully, and that they had encountered medical staff who lacked empathy, did not believe them and/or did not understand their needs or culture.<sup>53</sup>

Incidents of anti-Indigenous racism have resulted in Indigenous clients experiencing a range of mental and physical health challenges including stress, depression, post-traumatic stress disorder, increased levels of anxiety, serious injury, disability, obesity, high blood pressure, substance use, and risk of premature death.<sup>54</sup> Yet governments, health agencies, and medical administrators too often deny the existence of systemic racism and instead attribute racist behaviours to the personal failings of Indigenous clients. This not only hinders health care effectiveness, but also discourages Indigenous clients from seeking necessary care, further contributing to harmful health outcomes.

## Racism and Advocacy Across the Champlain Region

“She woke up, she was unconscious when I first saw her, she woke up and she was as any of us would be, startled like – *where am I, this is not where I was when I passed out* – and they were all over that and they physically held her down and then they handcuffed her to a bed and it was just crazy. They’ve got a security guard. The whole thing was crazy. I felt really powerless from where I was and all I could do is bear witness to it... and one of the most insulting parts for me is the way the staff were talking about the whole situation – including the women – very derogatory at their workstation... with no consideration for who might be overhearing... They were really surprised that I would call them on it. They were really surprised that I would be bothered by their – *oh that is just some other ‘Indian drunk’* – but it was clear to me that she was being treated gruffly because of the colour of her skin.”

-Witness who was in the ER for abdominal pain during this incident

McCullum and Perry remind us that while, “the histories of colonialism and dispossession... are pervasive and global... they are also local and specific.”<sup>55</sup> That is, ideological and institutional structures that exist at a national level play out in everyday lived experiences. Anti-Indigenous racism and the experiences of everyday indifference and violence are

very much locally generated, even if the structures that produced them are not.<sup>56</sup> This understanding is necessary to finding solutions, as we consider the system of hospitals, medical centres, and health services across the Champlain region.

The Champlain Local Health Integration Network (Champlain LHIN), serves the robust and diverse Indigenous communities within its reach and covers the following geography:

- Stormont, Dundas & Glengarry, including the Mohawk Nation of Akwesasne, the second largest First Nation in Canada;
- Prescott & Russell;
- Ottawa, the nation's capital with its diverse and rapidly growing Indigenous populations, including the largest number of Inuit outside their Arctic homeland;
- North Lanark & North Grenville; and
- Renfrew County, including the Algonquins of Pikwakanagan First Nation.

The 2016 Census reported 41,155 people identified as First Nations, Inuit, and Métis in the Champlain region.<sup>57</sup> The actual number may be significantly higher than that. Of note, the 2016 census data has been openly criticized for its methodology and underreporting of the Inuit in Ottawa and Mohawks of Akwesasne near Cornwall while over-counting Métis population.<sup>58</sup>

Recognizing the need to better serve this population, the Champlain LHIN has worked in partnership with the Indigenous Health Circle Forum (the Circle) on a number of projects. On behalf of the Circle, and in partnership with Champlain LHIN, the Wabano Centre for Aboriginal Health spearheaded and published two reports highlighting local stories and personal experiences to bring the voices of Indigenous young people forward: *My Life, My Well-Being (2016)*; and *Now, Now, Now: Mental health and Indigenous Youth (2017)*.<sup>59</sup>

Both reports focused on the mental health needs of Indigenous youth and have been instrumental and foundational for the Circle's public education and advocacy efforts. The stories and findings shared in these reports brought to light how ongoing colonial structures contribute to inequities and poor health outcomes while also exposing examples of racism and discrimination they faced when accessing essential services. Out of 305 youth surveyed in the *My Life, My Wellbeing* study, more than half reported that they have been discriminated against because they were Indigenous and stated that "racism and disrespect were the main reasons they hesitated to access services."<sup>60</sup>

Building on these initiatives, and understanding the importance of locally produced cultural safety training, in 2017 the Champlain LHIN and the Ministry of Health and Long-term Care provided additional funds to Wabano to begin a project that would lead to the development of an in-person Indigenous Cultural Safety (ICS) training program.

Simultaneously, Ottawa Public Health (OPH) declared their commitment to Reconciliation by stating they will "work in partnership with First Nations, Inuit, and Métis peoples and communities to advance Indigenous health equity."<sup>61</sup> To that end, with one-time funding from the Ministry of Health and Long-Term Care, OPH collaborated with Indigenous and non-Indigenous health sector partners to begin discussions to create an Urban Indigenous Health Strategy for Ottawa. This discussion also identified ICS training as a top priority for the region, with a specific focus on addressing anti-Indigenous racism.

Wabano's intention for developing a face-to-face ICS training program was to address unconscious assumptions that health professionals might have about Indigenous peoples, and explore how these assumptions or biases can influence thoughts, interactions, and practical service decisions affecting Indigenous patients. In this context, it was important to collect local stories of anti-Indigenous racism for the following reasons:

1. To document lived experiences, so that current realities could be shared with those in the health care system; either those who need to change attitudes and actions, or those who are able to effect changes in the system;
2. To establish a baseline of data about current realities in order to identify the content needed in the training to bring about change;
3. To identify priority service areas and providers to receive the ICS training; and
4. To develop and design the content required for the face-to-face training, using stories grounded in real life local experiences.

Wabano's starting point for the research project was to acknowledge the reality that Canada, nationally, and the Champlain region, locally, are colonial spaces, and that anti-Indigenous racism is very much a reality for many people residing and accessing health services in the region. The hope of the *Share Your Story* research project was to explore racism across the Champlain region's health institutions as a means to generate local solutions and recommendations that would regain and support Indigenous confidence in the health sector.



# The Share Your Story (SYS) Project

# The Share Your Story (SYS) Project

With support from other sectors of the health services community, Wabano began collecting baseline data about health care practices and experiences across the Champlain region in 2017 and throughout 2018. This included recording stories of experiences within the system that could later be used as part of Wabano's face-to-face Indigenous Cultural Safety (ICS) training curriculum.

As in all initiatives undertaken by the Wabano Centre for Aboriginal Health, it is done with the spirit and intent of its vision in mind. That is, to 'make possible a world in which all First Nations, Inuit, and Métis people have achieved full and equitable access to the conditions of health. With this conviction to advocate for change and improve the health and wellbeing of Indigenous peoples, this project came into being.

The first step was a pilot project. Seventeen stories were collected and used as the basis to begin conceptualizing how to design the larger research program (see Appendix B for one of the first documented stories). Feedback and content from those first interviews were used to refine both the questions and methodology for the next round. An interview guide for *Share Your Story* was developed, as were guidelines and ethics protocols for training the research assistants who conducted interviews and collected the rest of the stories.

The SYS Project was set out to answer the following questions:

1. What are Indigenous peoples' experiences of racism and discrimination in the health care system?
2. Did the participant's Indigenous identity contribute to their experience of discrimination?
3. Where did these experiences occur and what type of service was being utilized?
4. What are the "hot spots" in the health care system in the region that require the focus of cultural safety training?
5. What are the effects of anti-Indigenous racism on the mental health and wellbeing of Indigenous people?
6. What are the effects of anti-Indigenous racism on physical health and access to health care services?
7. What does culturally safe care mean to Indigenous people?

The Share Your Story project was soon to get larger and more inclusive. As the Wabano-led project was already getting underway, the Ottawa Aboriginal Coalition (OAC) had proposed, and received funding for a similar project.<sup>62</sup> Their project was to also collect Indigenous people's stories about their experiences of racism and discrimination within the health care system in Ottawa so that the Coalition could use them to effect change. To avoid unnecessary duplication, or over-burdening the local Indigenous community with two very similar research projects, in September of 2018, Wabano and OAC agreed to collaborate on a large-scale project funded by OPH and developed and administered by Wabano.

In October of 2018, the Share Your Story (SYS) advisory committee<sup>63</sup> was formed and CORE Consulting and Research<sup>64</sup> was hired to work with the advisory committee and develop the research methodology as well as conduct the research by training interviewers and analyzing the resultant data. The SYS project followed a Community-Based Participatory Research Approach where community members, organization representatives, and researchers are engaged in all levels of research process with the goal of advocating for equity and facilitating change to benefit the community.<sup>65</sup>

The SYS advisory committee was involved in setting the research agenda, reviewing and contributing to the methodology, developing questions, interpreting the results, determining what needed to be highlighted, selecting stories for the cultural safety training program, setting the direction for the companion SYS education video, and finally, reviewing and providing feedback on the final report.

First Nations, Inuit, and Métis community members who had experienced incidents of racism or discrimination within the past 7 years in the health institutions across the Champlain region were invited to participate.<sup>66</sup> As well, the invitation to participate was extended to:

- Parents of First Nations, Inuit, and Métis children who witnessed their children experiencing racism; and to
- All other individuals, Indigenous or non-Indigenous, who witnessed anti-Indigenous racism in the health care system.

The health care system was defined to include hospitals, community health, and mental health services, addictions centres, clinics, family health teams, pharmacies, medical examination centres, dental clinics, and paramedic services in Ottawa or surrounding areas.

The SYS project was interested in subjective experiences of racism where people felt that the poor care they received, or the harm that followed, was a result of them being Indigenous. The project was also interested in whether people felt that care was denied or withheld because of their race, and whether they believed they were not included or informed about the care they were to receive, or resources that they were entitled to, because of their race. Importantly, SYS was not seeking stories about incompetence, human error, or iatrogenesis (side effects or complications of treatment); the focus was on collecting stories about racism or discrimination as experienced by Indigenous clients by health institutions across the Champlain region.

# Methodology

The SYS project, rooted in the Community-Based Participatory Research Approach, employed a mixed method design where both qualitative and quantitative data was gathered. Qualitative data gathering was achieved through individual interviews that asked participants to share their experience(s) of anti-Indigenous racism in health care.

Before proceeding with the interviews, the difference was explained to participants between poor care based on lack of knowledge, expertise or experience, and poor care based on unconscious or conscious biases related to beliefs about race. Differences were also explained between general inefficiencies in processes or protocols beyond the control of the individual service provider...versus poor services due to deliberate withholding of care, including medicine to participants. The interviews were conducted without interruption and in a safe environment created by the interviewer, who was either Indigenous or worked for an Indigenous organization.

The mixed method design employed during interviews allowed for both the collection of stories (qualitative) and validation of personal and witness experiences (quantitative). The validation was done by obtaining all relevant information about experiences, participants, and institutions where the racism/discrimination experiences had occurred. The interviewers also needed to fill out a questionnaire validating the stories and information they heard.

In addition to interviews, the qualitative portion involved three focus groups with: 1) First Nations participants; 2) Inuit participants; and 3) witness participants of mixed backgrounds who shared their first-hand observations of racism and discrimination against Indigenous community members. Initially, there was a plan to have a fourth focus group with Métis participants, but there were very few individuals who came forward to share their stories from this community, so this focus group

was not held. However, the stories from Métis community members, and recommendations from them as collected at the end of their interviews, have been included and integrated into findings and recommendations.

The focus groups followed a *sharing circle* format where participants were invited to provide recommendations on how to address racism in health care and create culturally safe places for Indigenous peoples in the region. The First Nations and witness focus groups were facilitated by a First Nations research assistant, with the support of a First Nations Elder. The Inuit focus group was facilitated by Inuit and First Nations research assistants, with the support of an Inuit Elder.

Eighteen research assistants were recruited and trained. Six were research assistants not affiliated with any of the OAC organizations. Eight were staff of Wabano (two of which were members of Akwesasne); two were staff from the Algonquins of Pikwakanagan First Nation, one was staff from Tungasuvvingat Inuit; and the final one was a staff member of the OAC.

Of those eighteen research assistants, eleven were First Nations, five were Inuit, one was Métis, and one was a non-Indigenous employee of an Indigenous organization. Most of these individuals had backgrounds in service provision and either were part of, or worked for, Indigenous communities in the region.

The research assistants were trained to conduct interviews, administer questionnaires, transcribe interviews, and enter data into a secure online system. They were also trained in the ethical principles of Indigenous-specific research, including OCAP™ (ownership, control, access, and possession), and in how to ensure both privacy and confidentiality. Two out of eighteen research assistants were additionally trained to conduct the focus groups.

In addition to their training, research assistants were provided with an interviewer guide developed specifically for this project. The guide covered both qualitative and quantitative information-gathering methods. It provided further instructions on trauma-informed principles for working with participants with first-hand experiences of racism or discrimination, as well as with those who had witnessed such incidents.

The interviewer guide included a script on how to introduce the project, obtain informed consent, create a comfortable and safe environment for participants, and conduct debriefing sessions. The interviewer guide also included a form for gathering socio-demographic data, a list of health care organizations for interviewees to reference in identifying locations where they had experienced or witnessed acts of anti-Indigenous racism, a post-interview validation questionnaire, and an interviewer questionnaire as well as instructions on how to administer these questionnaires.

The *Socio-Demographic Form* used for each participant in this project was a modified version of Wabano's standard intake form. It consisted of two sections focused on gathering personal information and family history, as well as socio-demographic information. Under personal information and family history, there were nine questions related to age, gender, sexual orientation, Indigenous background, and whether or not the interviewee had experience with residential school, the 60s scoop, or other direct child welfare interventions. Socio-demographic information was captured in seven questions gathering information about household composition and income, employment status, level of education, and whether or not the interviewee had any disabilities.

The *List of Health Care Organizations* was a comprehensive list of frequently accessed organizations and institutions across the Champlain region, including hospitals and community-based mental health and addictions agencies, health centres, and support service organizations. The list was used to help participants select the most significant negative experience of racism or discrimination to share in their interview.

The *Validating Questionnaire* was developed for this project to clarify and confirm details related to the participants' shared stories/ experiences. This interview-based questionnaire consisted of 26 questions and could be broken down into four sections:

1. *Story details* including date, location, who was involved, witnesses (if any);
2. *Incident clarification* including questions intended to ascertain how health professionals knew that a participant was Indigenous; whether discriminatory behaviours were experienced such as name calling or whether people were threatened, ignored, blamed, or refused tests/procedures/medications, etc.; whether any racial discrimination experienced intersected with other discrimination based on gender, sexual orientation, age, or disabilities individually or in combination; whether there was differential treatment in comparison to others; whether anti-Indigenous racism was experienced by others in the same institution; and whether health professionals appeared to have any knowledge of Indigenous peoples and/or an interest in Indigenous culture(s);
3. *Access to care* questions to assess whether or not participants would go back to the same service provider or the same institution after a racist encounter; and
4. *Overall experience of racism* to assess the overall frequency of anti-Indigenous racism and discrimination experienced by participants in health institutions across the Champlain region, the impacts of these experiences on their physical and mental health, and their feelings of trust towards the health care system.

The *Interviewer Questionnaire* developed for this project consisted of 10 questions with the intention of corroborating the anti-Indigenous racism experiences or stories interviewers heard from SYS project's participants. For example, the interviewers were asked to rate to what extent the story shared was an example of anti-Indigenous racism. Interviewers were also asked to recommend stories to be included in the future face-to-face ICS training program curriculum.

The *Witness stories* required a separate protocol designed for collecting qualitative (stories) and quantitative data from participants who came to share about anti-Indigenous treatment they had witnessed. Most of the protocols mirrored closely the protocols and questions designed for participants who had experienced anti-Indigenous racism directly. A difference, however, was a modified socio-demographic form that captured information both about the witness and about the person experiencing anti-Indigenous racism directly.

All participants were compensated for their time and given a \$25 gift card as well as offered and/or provided with mental wellness supports. The research team also offered to connect participants to an Indigenous service provider located at Wabano who could support any individuals wanting to launch a formal complaint against an institution where anti-Indigenous racism had been experienced.



## Findings

The following sections outline the results of the SYS project, broken into two parts. Part One focuses on the SYS participants, noting perceived links between their experiences of anti-Indigenous racism, and their respective identities within various categories, including gender, sexual orientation, age, education, and employment status. It also co-relates their ties to such acknowledged historical traumas as residential school, foster care and the 60s scoop.

The sections in Part Two focus on the SYS Stories themselves, drawing from the content to identify common themes, systemic, and behavioural patterns, “hot spots”, and health implications of the reported experiences.





# 208

victims or witnesses  
of racism interviewed  
from across the  
Champlain region

# 146

participants  
from Ottawa

# 315

stories of  
racism collected

## Part One - Participants

Two hundred and eight individuals came forward to share either their personal experiences of anti-Indigenous racism and discrimination, or those they witnessed in health institutions across the Champlain region. Some participants shared more than one experience, for a total of 315 accounts of racism and discrimination.

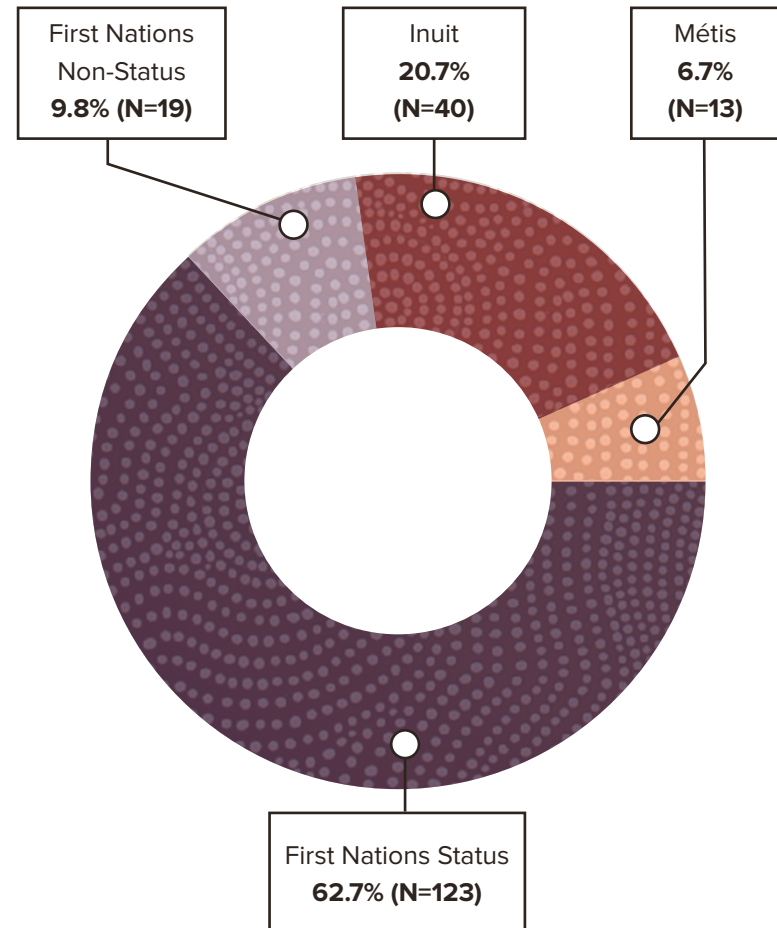
Of the above, eighty-six participants reported they had been present at times when they witnessed racism and discrimination against others. This group was a mix of Indigenous and non-Indigenous parents, service providers, students, and other patient/clients of the system.

## Identity and Racism

As indicated in Graph 1, the majority of Indigenous victims of racism (self-reported or reported by witnesses) were identified as First Nations 63%, Inuit (21%), Métis (7%) and First Nations Non-Status (10%). This breakdown by Indigeneity within the SYS Project differs from the national, provincial, and regional breakdowns.

The latest Canadian census indicates that 58% of the Indigenous population reported as First Nations (FN), 4% Inuit, and 35% Métis.<sup>67</sup> The Ontario's LHINs Environmental Scan reports 64% FN, 1% Inuit, and 32% Métis population breakdown in Ontario and 53% FN, 3% Inuit, 41% Métis in the Champlain region.<sup>68</sup> As mentioned previously, census breakdowns need to be treated with caution - there is underrepresentation of some Indigenous groups (i.e., First Nations and Inuit) and over-representation of others (i.e., Métis).

**Graph 1. Victims of Discrimination:  
Indigenous Ancestry (based on self and witness reports: N=195)**





# 76%

of SYS participants felt they could have received better service if they were able to hide their Indigenous Identity (n=146).

# 93%

of these individuals indicated they have felt this way sometimes to always.

The SYS sample had significantly higher percentages of First Nations (Status and Non-Status) and Inuit participants, and lower percentage of Métis, as compared to the Indigenous population break down in census data. As the invitation to participate in the project did not pre-determine numbers or quotas for any one group, this participation profile suggests that individuals who are most easily identifiable to others by colour and other physical traits, and by last name, address, or documented identities such as status or nation member cards, may experience greater levels of racism within the health care system. Three quarters of those who participated stated they felt that way, and as a result, they responded in greater numbers to the call for stories.

This is consistent with the observations noted by the project's interviewers, as well as the accounts given by those participants who were witnesses to the racialized treatment of others, as follows. The SYS interviewers reported that 92% percent of participants looked Indigenous to them, based on skin tone (75%), physical appearance (22%) and clothing (2%). Similarly, SYS witnesses reported that 87% of the victims in the incidents they saw looked Indigenous to them, based on their skin tone (70%) and physical appearance (29%).

Of further note, several participants indicated that they sometimes prefer not to self-identify in health care settings because they fear racism and discrimination, especially when proof of identity is required for specific health benefits such as Non-Insured Health Benefits, or when direct identifying questions are asked.

“My last name is a different last name. They asked me where it came from. Then I said it was Inuk... and then their behaviour started to change around me when I would ask for more meds.”

-Inuk Female Participant

“I dropped my stuff and the nurse picked up my ID and noticed my status card. And right off the top he said (phrase in French) – ‘*oh another crack head Indian*’.”

-First Nation Male Participant

“In the work that I do in the community I am constantly hearing about... particularly those of my siblings in spirit who are visibly Indigenous... If you have a benefit of pale skin, the benefit of being able to pass, then you will experience less discrimination in the health care in Ottawa. But if you are brown, you are [screwed] from the minute you walk in the door - you are a lesser priority from the minute you walk in the door.”

-Indigenous Male Witness

## Gender, Sexual Orientation, Age and Racism

The majority (68%) of SYS participants were women. The gender composition of the SYS sample (Graph 2) accurately reflects the same general pattern as outside this project, where women generally access health services more often than men. And so can also be subjected to incidents of racism and discrimination in health care more often than men.<sup>69</sup>

The same consistency is not true for the two-spirited. While there were 1% of individuals reporting their gender to be two-spirited, a sexual orientation breakdown further revealed that 13% of SYS participants reported a diverse sexual orientation including bisexual, two-spirit, gay, and queer.

When asked whether participants were discriminated against based on other factors besides race, they additionally specified gender, sexual orientation, age, and disabilities (see Table 1).

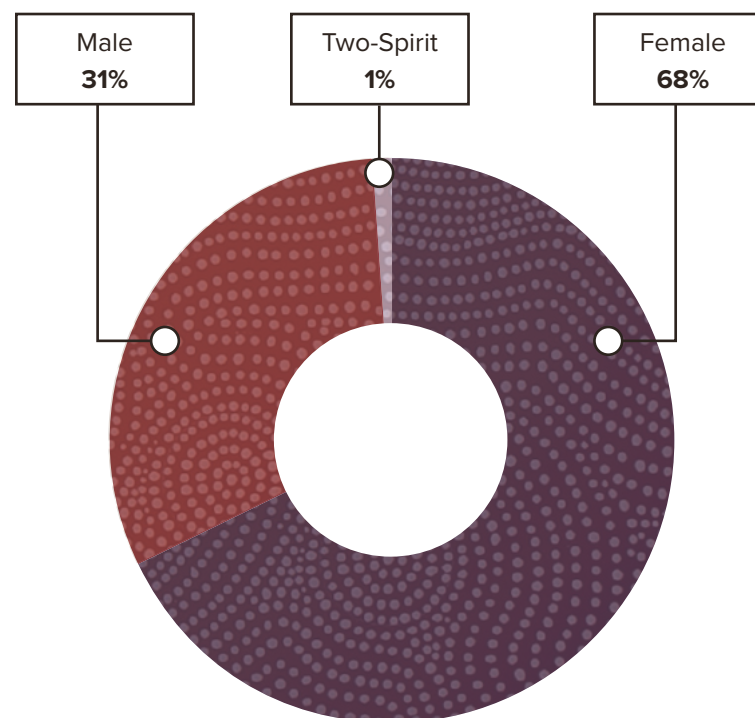
**Table 1. Other types of discrimination reported by victims of Indigenous racism (N=184)**

|                    |     |
|--------------------|-----|
| Gender             | 13% |
| Sexual orientation | 7%  |
| Age                | 16% |
| Disabilities       | 12% |

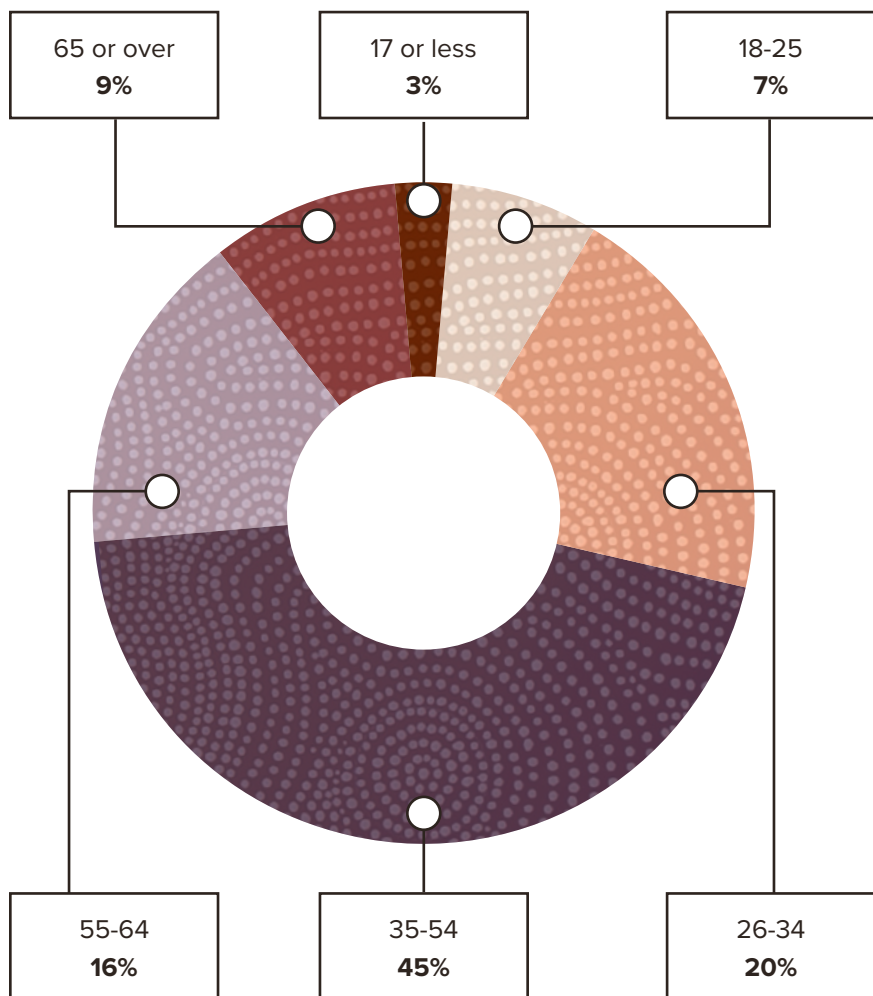
**Note:** the percentages are calculated based on multiple choice response options where each participant could choose additional sources of discrimination related to the reported incident.

Further analysis revealed that 26% of all reported incidents of anti-Indigenous racism also included one or more other types of discrimination, based on gender, sexual orientation, age, or disability. The story below is an example of this. It highlights multiple biases on the part of health professionals in an emergency department. Such a dismissive response could have resulted in a First Nations woman's death, if not for the advocacy of her child welfare (CAS) worker.

**Graph 2. Victims of Discrimination: Gender (based on self and witness reports; n=195)**



**Graph 3. Victims of Discrimination:  
Age (based on self and witness reports: n=157)**



“I was working with a mom. She was an older mom in her late 40s or early 50s. She has a history of mental health... not really any addictions. We [workers] were really worried about her... her daughter was concerned; her daughter was a pre-teen and actually had placed herself with an aunt because mom wasn't doing well.

This time again...they [hospital staff] wanted to send her [client] home. And because she couldn't give consent because she was completely in psychosis, I said 'There is no way you are sending her home, no way... run tests, I don't care what you have to do, I will stay here the whole time, but I am not bringing her home'. I said 'Because she is going to die if you send her home'.

So he, that doctor was very frustrated with me and was basically like 'We'll see' and took off. The doctor insinuated that she had overdosed on her medication and that 'She's irresponsible, she's always here', 'she probably just overdosed'. She was a heavier woman too, so they insinuated that she's not very ambitious, she should try and change her life. They had completely labelled her.

What it turned out... had nothing to do with her overdosing. It had to do with the fact that she had fallen because she has mobility issues, and she has mental health, like, severe depression especially around winter time, it was winter time... she will isolate herself is what she will do. And she has mobility issues. So she had fallen and the infection from the fall had become toxic.

I know if it would have been someone else who didn't look the way that she looked and hadn't had the mental health issues that she had that they would have ran the tests right away. But because of her mobility issues, because she was Indigenous, because they knew her, because she would go there often, because she was worried about her mental health, they just wanted to shrug it off.”

-Ottawa CAS Worker shared this story

The average age of participants in the SYS project was 42.3 years.<sup>70</sup> This differs from ages in national data sources. The 2016 census reported the average age of Indigenous people was 32.1 years, almost a decade younger than the average age in the non-Indigenous population (40.9 years)<sup>71</sup> and the average age of the SYS participants. According to the national reports, close to half (46%) of the Indigenous population is under the age of 25 in Canada,<sup>72</sup> whereas the majority of participants (65%) in

this project were above 35 years of age and only 13% of the sample were under the age of 25. This suggests that the SYS participants were older than the average Indigenous population in Canada.

As an example, the story below is of an older gentleman who was reluctant to go to the hospital but when he did, he was lost in the system for three days.

“I broke my ankle at home. I’d been hobbling around for about a week, ten days at home with a broken ankle... because I hate hospitals.

So, my wife convinced me to go to the hospital... This was Monday, so, Wednesday, I was to go in for day surgery. I arrived early, and they took me into the room. I changed, and I was waiting on the bed. 2:00 came by and nothing, 3:00 came by, nothing. The doctor came by and said that they lost my file... and he wouldn’t be able to perform the surgery because of swinging shifts. 4:00 came by and still nothing. And in the meantime, I still haven’t eaten... they took me from the waiting area there and moved me up to the third floor... the next day, I’m still waiting. And I waited all day. Getting restless... and, still, same thing. I fasted all day. And they gave me some sandwiches again

in the evening... I woke up Friday. I think it was about noon, finally they came in and said we’re going to take you to surgery. And the doctor, before they wheeled me in, the doctor said, ‘We lost you. We had no idea where you were’, I said ‘Well I was on the third floor. You moved me from the waiting room to the third floor and I was sitting up there for two days doing nothing but fasting’. And finally, eventually they got the surgery done. I believe that, had I been non-Native, I may have been treated a little different. Either that or it’s complete incompetency by the whole hospital staff... And I can’t believe... I’ve never heard of a lost file or of someone being lost in the hospital.”

-First Nations elderly male participant who was 66 at the time of the reported incident



# 78%

of SYS participants reported that they “sometimes” or “always” experience anti-Indigenous racism in the health care system.

The older age of SYS project participants raises more complex factors for consideration beyond the possibility that promotional materials did not reach enough youth or young adults. It has been previously noted that Indigenous people feel fearful, disrespected, and reluctant to access health care services. As a result, it is possible that they only seek help in the most critical instances, which could be a factor of aging. With age and if unaddressed, the medical conditions could be more complex and acute, requiring an interaction with a medical professional.<sup>73</sup>

As with the general population, the older you are, the more health conditions you might develop and the more you may need to access the health care system. For Indigenous clients, however, the more frequent the contact, the greater the exposure to possible discrimination. Therefore, with age, SYS participants may have accumulated multiple instances of racism and discrimination and reached a tipping point compelling them to share their stories with us. In fact, a majority of participants (78%) in this project reported that they *often* experience racism and discrimination in health care.

The stories of discrimination against younger individuals in the project (18 years old or less) were often reported by witnesses (62%), either the parents of children and youth or their support workers. Their experiences included less concern and care compared to non-Indigenous others, not being believed, and being ignored, dismissed, stereotyped, or verbally abused. One of the parents shared a story of racism against her daughter:

“She [my daughter] had a very large abscess that had developed as a result of her ruptured appendix and this abscess was over 11 cm... she was in an extreme amount of pain... medication was denied to her... an anesthesiologist walked through the door and said ‘Let’s get this very clear, you will not be walking out of this hospital without being in a lot of pain. Given your history, you will likely be an addict... in fact, you already are an addict.’”

**Note:** the Inuit youth has never tried drugs or alcohol in her life

## Education, Employment, and Racism

The following table presents information about the financial security and education of SYS participants.

**TABLE 2. Financial resources, employment and education**  
(Total does not add to 100% due to overlapping categories)

| Financial Resources                | Whole Sample (N=160) | Self-reported Racism Sample (N=129) |
|------------------------------------|----------------------|-------------------------------------|
| Have a job                         | 46%                  | 41%                                 |
| Ontario Disability Support Program | 28%                  | 30%                                 |
| Ontario Works                      | 22%                  | 25%                                 |
| Pension                            | 8%                   | 9%                                  |
| Employment insurance               | 2%                   | 2%                                  |

A combined total of 59% of SYS project participants had a post-graduate, university or college degree. Another 40% had secondary school education. Project findings make it clear that the attainment of higher levels of education does not protect Indigenous community members from incidents of aggression and racism in health care. One Inuk woman shared a story of being called stupid and handcuffed to the bed when she was brought to the hospital after a horrific assault and head injury.

“I woke up in the hospital and the police officer was there... I had 3 big scars on the back of my head... and one of the emergency nurses asked me what I do, where I work. I told her that I work for the National Inuit Women’s Association... and I am a 3rd year student in epidemiological... health research... and that’s when she said, ‘No, she’s stupid! There is no such thing as Epidemiology Research!’ And the police officer that was there... had me handcuffed to the bed. And I said, ‘What is this for?’ When I was the victim, and all I could say was ‘He tried to kill me’.”

**11%**  
University BA

**6%**  
University  
Post-Graduate

**40%**  
Secondary Education

**42%**  
College

Despite the relatively high levels of educational attainment for most of the participants, only 46% of respondents were employed. This pattern is similar to what has been stated through Statistics Canada's latest census reports.<sup>74</sup> Indigenous peoples, especially Indigenous women, continue to be underrepresented in Canada's labour markets. Even though moving to the city from rural communities might bring higher education and employment opportunities, many Indigenous people continue to experience lack of economic opportunities, social exclusion, discrimination and poverty. Based on our project, only 6% of participants made over \$60,000 a year, while 36% made under \$15,000 per year.<sup>75</sup>

It has been found in other research that a perception of somebody as being financially poor compounds already existing assumptions about Indigenous people as "drug seeking" or "system dependants/abusers who rely on public service too much". This can lead to dismissal or diminishment of health issues by health professionals in inner-city emergency departments.<sup>76</sup> Consequently, Indigenous people are worried about how they are going to be perceived when accessing health services and think about how to appear less rough or poor or intoxicated. One of the participants shared a story of going to the hospital with an open sore on his foot from boots that were too uncomfortable and too worn out. He tried to clean himself up before going up to triage.

"I... went to the bathroom, tried cleaning up the best I could, washed my hands, washed my face. I was a mess, a terrible mess... I cleaned up the best I could... I was coherent. Aware of what I was doing, aware of my surroundings, aware of my

behaviour, aware of my actions and I wasn't inebriated at all... I went up to the triage... I kind of felt slighted there... just because I looked undesirable... I didn't feel very good about myself at all. I don't know how long I waited but it was hours and hours and hours before I finally got admitted. They kept suggesting to me that I call detox... I was told repeatedly that there was no space available for me. But I also said that I needed some treatment for my foot."

-First Nations Male Participant

Another participant shared how worried he was about being perceived as a "drunk native person" after he had slipped on ice and broke his foot.

"... I knew it was broken but the ambulance driver... down played it... they asked the basic question - *have you been drinking?* And it was Christmas Eve, I had... some beers, I was like yes... I didn't even think... my heritage, my culture would come into this... when I said I had some beers... it's like they looked at each other like *yeah right* - do you know what I mean? So we're going to the [hospital]... got the wheelchair and... I'm soaked, my pants are soaked... I smell like alcohol... so it looks like I'm another drunk native person who's wet himself, you know, who's peed himself... and it's right off the bat... embarrassing and uncomfortable."

-Inuk Male Participant

## Intergenerational and Historical Trauma

Indigenous peoples live with high rates of intergenerational trauma as a result of systemic, state-sponsored events, programs, and policies. Several of these relate directly to health care and services, and historic patterns of abuse within those systems. Present-day impacts are far from over, as we heard from several participants in the SYS project.

The majority (78%) of participants reported that they either “frequently” or “sometimes” encounter racist incidents in the health care system. Several talked about their recent incidents of racism or discrimination

while also referencing other previous or historic events as evidence of multiple and cumulative traumas.

The phenomenon of Historical Trauma Transmission was studied and discussed by Maria Yellow Horse Brave Heart in 1998 and advanced by Cynthia C. Wesley-Esquimaux and Magdalena Smolewski in 2004. They argued that historical trauma is more complex than a singular event that might lead to the development of a post-traumatic stress disorder (PTSD):

.....

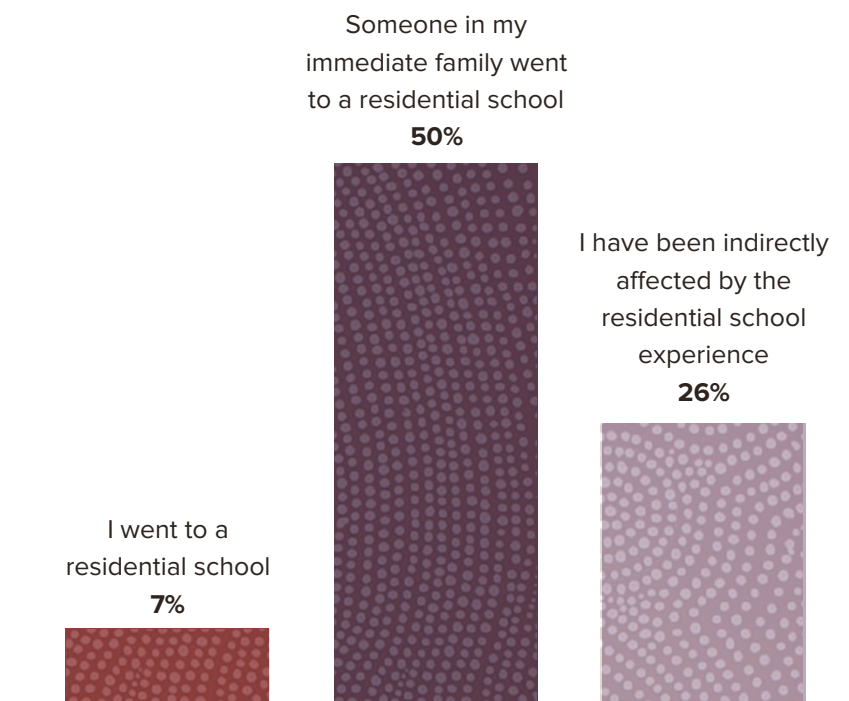
“the setting for chronic, complex or endemic PTSD first manifested itself in Aboriginal communities over 500 years ago [and it] has never disappeared from Aboriginal people’s lives, from their past, present and now from their future. These various forms of post-traumatic stress disorder are part of a historic trauma...emotional and psychological wounding across generations resulting from massive group tragedies<sup>77</sup>.... For Aboriginal people, there was never enough time in between various traumas to prevent the recall of traumatic memories still residing in their collective memory. With no access to resources to reformulate their culture and identity, the trauma became layered and cumulative, thus, affecting successive generations”.<sup>78</sup>

.....

The most widespread tragedy with long-term impacts is the system of forced residential schooling for Indigenous children in Canada. It lasted well over a century and ended barely twenty years ago. Thousands of Indigenous children died in those schools. Many of those who did survive were severely traumatized and disconnected from their families and communities.<sup>79</sup>

Half of the *Share Your Story* participants (see Graph 4) noted that someone in their immediate family had gone to residential school, while 7% had themselves been residential school students and 26% reported being indirectly impacted by the experience.

**Graph 4. Residential Schools Experience (n=171)**



**Note:** the above categories are not mutually exclusive; participants could endorse one or more item

As residential schools began to close, the forcible apprehension of Indigenous children continued by provincial child welfare authorities. Indigenous children were removed from their communities and placed up for adoption with non-Indigenous families during the 1960s, an era known as “the 60s Scoop”.

This practice of child apprehensions added to personal and collective traumas of Indigenous peoples with severe and long-lasting impacts on their sense of self and wellbeing. In fact, 48 SYS participants (29%) stated that they were personally impacted by the 60s scoop.

Sadly, the practice of child apprehensions continues to this day and it happens in hospitals and maternity wards. Mere minutes or hours after their birth, Indigenous babies are seized from their mothers through established systemic mechanisms including *birth alerts*—the practice that has permitted child welfare societies to alert hospitals about newborns perceived to be at risk and requiring their protection. Hospital staff, in turn, often without any basis for concern, call CAS thereby assisting child welfare social workers in seizing babies.

*“I was giving birth... they said they were going to give my baby a needle... they never came back, he [my son] never came back... it just happened so fast, they were mean to me.... They said, you’re already on your fourth one, you don’t need any.”*

-First Nations Participant

This controversial practice of *birth alerts* which has disproportionately targeted Indigenous families was recently banned in Ontario as of October 2020. Indigenous communities noted the ban as long overdue. They hope it will lead to an end to systemic racism, violence and discrimination against Indigenous women in both child welfare and health care settings, and a reduction in the number of children in care.

It is not just the traumas of forced child removal that is passed from generation to generation, but also a fear of health care institutions and professionals. In fact, the intergenerational and long-lasting impacts of trauma on individuals' perception of personal safety have been widely documented.<sup>80</sup> One SYS participant talked about how her grandfather's experience in a day school (see terms and definitions) has affected her own perception of health care, and the perceptions and reactions of her own child.

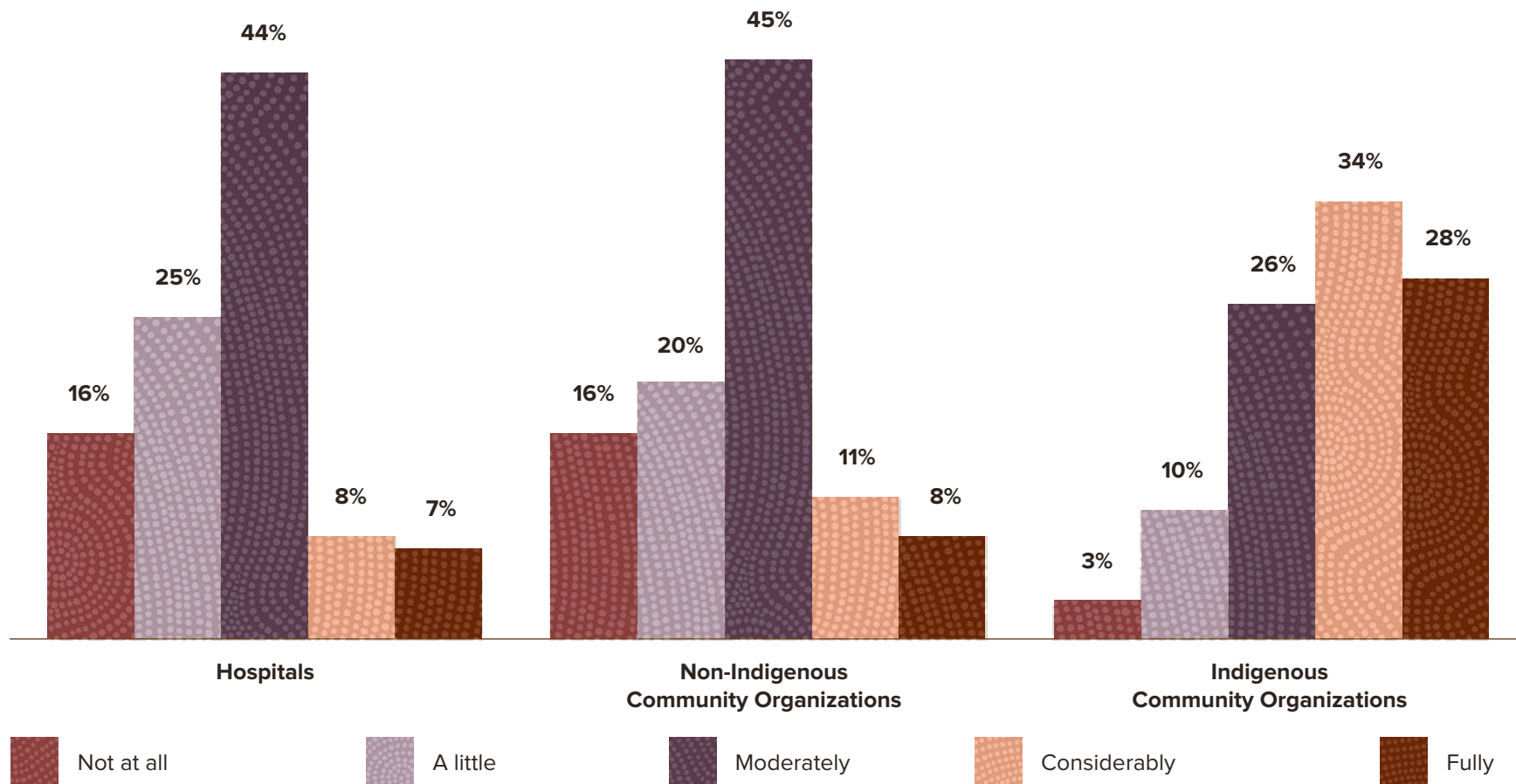
“For me to go see a doctor takes a lot of courage to begin with... My grandfather went to day school and he was sexually abused for most of his childhood... and his trauma also has to do with the medical system. From a very young age I can remember doing everything and anything to avoid going to the doctors... And I can now see it in my four year old... She has some of the same reactions I did... I think that was passed down from my grandfather, to my parents, to me, and to my daughter...”

-First Nations Participant

Graph 5 shows the level of trust in health institutions SYS participants endorsed. Higher levels of mistrust were reported towards hospitals and non-Indigenous community health clinics in comparison to Indigenous community organizations. More than a third (41%) reported they had little to no trust in hospitals. Only 15% indicated that they trusted them considerably or fully.

By sharp contrast, the trust in Indigenous community organizations was much greater, with 62% reporting considerable or full trust in Indigenous-led clinics and community health and social services. Only 13% reported little or no trust in them.

**Graph 5. Experience of anti-Indigenous Racism in Health Care System (Champlain LHIN): Indigenous Community Report-Level of Trust in Health Institutions**



## Part Two – Stories

The following section aims to describe and analyze the nature and range of experiences of racism and discrimination across the Champlain region and its system of services. Where did the incidents happen? What were the impacts of those experiences on physical and mental health and wellbeing? What is the ongoing relationship to access to health care services?

### Occurrences of Anti-Indigenous Racism Across the Champlain Region

Three hundred and fifteen stories of anti-Indigenous racism were collected from the Champlain region in late 2018 and early 2019. Of these, 73% were personal experiences and 27% were witnessed accounts; 55% of stories came from within the city of Ottawa and 45% from various parts of the Champlain region beyond Ottawa.

Of all the stories shared, 91% were rated by the research interviewers as clear cases of anti-Indigenous racism based on criteria developed by the research team.



# 174

Stories in urban setting (Ottawa)

# 141

Stories in rural setting (Cornwall, Pembroke, Renfrew)

**Table 3. Characteristics and Frequency of Perceived Racist/Discriminatory Behaviours of Health Professionals**

| Characteristics of Perceived Racist Actions of Health Professionals | Personal (N=221) |          | Witness (N=85) |          |
|---|------------------|----------|----------------|----------|
|   | Count            | Total N% | Count          | Total N% |
| Ignoring or being dismissive  | 170              | 77%      | 69             | 81%      |
| Lack of concern for you in comparison to others                     | 163              | 74%      | 69             | 81%      |
| Lack of attention to you in comparisons to others                   | 146              | 66%      | 61             | 72%      |
| Negative tone of the voice (angry, condescending, annoyed)          | 136              | 62%      | 60             | 71%      |
| Negative facial expressions (angry, condescending, annoyed)         | 136              | 62%      | 57             | 67%      |
| Ridiculing and condescending  | 126              | 57%      | 41             | 48%      |
| Not believed  | 124              | 56%      | 45             | 53%      |
| Short interaction with health professional                          | 114              | 52%      | 39             | 46%      |
| Longer wait time in comparison to others or standards               | 105              | 48%      | 44             | 52%      |
| Patronizing   | 88               | 40%      | 38             | 45%      |
| Refusing tests/procedures/medications                               | 84               | 38%      | 27             | 32%      |
| Blaming   | 64               | 29%      | 16             | 19%      |
| Racist remarks, name calling  | 54               | 24%      | 16             | 19%      |
| Coerced into taking medication or having a procedure                | 37               | 17%      | 16             | 19%      |
| Wrong dosage of medication  | 33               | 15%      | 9              | 11%      |
| Threatening   | 31               | 14%      | 17             | 20%      |
| Calling security or police without just reason                      | 17               | 8%       | 7              | 8%       |
| Calling child welfare based on an unfair judgment or assessment     | 13               | 6%       | 3              | 4%       |

## Behaviours

The incidents of racism documented in this project consist of diverse forms of discriminatory and negative behaviours by health professionals. They differ in severity and subtlety (overt vs. covert). Table 3 shows the frequency of discriminatory behaviours from service providers as experienced by Indigenous community members in encounters with them.

Overall, the stories shared in this project reflected a large majority of experiences where individuals were not believed, were ridiculed with condescension, were not given a lot of time and/or waited longer for help than non-Indigenous clients while seeking medical health services, and were patronized or blamed for their medical problems.

More than 60% of the stories shared the experiences of participants who were ignored or dismissed, not shown concern or attention in comparison to others, spoken to in a negative tone of voice or shown facial expressions of anger, condescension, or annoyance by their service providers.

In terms of medical treatment, 38% of stories noted the refusal of tests, procedures, and medications by medical personnel, while 17% of stories reported that participants felt, or were, coerced into submitting to a medical procedure, or given medication that they did not want. Further, 15% of stories reflected that, clients were given the wrong dosages or wrong medication.<sup>81</sup>

As reported in Table 3, there was a wide range in the frequency of negative behaviours of service providers. The most common behaviour was ignoring, occurring 77% of the time in personal accounts, and 81% of the time in witnessed accounts. The least frequently occurring behaviour was having security or child welfare called by service personnel (6% to 8% of the time).

The frequency of most discriminatory behaviors was validated by both groups of participants, those with personal experiences and those who witnessed them. There were notable distinctions between the two groups in the frequency of the following three reported behaviours: negative tone of voice; ridiculing or condescending behaviours; and blaming participants for their conditions.

Participants who shared their personal stories reported higher frequency of being ridiculed (57% of the time) and blamed (29% of the time), in comparison to the frequency of the same behaviours as reported by the witness group. Their reports noted being ridiculed at 48% and blamed at 19%. It is possible that relative proximity to the incident could be a factor in a bystander simply not hearing what is being said and the undertones of the message (e.g., ridicule or blame).

By contrast, the reports from the two groups revealed fewer incidents of hearing negative tone of voice (62%) or being threatened (14%) by those experiencing it, compared to the witness group. Witnesses heard negative tone of voice (e.g., anger, annoyance) in 71% of their accounts, and threatening behaviours in 20% of events. It is possible that over time, and with frequency, negative tone and threatening behaviours have

become somewhat normalized to those experiencing it, to the point of not even noticing it as much as a bystander might hear and see it.

The negative behaviours of service providers as recorded in this project also covered a range in severity of aggression or harm. Below is a story of an Inuk woman who had a tubal pregnancy and internal bleeding; she was dismissed, labeled as alcoholic, and sent home. This participant believed that she would have died if it wasn't for the intervention of Indigenous health professionals.

“... I was really in pain constantly for three days, without knowing that I was internally bleeding... they took me, they were just looking at me like I've been drinking, or that I've been drunk...Then, when I smelled... the hand sanitizer, I'm like 'Hey, someone's drinking hard liquor in here or what?' and then the nurse came up to me and told me 'I think it's just you, you've been drinking'. And I'm like, 'I've been in pain for three days, I haven't been drinking'... So, the doctor came... He didn't even bother to check my blood... or didn't even bother to check me thoroughly... I think he was looking at me like I am faking it... just because... I'm another Aboriginal or Inuk... So, I ended up walking out because they did not want to really check what's wrong with me or check my blood... so I ended up going to [Indigenous Health Team - IHT] and they ended up checking my blood. Within one hour they called me back and told me that I... [had] tubal pregnancy so I was internally bleeding for three days and never got help... but [IHT] got me to [the hospital] and... they took me in right away and did the surgery and they saved my life. I'll never forget that because that doctor was looking at me like I'm just another drunk. I'll never ever forget that...”

For Indigenous people who *do* have substance abuse issues and require medical help, the situation can also be dire. This was the case of a First Nations woman who reported that she was brought to the hospital by police because she overdosed.

“... and this time it was the fentanyl... usually, I don’t do that hard [stuff]... and I went down, and they brought me back with NARCAN and the police officer says ‘*Why don’t you just leave her for dead? Don’t even bother to try and bring her back’...* and then they dragged me downstairs and they made me sit up instead of laying down. On the gurney, they made me sit up and then they took me aside and they pushed me aside while everybody else is getting done and no one even checked on my pulse... and the doctor came in ‘*oh you just need a place to sleep’...* I don’t need a place to sleep, I got my own place. They didn’t even check my pulse... my heart... and all those people were going ahead of me... and nobody is checking on me: to see if I was okay or not, to see if I am dying or something. I could have died right there and they wouldn’t have cared.”

Covert incidents of racism and discrimination - the more invisible things such as ignoring or demonstrating a lack of concern for Indigenous patients in comparison to other patients - were reported more frequently by participants than overtly aggressive or harmful behaviours such as racist remarks, insults, name calling, inflicting pain, threatening, or calling security or child welfare authorities.

Overt racism was recounted by a First Nations man who was in pain for four days, called Telehealth Ontario, and was advised to go to the hospital immediately with a possible burst appendix. He was placed in the waiting room and security was called to guard him.

“... I walked into the Emergency Room – I was obviously hunched over, holding my stomach because of the pain that I was in...

They just took down my information, they didn’t do anything immediately, they just gave me some Gravol and told me to go sit in the waiting room. And so finally my pain intolerance got to the point where I actually started throwing up... they posted a security guard on me... And once they completed that they said *sit down in the waiting room* some more – yep, with the security guard watching me, of course... when they finally got around to dealing with me, I had actually been sitting in the emergency room for 6 hours...

And so she asks, ‘*does it hurt when I press here?’* and – she didn’t even press hard – she just started pushing on the surface and already I was screaming. She’s like, ‘*Okay yeah, that’s definitely looking like appendicitis. We’re going to get you in for surgery’...*”

Another First Nations man recalls checking himself into the hospital because of an intolerably severe sore on his foot. He described the abuse he experienced from one of the nurses.

“... He [the nurse] used to call me (French word for crack head), sometimes he'd come in and (French phrase translates to 'where are your feather?') 'Where are your feathers aujourd'hui? You don't have any feathers today.' He used to call me 'Chief' a lot. But (French phrase for) 'What do you want, Chief?'... thinking that I don't understand and he would repeat in English 'How can I help you today?' or 'What do you need?' but he wouldn't say it like that in French, he would say it (French phrase for what do you want Chief?)

So, I basically just took it. A lot of times I wouldn't even respond to him. I would just be lying in my bed and I would let him change the bandages on my foot and dress my foot again. There was a female nurse I don't know if she was a shift changer or she was new but she was French as well. And I could hear them talking French sometimes and that's when he said (phrase in French translates to just another crack head Indian)... they were talking derogatory about me, I knew I could understand some of the things that they were saying. And there was that other word it was the English translation of it is, is essentially, *these people disgust me*.

... he was very rough with my foot... very cold and impersonal and when he would change the bandage, I would ask him to be careful and he wouldn't be careful he

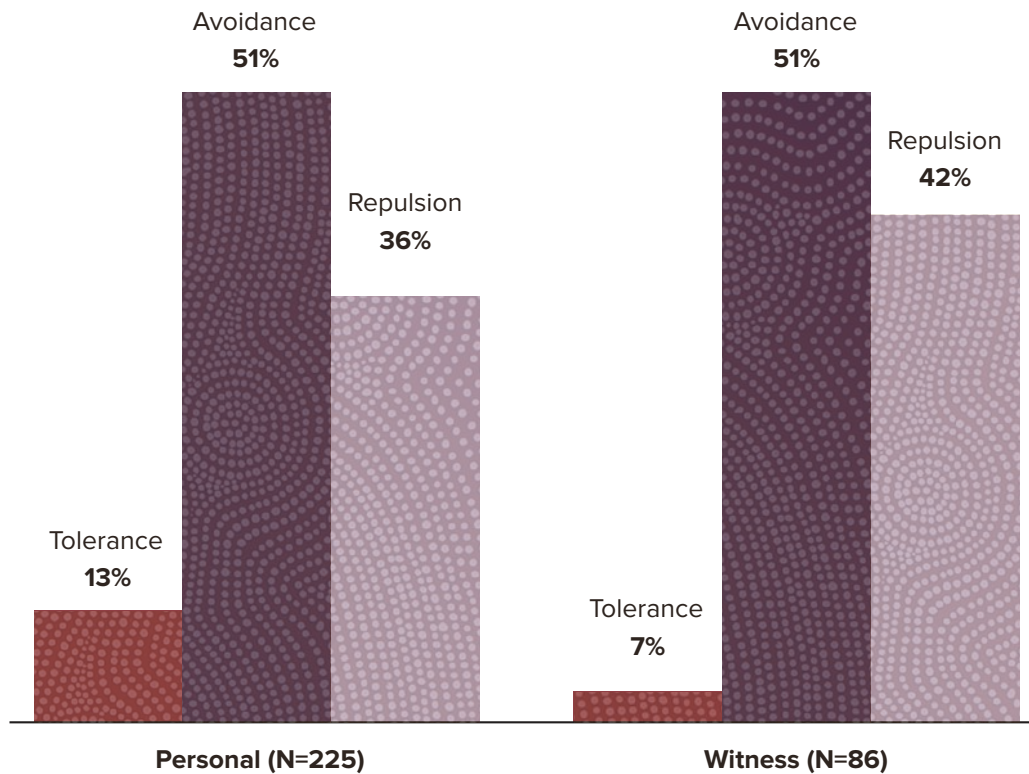
would just rip it off and slam my foot down. You know? Bang it, move it around, poke it, it really hurt. He'd start causing me physical pain, I mean the emotional pain of hearing him say those things about me, it didn't upset me as much as him being so rough... that freakin' nurse used to always come in and just smash, slam the door at night. Like you know I literally believe he woke me up on purpose, not just to check on me but, I know that that's their job but to intentionally, you know instead of 'Hello Mr. (removed name)' I would wake up and there would be somebody banging my foot so it would be... a rude and startling awakening and painful as well... I'm not a little guy but I know I must have looked, pretty, pretty, helpless.”

”

In preparation for this project, multiple definitions from various sources were considered before deciding on three categories for grouping negative responses or behaviours of service providers towards Indigenous people.<sup>82</sup> Interviewers were asked to rate each reported story using these three definitions: Tolerance, Avoidance and Repulsion. Graph 6 shows the results of interviewers' total ratings for personal, and for witnessed stories.

Based on the above listed categories of behaviour, 87% of personal stories were rated by interviewers as severe forms of negative response or harmful behaviours (avoidance and repulsion). Results were even slightly more damning from the perspective of witnesses, where 93% of their incident accounts were classified as avoidance or repulsion.

**Graph 6. Interviewer Report: Negative Responses to Others**



**Tolerance:** The service provider did their job and was not disrespectful, but was not warm, did not initiate a friendly conversation, and was not interested to know any details about the patient or the patient's situation.

**Avoidance:** The service provider was avoiding the client and the whole issue (e.g., limited eye contact, didn't pay attention, wasn't responsive to patient's questions, did not want to deal with the person). Other signs include, short interaction, ignoring, dismissive, passive aggressive tone.

**Repulsion:** The service provider clearly disrespected the patient, showed clear dislike, acted harshly towards the client, was threatening or condescending, blamed the client for his/her condition, and/or treated the client unfairly.

## Assumptions and Stereotypes

SYS participants believe that the poor treatment they experienced was a direct result of ignorance about Indigenous cultures, histories, and current realities. They believe that negative stereotypes about Indigenous peoples shape how they get treated by health professionals.

Historian Daniel Francis studied the issue of negative stereotyping. He wrote: “Lacking any real knowledge of Native people, non-Natives have felt free to imagine all manner of things about them. Indians were savages; Indians were natural mystics; Indians were militant warriors; Indians were disappearing; Indians were the original environmentalists... the Indian was a white man’s fantasy, a screen on which non-Natives projected their anxieties and assumptions about their place in ... the world.”<sup>83</sup> It is this mythology that shapes the manner in which both Indigenous and non-Indigenous Canadians understand themselves and dictates the ways in which people behave towards each other.

Through education, commerce, sporting events, and media, Canadians absorb a range of images based on stereotypes that displace accurate, respectful, truthful representations of Indigenous peoples.

In the athletic world, for instance, Canadians, like Americans, are financially and emotionally invested in sports teams with names like Redskins, Indians, and Eskimos. Sport franchises have recently and very reluctantly retired those three particular names, but the Braves, Blackhawks, and Chiefs remain.

Media and the arts have also often played contributing roles in cementing stereotypical images in movies, literature, and in the news. Beverly Slapin, co-author of “Through Indian Eyes: The Native Experience in Books for Children”, wrote about her own beliefs as derived from books she’d read as a child:

Like many others outside the Native world, I grew up with the prevailing stereotypes of the people. I learned that “Indians” whoop and holler and run around in little more than war paint and feathers, brandishing tomahawks and dancing on one leg; they scalp, torture and menace innocent settlers; they beat on tom-toms and live in “teepees”; their language consists of raising one hand shoulder high and grunting “how” or “ugh!”; and they are not women, men and babies, but “squaws”, “braves” and “papooses.” Then, as now, Indians jumped out from comic books, greeting cards, games and toys, food packages, advertisements, movies and TV. I can still see, in my mind’s eye, images of “Indians” attacking stagecoaches and covered wagons (and in my childhood nightmares, attacking me.... Little has changed...<sup>84</sup>

From the stories, the following common five stereotypes emerged as SYS participants provided examples of discriminatory assumptions as part of their lived experiences from health institutions across the Champlain region:

1. Indigenous people are racially inferior;
2. Indigenous people are diseased, addicted, and mentally unwell;
3. Indigenous people are a burden;
4. Indigenous people are angry and aggressive; and
5. Indigenous people are bad parents.

## STEREOTYPE #1

# Indigenous peoples are racially inferior.

The belief in Indigenous inferiority originated as a justification for claiming Indigenous land. Claiming sovereignty over North America relied on religious and intellectual canons that dehumanized Indigenous peoples as inferior, as inherently uncivilized, and at the same time it encouraged people of European origins or descent to see themselves as possessing a superior form of civilization—politically, economically, culturally, and spiritually. Canada as a nation-state inherited this belief system from its colonial founders and continued to create systems and structures, policies, and legal frameworks that defined Indigenous peoples as incapable of managing their own affairs.

There is evidence in this project that underlying revulsion, lack of empathy, and disdain still exist in the health care system and are clearly felt by participants who shared their accounts of racism.

*“Leave her, these are the native people, and she thinks that she’s more important than anybody else... these people are just junkies and alcoholics.”*

-Witness Nursing Student

Those were the instructions of an experienced nurse to a nursing student who had been trying to help a young Indigenous mother who just had an emergency C-section and needed help.

This was not the only account inferring that Indigenous people are inherently, genetically, biologically, and socially inferior. Consciously or unconsciously, too many in the health profession treat Indigenous patients with profound disrespect and quite differently than they would treat non-Indigenous patients.

*“I dislocated my shoulder and I had to go to the hospital to get it set again... I was in the waiting room for a long time like maybe an hour, not the waiting room but the little doctor’s room... I can handle a lot of pain, but the pain got to unbearable pain, and I started to cry out you know when you yell asking for help and a woman came in, a nurse, and I asked her how long it was going to be for the doctor to see me and she started using a mean tone... ‘Well you weren’t supposed to be taken off you brace’ and she started giving me shit and she said... ‘Why did you do that to yourself you should have listened to the doctor you shouldn’t have been coming back here’ and at one point she had said... and I’ll always remember this - ‘You people never listen to anything that you’re told’ and... I asked her what do you mean *you people* and she said ‘You know what I’m talking about’ she says ‘You people are stupid’.”*

-First Nations Male Participant

## STEREOTYPE #2

# Indigenous people are diseased, addicted, and mentally unwell

“... it is a bias that people tend to have when they see an Aboriginal person and they think right away – *drugs, alcohol, poverty, mental health.*”

- Métis Female Participant

From the beginnings of Canada onward to modern days, generalized discourse about Indigenous people as “uncivilized savages” has shifted to thinking about them as lower class, poor, dirty, not very smart, obese, and rife with communicable, or simply chronic, diseases brought on by poor lifestyle choices.

“... He overheard nurses and the doctor mention that he is what they call a HONDA and what that means is high blood pressure obese native diabetic alcoholic... and he was not too pleased about that when he found out what that meant and he never he never went back...”

-Witness Participant

“... Just hearing stuff about like being overweight that most natives are... I went there because some guy beat me up... so they said something like about natives, like *they're all drunks and overweight and have health problems like diabetes and stuff. But I wasn't diabetic, I was just overweight...*”

-First Nation Female Participant

Since the fur trade that formed so much of Canada's earliest economies, and also informed its earliest interactions with the First peoples of the land, there has evolved a pernicious and persistent belief that Indigenous people are more susceptible to alcohol dependency than others. As a result, there has evolved a damaging stereotype of the “drunken Indian,” a continuing go-to diagnostic assumption in many service encounters with non-Indigenous health professionals. The consequence of such a harmful stereotype is that Indigenous clients often do not receive the care or attention required to manage actual health crises.

“Apparently, he left his keys at a friend’s house and they weren’t answering their phone so he tried opening the window that was a bit open. And the glass broke. So, we had to call 911 to get an ambulance and when we got to the emergency, I noticed these people were making strange faces as if we were not welcome. We went there by 11:30 at night... he had a really bad cut and he was bleeding... like, a lot of blood. His bandage was full of blood, but the nurses and doctors weren’t doing anything... They started calling him an alcoholic and saying that he was intoxicated then started saying that these are crack head or Eskimo. All these names were said to him and he didn’t like, we didn’t feel equal, we weren’t treated right. From there, I started pressing for the nurses to come to see him, but they ignored me and they kept walking by... they were saying something in French and at the end they would say ‘Eskimo’. And from there we waited... they finally disinfected the wound and numbed it and stitched it. And, we finally went home at 5:30 in the morning.”.

-Witness Family Member

Some Indigenous people have chronic health conditions, mental health issues, and/or substance dependency. However, it is absolutely *not* true that *all* Indigenous people have some or all of the above or come from dysfunctional backgrounds. Therefore, assumptions that any Indigenous person is drunk or drug seeking or unworthy of quality medical attention is a failure by health professionals to fulfill their pledged responsibilities to provide care.

“I had a bad hernia... and I was in so much pain and they thought I was a drug addict wanting drugs... just because I’m Aboriginal they thought I was there for something other than the actual pain...”

-Inuk Female Participant

Duty to care standards demand proper and equitable assessment of biomedical conditions. Ignoring, blaming, or punishing patients for their conditions based on malignant stereotypes is racist and a breach of professional oaths.

### STEREOTYPE #3

## Indigenous people are a burden.

The system of separateness and isolation that Canada imposed on Indigenous peoples was part of the historic plan to displace them, or centralize them, away from vast traditional territories to much smaller tracts of land. Many of these smaller tracts, often formalized as reserves, were intentionally resource-poor and often remote, with limited educational and economic opportunities.

For their vast, resource-rich lands on which the Canadian economy has been built, Canada has compensated Indigenous peoples meagrely, with laws and policies that assign under-resourced social programs specifically for Indigenous people, including inequitable health services. General ignorance or misunderstanding of this history has often left non-Indigenous Canadians to complain that Indigenous people get things for free that others do not. Yet Indigenous societies bear the actual burden of such policies, with all that they have lost by way of lands and opportunities, and with all that has been put on them by way of the judgments and labels.

SYS project participants gave glaring examples of the weight of such labelling. As patients, they were refused medications as soon as service providers discovered that they were entitled to Non-Insured Health Benefits (NIHB), or they had care withheld, or they were questioned about why they were brought to Ottawa facilities from rural or remote regions, and at times were asked to find a different service provider that deals with Indigenous people.

**Story 1:** “the ambulance was called because the patient had dislocated his shoulder. The hospital service providers did not give him pain medication. He self-disclosed his Indian status to ask if his prescriptions would be paid for. He was told that all he would need is Tylenol/Advil. The participant felt like the amount of pain that he was in was dismissed by the hospital staff.”

**Story 2:** “the participant had a bad infection, which was close to flesh-eating disease. It was caused by a very small cut from sharp metal blinds. He went to the hospital to get treatment. It turned out that he needed antibiotic. He was told when he was at the hospital: ‘You don’t even look native.’ The hospital staff were making derogatory comments about him getting free dental and medication benefits because he was native.”

-Interviewer’s report for First Nations male who did not want to be recorded

“...and what really upset me... telling me that I should seek support at my reserve and asking why I left...”

-First Nations Female Participant

*“You people are all the same. I am sure there are doctors that deal with Inuit. He said you know, ‘you should go there’.”*

-Inuk Female Participant

## STEREOTYPE #4

# Indigenous people are angry and aggressive

Media and the arts have often played contributing roles in cementing stereotypical images in movies, literature, and in the news. In recent years such social movements as *Idle No More*, and ongoing pipeline, development, and harvesting debates have generated media content and images casting Indigenous people who legally protest perceived injustice as radicals, militants, troublemakers, or terrorists.

“I have witnessed that person trying to advocate for themselves being told that they’re being argumentative when they’re speaking in a tone no more than I am speaking to you right now. Because they are visibly Indigenous they’re being argumentative and if they don’t settle down security will be called and security is called.”

-Witness Service Provider

Caricatures can stick for a long time. They are part of the legacy of the Canadian system of beliefs and values that for decades refused to acknowledge Indigenous people legally, as persons. Indigenous Canadians were the last in the country to get the right to vote, while also being deprived of the right to raise their own children. As the Truth and Reconciliation Commission (TRC) reported, Canada’s political leadership had concluded that they had to be contained for their own good and for the safety and wellbeing of the country.<sup>85</sup>

Such inherited beliefs are painful and injurious to the Indigenous people targeted. They may also set the stage for health care professionals to react by calling security or police whenever Indigenous patients become upset, or frustrated, or even assertive as they advocate for themselves. This project has documented instances of this, as well as patient perceptions of being forcibly sedated without just cause or consent.

“I was in the hospital because I had pain in my abdomen... I had a C-section so it was really painful... it was a nurse... she put me in an isolated room... when I was ready to go in to see the doctor and I wasn’t even being very loud. And she kept telling me to *be quiet* and even though I was in pain, I mean, like it wasn’t very nice of her to keep telling me and being rude and having a mean demeanor and keep telling me to be quiet and I wasn’t even loud... she ended up having like an intravenous at the time they were giving me fluid, and she put like a little baggy of something... I don’t know what it was... but she ended up giving me something else for me to calm down and I wasn’t even aware of what it was...”

-First Nations Female Participant

## STEREOTYPE #5

# Indigenous people are bad parents

Some stereotypes have taken root in legally sanctioned government policies, spreading widely for generations. The earliest proclamations about Indigenous people as ‘bad parents’ came straight from the top... from Prime Minister John A. Macdonald back in the 1800’s. He justified the residential school system with this racist stereotype about Indigenous parents:

**“When the school is on the reserve the child lives with its parents who are savages... Indian children should be withdrawn as much as possible from the parental influence, and the only way to do that would be to put them in central training industrial schools where they will acquire the habits and modes of thought of white men.”**

- Sir John A. Macdonald, 1883, House of Commons

When the residential school era finally began to wind down in the second half of the 20th century, it was simultaneously replaced with child welfare practices that continued to remove Indigenous children, perpetuating the image of all Indigenous peoples as incapable parents. This includes the previously-mentioned 60s Scoop of adoptions into non-Indigenous families, and most notably, the current child welfare system that has the greater numbers of Indigenous children in care than at the peak of the long residential school era.

With so many Indigenous children now in the child welfare system, the 60s scoop has been replaced with what is now widely known as “the Millennial Scoop”. This is the latest in a century and a half of continuous federal, provincial, and territorial laws, policies and practices that deprive Indigenous parents of the responsibility and opportunity to raise their own children. *Mother blame* is used by child-welfare authorities and health professionals to remove children from women deemed to be bad mothers, when the real issue is often as a result of poverty. The assumptions and language of mother blame is embedded in policies such as “the best interest of the child” which then justify the removals of children by federal and provincial authorities.<sup>86</sup>

Indigenous women in particular, have been constructed as bad mothers in such a way that the taking away of children by state authorities or sterilization of Indigenous women through the 20<sup>th</sup> century was not only seen as natural, but also completely appropriate. Reported by a witness, below is a disturbing account of a teenage girl who was being chemically sterilized, based not only on the assumption that her parents are bad, but also that she is promiscuous and would get pregnant if there is no medical intervention.

“I was standing by the triage nurse, in the back of the emergency room where the ambulances come in. The paramedic had just brought in a young Indigenous person, who was living in a group home; who had called 911 because she was thinking about taking her life. When the nurse and the paramedic were discussing her medical history, they listed 5 or 6 birth controls, that the child who was about 14 was being prescribed and taking, all at the same time.

The nurse stated *that is chemical sterilization*. And then the paramedic said, ‘Yeah well, you know these people, they raise themselves, and if the doctors need to do that, then the doctors need to do that.’ And the nurse said, ‘You’re right, she probably had no parents in the home. And this is what the doctor has done to avoid having another child by a teen parent.’ And the patient was a very nice girl, but she was not treated very well when she came in.”

-Witness Participant

The removal of Indigenous children, sterilization of Indigenous women, together with stereotypes that have until recently permeated school curricula, has fed societal beliefs that Indigenous children are better off without their parents. Indigenous families still carry that burden and associated deep fears today.

In this project, young parents shared stories of being ignored, rudely spoken to, and blamed for any condition a baby exhibited in maternity wards or emergency departments. In most reported cases, health professionals pressured parents into submission by either threatening to call the Children’s Aid Society (CAS), or actually making that call, with the intention of having a child removed with questionable cause.

“I had my first born... My partner and I were at the hospital... where she was giving birth and after she gave birth we were both so exhausted cause we were both staying awake all night... so the nurse comes up and says we can sleep all night – she’ll watch over the baby overnight. We woke up and then the staff said... your son vomited while you were asleep and you didn’t do anything about it... two workers in the room trying to get us to sign him over to CAS... they said we were careless we weren’t ready for our baby...”

-Inuk Male Participant

## “Hot Spots” Across the Champlain Region

**Organizations and Institutions.** Hospitals, both in Ottawa and outside of Ottawa had the highest percentage of identified instances of anti-Indigenous racism and discrimination at 70.8% in the urban setting of Ottawa and 65.2% in rural communities such as Renfrew and Pembroke (see Table 4).

**Table 4. Frequency of Anti-Indigenous Racism by Type of Organization**

| Type of Organization  | Urban (Ottawa) |       | Rural (Outside of Ottawa) |       |
|---|----------------|-------|---------------------------|-------|
|   | Frequency      | %     | Frequency                 | %     |
| Hospitals   | 121            | 70.8% | 86                        | 65.2% |
| Community Services (family clinics, private doctor’s office, mental health, addictions and social services, paramedics) | 32             | 18.7% | 31                        | 23.5% |
| Community Specialized Health Care (dentists, optometrists, etc.)  | 6              | 3.5%  | 4                         | 3.0%  |
| Other Institutions and Businesses (schools, detention, senior residence, group homes, pharmacies, etc.)                 | 12             | 7.0%  | 11                        | 8.3%  |

Community health services, including community health centres, family health teams, and private doctors’ offices accounted for the second highest reported frequency of anti-Indigenous racism and discrimination in both urban and rural settings.

Other institutions and businesses where health care was provided, such as detention centres, seniors residences and pharmacies, accounted for the third highest category of organizations where anti-Indigenous racism was reported. These incidents were reported more frequently occurring in the city as opposed to rural communities.

“[in pharmacy] there’s always new staff coming and going and they never treat you the same... they always treat you like you’re someone lesser than a person... like you’re a second class individual.”

-First Nations Male Participant

When comparing the rate of racist incidents between urban and rural settings, there were no considerable differences between the percentages of racism related to different types of organizations or the rank order of the organizations.

**Services and Departments.** By far, the highest incidences of anti-Indigenous racism (43%) was experienced in hospital emergency departments. The second highest percentage happened in the community health clinic setting, where it was 16%. An additional 10% of anti-Indigenous racism was experienced in the hospital maternity ward (see Table 5).

Based on an analysis of frequency, two departments in hospitals (emergency and maternity) as well as two areas of health service provision in the community, (community health clinics and paramedics), are identified as the hot spots for anti-Indigenous racism.

### The “Hot Spots” across the Champlain region were:

**In Hospitals:**

1. Emergency
2. Maternity

**In Community:**

1. Health Clinics
2. Family Health Teams
3. Paramedics

**Table 5. Frequency of anti-Indigenous Racism by Service or Department**

| Racism by Service/Department | Count | Percentage |
|------------------------------|-------|------------|
| Emergency                    | 128   | 43%        |
| Health Clinic                | 48    | 16%        |
| Maternity                    | 29    | 10%        |
| Paramedics                   | 14    | 5%         |
| Mental Health                | 13    | 4%         |
| Dental                       | 9     | 3%         |
| Surgery Unit                 | 9     | 3%         |
| Specialist                   | 9     | 3%         |
| ICU                          | 6     | 2%         |
| Diagnostic                   | 6     | 2%         |
| Social Services              | 6     | 2%         |
| Optometry                    | 4     | 1%         |
| Pharmacy                     | 4     | 1%         |
| Other                        | 4     | 1%         |
| Neurology                    | 3     | 1%         |
| Inpatient                    | 3     | 1%         |



**Service Providers.** SYS participants were asked to identify the ethnicities of the health professionals they had dealt with or witnessed. The participants noted in 280 interviews they believed 81.1% of service providers were white Canadians, with 62.5% being anglophone and 18.6% being francophone. The other ethnic groups that were identified comprising more than 1% of reported incidents included East Asian (6.4%), South Asian (3.6%), other white (2.5%), Black or African origin (2.1%), and Arab (1.8%).<sup>87</sup>

The stories shared in this project are all accounts of individual interactions with a particular service provider or a group of service providers. While the responsibility of service providers who carry racist beliefs and display racist behaviours is clear, it is equally important to examine the responsibility of bystanders (e.g., other employees, supervisors), and health institutions where harmful behaviours occur. More specifically, we need to look at available mechanisms (e.g., complaint processes) and their effectiveness to address harmful behaviours of individual service providers and the impacts of these behaviours on individuals seeking services.

The presence of effective mechanisms to handle and address clients' complaints was not directly examined in this project. However, some of the stories revealed that the culture of some health institutions do not promote self-reflection and receiving negative/corrective feedback from their clients. On the contrary, those SYS participants who attempted to complain generally felt dismissed or ignored, or they were afraid to complain because they felt that this would make matters worse for them or their family members.

“...the lady who does the surveys came around... and asked, ‘How was your experience at our hospital?’ and I was trying to tell her ‘It was horrible, nurses are negligent...’ and she said, ‘Oh, that’s not what I was talking about, how was your surgery?’ I had to tell her that I was being discriminated against and she completely ignored that... My surgery had nothing to do with the overall experience... she wouldn’t let me to complain... She was ignoring me. And I said the surgery was okay because I was highly medicated what else can I say about that? I could not complain about what just happened? I was completely dismissed.”

-SYS First Nations Participant

“I made a conscious decision to make no complaints while we were in the hospital because when you are in the hospital 24 hours a day you are very vulnerable... it was very apparent, there were many, many incidences of unconscious racism that were occurring that we couldn’t say anything about... really, we needed to protect our daughter first and worry about our values later.”

-SYS Witness Parent



**73%**

of SYS participants reported the experience had a considerable or extreme negative effect on them.

### **Impacts of Racism on Mental and Physical Health**

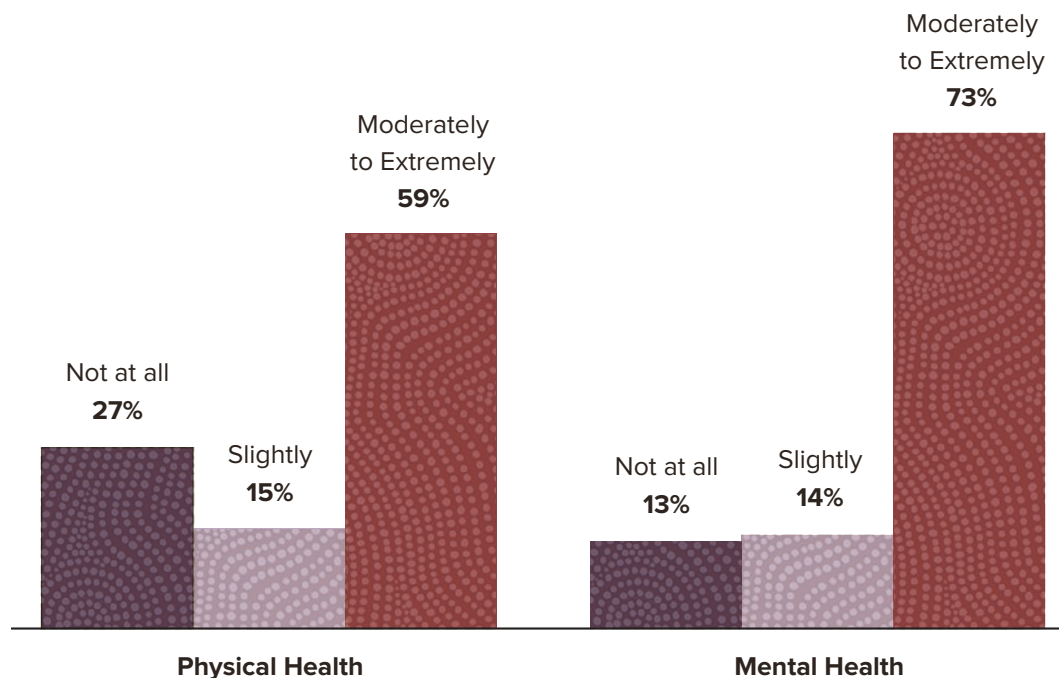
The effect of anti-Indigenous racism and discrimination on mental and physical health of SYS participants were examined through two questions.

The first question was to what extent the incident that they experienced had affected them negatively.

Of the responses, 22% noted that they were somewhat and moderately affected. Only 10% believed the reported experience had little impact on them.

The second question asked participants about their overall experience of racism and discrimination in the health care system, and the collective impact of these experiences on their physical and mental health. The graph below shows the response to this inquiry.

**Graph 7. Negative Effect of anti-Indigenous Racism on Physical and Mental Health**



For physical health, clearly more than half (59%) of respondents felt that their experiences of racism and discrimination had negatively impacted their physical wellbeing. Even more significantly for mental health, nearly three-quarters (73%) of respondents, reported that their experiences in the health care system had negatively impacted their mental wellbeing.

These findings are consistent with numerous reports published in Canada and around the world demonstrating harmful effects of anti-Indigenous racism on both the physical and mental health of Indigenous people. The physical health impacts include increased levels of serious injury, disability, high blood pressure, and risk of premature death. The mental health effects involve elevated levels of stress, depression, anxiety, symptoms of post-traumatic stress disorder, increased substance use and associated shame, diminished self-confidence and lowered self-esteem.<sup>88</sup>

## Racism and Access to Health Services

Indigenous people in this project generally do not often seek health care services as a preventive measure. Rather, they seek help when a serious intervention is required, but still only when they have to in the most critical instances, due to their lack of trust in the system as

identified earlier in this report.<sup>89</sup> As a front-line worker explains below, ongoing mistreatment, aggression, and stereotyping that results in poor care, leads to a disinclination to seek help again. This can result in acute conditions that require emergency care.

“... I’ve watched it happen. I’ve heard the stories from my beautiful brown siblings about the kinds of things that they are experiencing in the health care system. And how people will avoid going to doctors, avoid seeking health care because they just don’t want to expose themselves to that [s\*\*\*] anymore, they don’t, it’s exhausting. So then what happens is they end up in an ER because something has gotten so bad for them finally that they can’t avoid it; and ER is a stressful place anyways. You’re not getting the best of anybody whether going there for services or the people providing service because they’re over worked...”

- SYS Witness Participant

We asked each participant who shared their personal story whether or not they would go back to the same service provider. Seventy percent of the participants stated that they would not return to the same service provider. Furthermore, when we asked whether or not they would return to the organization where the discrimination occurred, almost half (47%) stated that they would not.

Among those who answered that they will go back to the organization or department again (n=107), 72 participants indicated that they would *not* go if they have other choices, and 23 participants stated that they will go because there are other service providers in those organizations that are good. The rest (12 participants) in this group provided an alternative explanation (e.g., I want to show my strength) or did not provide a reason as to why they would return to the same organization or department.

This project further validated the negative impact of experiences of anti-Indigenous racism on willingness to access future health services. Participants were asked to consider all of their experiences of racism and discrimination in the health care system and report whether or not they have reduced their use of health services because of these experiences. Close to three quarters of them, 69%, reported that they had.

Reducing interactions with the health care system might minimize incidents of racism and discrimination and especially the impacts of repeated exposure to it. But it will not address the fundamental right and need of Indigenous people to access and receive equitable health care services. The risking of one's health is not a remedy for a systemic failure within health institutions to truly meet the needs of Indigenous peoples and communities.



# 69%

of SYS participants indicated that they reduced using the health care system as a result of racism and discrimination

# 82%

of these participants reported that they moderately to significantly reduced using the health system

# Summary and Conclusion

The conclusion is clear. There is a serious problem with racism and discrimination within health institutions across the Champlain region. Anti-Indigenous racism and discrimination permeate the system and are institutionally tolerated. It is compromising the health of patients. Lives are at risk. Priority action to change systemic racism within the health care system of Ottawa and surrounding areas is essential and urgent.

The findings within this report were gleaned from more than two hundred individuals who engaged in the SYS project between November of 2018 and April of 2019. They reported 315 unique incidents of racism in health institutions across the Champlain region. Over half of these incidents, 59.4%, occurred within the last two years, and 84.4% within the last seven years. Incidents occurred so frequently that 78% of participants reported they regularly experience racism when accessing health services. Three quarters of participants reported actively trying to reduce their interactions with health professionals as much as possible, even at the risk of their own health, to avoid racist treatment. The volume and patterns of incidents described indicate that they are not singular events, but rather part of a systemic reality.

Specific key findings from the SYS project demonstrate the widespread failure of the health institutions across the Champlain region to meet the needs of Indigenous peoples:

1. Experiences with racism and discrimination have been happening for years and continue to occur today;
2. Individuals with darker skin tones and who are easier to identify as Indigenous are more likely to experience racism;
3. Negative stereotypes about Indigenous peoples, including notions of Indigenous racial inferiority, are evident in the behaviours of health professionals responsible for treating Indigenous clients;
4. Reported behaviours of health professionals range from overtly to covertly racist:
  - **Overt Racism:** name calling, inflicting pain, neglectful misdiagnosis, calling child welfare or security without just cause;
  - **Covert Racism:** ignoring, inequitable levels of care or attention, denying or withholding medications and/or treatment.
5. Hospitals have the highest frequency of reported racism;
6. Complaints about racist service providers are often dismissed by administrators, so racist misconduct is not properly addressed;
7. Anti-Indigenous racism negatively impacts the health and wellness of Indigenous people; 60% of participants believing their physical health has been negatively affected; 74% that their mental health has worsened;
8. Collectively, these experiences have led to a lack of trust in, or willingness to access health services in the region; and
9. Collectively, these experiences have caused Indigenous people to delay or avoid timely, essential care.

## **The data is unequivocal:**

- It is supported by a substantive body of individual personal experiences and witnessed accounts.
- It is further cross-validated by participants' answers after they shared their stories and corroborated by interviewers' ratings.
- It is analyzed with reference to decades of national and international government-sponsored, independent, academic and media reports, all detailing context and examples of systemic racism, and the officially-sanctioned thinking behind it.

The new data in this SYS project again reveals that discrimination and racism are not artifacts of the past, or happening somewhere else. They are real and part of everyday interactions with health professionals working in clinics, emergency rooms, maternity wards, social service referral agencies, and paramedic services across the Champlain region. And they add to the existing burden of intergenerational trauma and multiple losses already experienced by Indigenous peoples in this country, compounding health-related impacts and complications.



# Recommendations

# Recommendations

The Wabano Centre for Aboriginal Health has worked in partnership with the Ottawa Aboriginal Coalition, with financial support from Ottawa Public Health to develop this project in a manner that would be consistent with Wabano’s own vision.

“we envision a world in which all First Nations, Inuit and Métis peoples have achieved full and equitable access to the conditions of health including: pride in ancestry, cultural reclamation, peace, shelter, education, food, income, a stable environment, resources, and social justice.”

This statement is a clear affirmation of the right of First Nations, Inuit and Métis peoples to quality health care as a fundamental human right. That right, and the Wabano vision, are also mirrored and further articulated in Articles 21 through 24 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Key phrases in those Declaration Articles include:

“... Indigenous peoples have the right without discrimination, to... health and social security... Particular attention shall be paid to the... needs of Indigenous elders, women, youth, children and persons with disabilities... and... full protection against all forms of violence and discrimination... the right to be actively involved in developing and determining health... and other... programmes affecting them and... to administer such programmes through their own institutions... and... the right to access, without any discrimination, to all social and health services. Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health...”.

Since Canada has fully endorsed UNDRIP, the Declaration also naturally presents itself as a central guiding vision for the entire health care system across the Champlain region.

This project, however, was undertaken because First Nations, Inuit and Métis peoples were registering serious concerns about how their human and Indigenous rights were *not* being respected in how they were being treated by health professionals and health institutions across the Champlain region. The personal testimonies captured in the SYS research speak very clearly to the many forms of anti-Indigenous racism and discrimination present in our local and regional health care system and, the high cost that these experiences have on Indigenous peoples.

Collaboration is key to the recommendations that follow. Ontario Health – the provincial agency tasked with connecting and coordinating Ontario’s health system to help ensure that Ontarians receive the best possible care – is the focus of all recommendations. It is acknowledged however, the Ministry of Health – who sets the strategic directions and priorities for Ontario’s health system and provides funding to support the delivery of care in the Ontario Health – East region are also a focus of the recommendations.

The proposed recommendations aim to bridge jurisdiction. The Ottawa Aboriginal Coalition is confident that Ontario Health and the Ministry of Health will collaborate to devise workable solutions that respond to each of the recommendations.

The recommendations that follow are expressed under seven themes drawn from familiar cycles of planning and accountability. This is to ensure a broad understanding that specific new commitments to address discrimination and anti-Indigenous racism are not meant as an ‘add-on’ to regular duties and services, ‘as time and resources allow’. Rather, going forward, the intent is to incorporate and operationalize anti-Indigenous racism goals as an integral part of the ongoing cycle of service delivery, and part of the ongoing process of service improvement to Indigenous peoples across the Champlain region.

The themes also correspond well to the fundamental values that are often described as “The Seven Sacred Teachings” or “The Seven Grandfather Teachings”. These are indicated and coloured in brackets to accompany and underscore the value of each theme.

Each theme then includes a statement of strategic purpose, and a list of suggested actions. Some of the actions also suggest specific steps or measures for consideration.



## RECOMMENDATION 1:

# Courage

## Ownership

### Strategic Purpose:

#### Galvanize Ontario Health's commitment to:

- Serve and support the Indigenous right to health;
- Offer kind and culturally competent care; and
- Provide equitable service provision and quality of care for Indigenous clients.

### Action:

- 1.** We call upon Ontario Health to support and contribute to a communications strategy that:
  - Denounces anti-Indigenous racism and discrimination harms of the past and present;
  - Declares intention to eliminate anti-Indigenous racism and improve access to quality and equitable health services; and
  - Acknowledges that improvement means change from status quo.
- 2.** We call upon Ontario Health to identify priority action-planning to eliminate anti-Indigenous racism and discrimination to address “hot spots” for discriminatory and racist behaviours. These include :
  - Hospital emergency departments and maternity wards;
  - Community health clinics and family health teams; and
  - Paramedic services.
- 3.** We call upon Ontario Health to establish a strong tone from the top. Institutional leadership and collective accountability must inspire all to embrace essential change.

## RECOMMENDATION 2:

# Respect

## Commitment to Equity & Collaboration

### Strategic Purpose:

**Confirm Ontario Health's commitment to ensuring that all Ontarians receive the best possible care by:**

- Reaffirming the contributions and commitment of local health institutions to the vision of eliminating anti-Indigenous racism and discrimination;
- Endorsing the essential expertise of Indigenous health leaders, institutions and service providers in the delivery of culturally competent and trauma-informed care and service; and
- Improving upon the delivery of equitable, responsible and reciprocal health services for Indigenous people by building and maintaining meaningful relationships between Indigenous and non-Indigenous health leaders, and communities.

### Action:

1. We call upon Ontario Health to engage regularly and systematically with local Indigenous health service partners and communities involved in the delivery of health services to identify, develop, and support champions of change within the system/sectors;
2. We call upon Ontario Health to act urgently to reduce harm and improve health care services for Indigenous people by jointly developing and implementing a comprehensive anti-Indigenous racism and discrimination strategy, including the "hot spot" areas identified in SYS project;
3. We call upon Ontario Health to define and communicate equitable health care service delivery standards and expectations;
4. We call upon Ontario Health to engage Indigenous health service partners and communities in designing and delivering service programs that:
  - Acknowledge and affirm the value of cultural knowledge and competency;
  - Improve system-wide understanding of Indigenous histories and related service experiences; and
  - Empower all service providers to stand against racism and discrimination.
5. We call upon Ontario Health to institute a comprehensive review of existing policies and procedures in each institution, including comparative analysis of gaps, blind spots and inconsistencies.

## RECOMMENDATION 3:

# Truth

## Expectations

### Strategic Purpose:

**Prepare for system-wide success in eliminating anti-Indigenous racism and discrimination by ensuring Ontario Health's clear understanding of the:**

- Overarching goals for system change and improvement;
- Roles of individuals within the system towards those goals;
- Associated accountabilities, rewards and consequences for individual performance; and
- Importance of client-centered care.

### Action:

- 1.** We call upon Ontario Health to direct institutional leadership to develop performance expectations and accountabilities that:
  - Identify strategic priorities that focus on improving Indigenous health outcomes;
  - Set specific organization-wide performance goals to eliminate anti-Indigenous racism and discrimination based on measurable results, with accountability requirements for leaders;
  - Develop and assign individual performance goals that align with organizational goals, with accountability provisions for individuals/units; and
  - Set evaluation targets and outcomes that are clear and measurable.
- 2.** We call upon Ontario Health to direct institutional leadership to commit to meaningful service and behaviour monitoring that will:
  - Co-design and implement procedures and practices for measuring quality of outcomes for Indigenous people, including but not limited to:
    - Timely access to health care services; and
    - Equitable quality of service provided, based on:
      - Number of complaints by institutional location and sector; and
      - Nature of complaints, such as, stereotyping, name-calling, demeaning behaviour; denial of medication or administering medications without consent; withholding of care, or substandard, differential care.

3. We call upon Ontario Health to implement a system of complaints management, beginning with:
  - Designing and establishing a ‘safe’ complaints mechanism for reporting incidents as experienced, or as witnessed, including whistleblower protections;
  - Identifying and assigning individual(s) specifically accountable for gathering, reporting and interpreting all such outcomes, including new position(s) as necessary; and
  - Considering the establishment of a race and equity ombudsperson.
  
4. We call upon Ontario Health to direct institutional leadership to commit to timely and transparent communications with Indigenous communities that:
  - Incorporates quality of service-related feedback;
  - Identifies and addresses problems as they arise; and
  - Acknowledges progress towards improvements in service to Indigenous people.
  
5. We call upon Ontario Health to direct institutional leadership to commit to improved human resources systems that:
  - Engage Indigenous partners in health care services, and relevant colleges, universities and governments, to develop strategies for attracting, recruiting, and retaining a more representative workforce;
  
- Sets specific targets for Indigenous diversity at all levels of personnel within the health care system, including senior management;
- Addresses systemic racism in lack of promotion opportunities for under-represented Indigenous personnel;
- Re-evaluates and communicates new mandatory requirement for anti-Indigenous racism and discrimination awareness and Indigenous cultural competency for all supervisory positions, and all job promotions within the system;
- Incorporates Indigenous diversity knowledge, anti-Indigenous racism and cultural safety training as measurable assets in all candidate evaluation for new hires; and
- Establishes mentorship programs, placements and assignments to allow Indigenous and non-Indigenous staff to learn from each other.
  
6. We call upon Ontario Health to:
  - Ensure adequate financial prioritization and budget allocations to achieve the goal of eliminating anti-Indigenous racism and discrimination.

## RECOMMENDATION 4:

# Love

## Standards

### Strategic Purpose:

**Support and nurture system-wide success in eliminating anti-Indigenous racism and discrimination by ensuring all health care professionals have a clear understanding of the standards of knowledge, treatment and human interaction required for competent, safe care.**

### Action:

1. We call upon Ontario Health to direct institutional leadership to:
  - Develop and/or refine anti-Indigenous racism and discrimination policies;
  - Review current practices such as “birth alerts” and the role hospital and community organization health institutions play in the apprehension of Indigenous babies and children;
  - Seek guidance from Indigenous leadership/ community for new policies and procedures related to real or perceived child protection issues with consideration of Indigenous historical context and multiple recent reports such as TRC Calls to Action 1-5.
  - Review practices related to pain management and how these practices impact Indigenous people; and
  - Address pervasive assumptions that Indigenous people are alcoholics and substance users.
2. We call upon Ontario Health to direct institutional leadership to commit to competent, safe care by collaborating with Indigenous partners to:
  - Create safe environments for service delivery;
  - Design and provide equitable spaces for Indigenous spiritual comfort and solace; and
  - Reflect Indigenous culture in decor and organization of space.
3. We call upon Ontario Health to direct institutional leadership to:
  - Review and/or design standards for quality service expectations;
  - Collaborate with Indigenous partners to identify additional standards needed to support and reflect an Indigenous anti-racism and discrimination strategy;

- Establish systems, roles and procedures for recording actual service delivery, and incorporating into performance evaluations, such as, but not limited to:
    - Wait time for Indigenous patients to register for service; and
    - Lapsed time between registration and treatment of Indigenous patients.
  - Establish systems, roles and procedures for reporting and documenting negative incidents or infractions, and incorporating into performance evaluations; and
  - Collaborate with Indigenous and non-Indigenous partners to consider development of an accreditation standard for Indigenous-welcoming, anti-racist workplaces.
- 4.** We call upon Ontario Health to co-create and fund mandatory anti-Indigenous racism training and to include anti-Indigenous racism training in orientation packages for all new employees. This will include:
- Regular communications and demonstration from leadership on the importance of Indigenous specific cultural competency and anti-racism learning; and
  - Schedule and assign training as mandatory professional development for all health personnel within the system.
  - Ensure that this training is included in the orientation of new staff.

## RECOMMENDATION 5:

# Humility

## Accountability

### Strategic Purpose:

**Underscore that eliminating anti-Indigenous racism and discrimination is complex, does not promise immediate results, and requires continuous improvement, time and vigilance.**

### Action:

1. We call upon Ontario Health to provide resources to:
  - Train or hire advocates and Indigenous navigators in hospitals and other non-Indigenous health institutions to ensure equitable access to health resources, language services and respectful, equitable care.
2. We call upon Ontario Health to:
  - Train or hire personnel (e.g., ombudsperson) to report and analyze the effectiveness of new anti-Indigenous racism and discrimination measures on an annual basis.
3. We call upon Ontario Health to:
  - Require institutional leaders and supervisors to receive and assess information related to anti-Indigenous racism and discrimination initiatives relevant to their sectors and assigned staff, with regular cycles for evaluation, ensuring awareness of:
    - Any and all new systems and sources of data that may be used as part of performance feedback;
    - Individual and organizational value of any new standards; and
    - Range of potential consequences for individual or unit violations of new standards.
  - Require institutional leaders and supervisors to incorporate into their evaluation discussions with assigned staff any complaints and/or compliments related to anti-Indigenous racism and discrimination on an ongoing basis; and
  - Require institutional leaders and supervisors to discuss and create opportunities for individual learning plans as needed, as follow-up to training.

## RECOMMENDATION 6:

# Honesty

## Oversight

### Strategic Purpose:

Reinforce that transparency, communication and external feedback from Indigenous communities and clients is highly valued in tackling systemic racism and anti-Indigenous racism and discrimination.

### Action:

1. We call upon Ontario Health to engage with Indigenous health partners, clients and community members to seek regular feedback of health service equity — both perceived and experienced;
2. We call upon Ontario Health to collaborate annually with Indigenous health partners, clients and community members to identify progress, gaps, continuing problems or new challenges; and
3. We call upon Ontario Health to develop a robust, feedback-rich process to correct or eliminate identified problems.

## RECOMMENDATION 7:

# Wisdom


## Continual Improvement and Renewal

### Strategic Purpose:

**Entrench the belief that eliminating anti-Indigenous racism and discrimination is not a short-term, one-time project, but an ongoing process that must be continually practiced.**

### Action:

1. We call upon Ontario Health to annually restate the system-wide goal of improved health care access for Indigenous people, better experiences in health care facilities and institutions, and better health outcomes;
2. We call upon Ontario Health to identify patterns of undue harm as identified in annual performance and accountability cycle; and
3. We call upon Ontario Health to commit to prioritization and corrective action in the entire health care system including identified “hot spot” areas.



**“I speak of change not on the surface  
but in the depth – change in the  
sense of renewal”**

– James Baldwin, American Writer



## Last Word

The general field of medicine and health care, together with a range of associated services, are seen in Canada as the caring professions. When racism and discrimination are allowed within them it not only damages patient health, as substantiated in this report; it also presents as a violation of the very lofty codes of conduct promised for these professions. While ethical codes differ by specific profession, they all highlight virtues, principles, and values that support the delivery of safe, compassionate, competent care for patient well-being.<sup>90</sup> The Canadian Medical Association, as one example, extols dignity, respect, and recognition of the “intrinsic worth of all persons.”<sup>91</sup>

In contemplating meaningful response to this SYS project, all parties across the Champlain region are challenged to reconsider these underlying, ethical principles that bind us together in our purpose to provide equitable care for all. We are also challenged to recall and recommit to the inspirational vision of the man Canadians identified a few years ago as the most important figure in the history of this country... Tommy Douglas, the founder of the Canadian Medicare System.

**We are all in this world together, and the only test of our character that matters is how we look after the least fortunate among us. How we look after each other, not how we look after ourselves. That’s all that really matters.**

- Tommy Douglas, Founder of Medicare

Indigenous peoples have always shared such concepts and philosophies in their worldviews. In the words of the Haudenosaunee Thanksgiving Address “Ohén:ton Karihwatéhkwen”,

**Today we have gathered and we see that the cycles of life continue. We have been given the duty to live in balance and harmony with each other and all living things. So now, we bring our minds together as one as we give greetings and thanks to each other as People.**

- Native Self-Sufficiency Center, Tree of Peace Society

### **And finally...**

Before Steven “Butch” Butler’s death at the age of 19, he shared the story of his interactions with Ottawa’s health care system. His experience in a system with a duty to serve the health care needs of all Ontarians was appalling. Sharing his experience with Wabano executive director Allison Fisher ignited an urgent call to action, but also spun the threads that bind the findings and the recommendations of the *Share Your Story Research Project*. See Appendix B for Butch’s Story.

Butch faced the final days of his young life with grace, dignity and courage, hopeful that one day his city and his community would put an end to anti-Indigenous racism and discrimination.

Among Butch’s final wishes...

**“We must strive to build a more caring world and as human beings never give up on efforts to bring about reconciliation based always on kindness and respect, patience and understanding for each other.”**

# Appendices

# Appendix A

## Truth and Reconciliation Commission of Canada

### Call to Action: Health

**18.** We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

**19.** We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

**20.** In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.

**21.** We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.

**22.** We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.

**23.** We call upon all levels of government to:

- i.** Increase the number of Aboriginal professionals working in the health-care field.
- ii.** Ensure the retention of Aboriginal health-care providers in Aboriginal communities.
- iii.** Provide cultural competency training for all health care professionals.

**24.** We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency

# Appendix B

## Butch's Story

Cystic fibrosis is an awful disease. For families witnessing the suffering of a loved one, there is no relativism, no “I guess it could be worse”, no scale of 1-10 on which to rate the horrors of the disease. There is nothing that can yield any real relief from the constant worry, the angst, the terror of living with death...not just as an inconsiderate visitor whose calling card is pain and chaos, not even as a sworn enemy who makes you want to scream at its relentless intrusion but as a full time, ever present, live-in member of the household who is always in the driver's seat.

This is not a happy story. It is not a hopeful story. But it is a hero's story. It is unabashedly and unapologetically Butch's story shared with the writer over the last few months before his death at age 19 in April 2018. It is a story about anger, hurt, kindness and courage. It is about the care of a child, growing determinedly into a man against all the odds. It is about racism, denial, cruelty and injustice. And, finally ... it is a true story.

Butch was born in 1998 healthy and of normal weight but an early and dramatic loss of that weight soon made it apparent that something was very wrong. It was only a month later that an Emergency room doctor at the North Bay hospital diagnosed the problem as cystic fibrosis, a fatal, genetic disease affecting the vital organs and respiratory system of the body and, in Butch's case, with no family history of the disease and one, they were told, which was rare among Indigenous populations. The family, reeling from the news, was sent to Sudbury to the CF clinic there for treatment. At seven months, infant Butch was released and the family returned to North Bay.

But after a couple of months, he was sick again from having to take enzymes orally to aid absorption of nutrients into his body. It caused terrible thrush in his mouth making it impossible for him to eat. This time he was transferred to Sick Kids hospital in Toronto. Through a six week stay, Butch rallied as he would many times to come. The family returned to North Bay but the realities of having a child with cystic fibrosis and the demands it would make on this young family's future were just beginning... a saga of lengthy hospital stays for their young son, endless treatments, hopeful if short-lived respites and small victories overtaken by constant setbacks.

Until he was four, he remained relatively stable going to Sudbury for CF maintenance treatments. But then he contracted a chest infection the family chose to take him to CHEO where he was treated until a move to the General campus of the Ottawa Hospital when he turned 18.

When he was seven years old the family moved to Ottawa for a year but then returned to North Bay because they were homesick for their community, the comfort of their extended family, familiar country and their culture and traditions. Butch still continued treatment at CHEO with his Mom and Grampa driving him back and forth. It soon became apparent, however, that a second, more permanent move to Ottawa for his Mom, Dad and two brothers was required to make Butch's care easier. This time the unexpected discovery of the Wabano Centre for Aboriginal Health and the support the family found there helped make the move and acceptance of their new life in the city less stressful.

Both Butch and his parents remember their experiences from this time very positively. In 2010, the Ottawa Citizen published an article featuring Butch as a CHEO 'poster child'. Both Butch and his Mom expressed their confidence in and their immense gratitude for CHEO staff and doctors. The article quoted Butch's mom as saying: *"CHEO is awesome. They've made it so he's not kicking and screaming when I take him to hospital. A lot of the people at CHEO are like family. When we were commuting from North Bay, Ronald McDonald House was also a huge help."* Butch says *he really loves going to CHEO but misses his birds when he's there. At CHEO he gets to do lots of crafts, play board games and video games and read...*

Butch was a gifted child blessed with a keen mind, quick wit and an unquenchable desire for learning. He was a happy child with a big heart and remarkable sensitivity to the needs of others around him no matter his own pain and circumstance. He laughed easily, was kind and had a smile and personality which would light up a room. He displayed remarkable courage overcoming much adversity in his young life. His close family was the very centre of his universe, his Mom holding the special place of his best friend and caregiver, never spending more than a few hours away from his side while Dad, his buddy, worked hard to care for the family and make ends meet. Butch approached each day with a strength and determination to live life to the fullest in spite of insurmountable challenges in his path.

He was a proud Anishinaabe and celebrated his Algonquin ancestry. He loved spending time with each of his grandparents learning 'the ways' of the land and history of his people from the Antoine and the Algonquins of Pikwakanagan First Nation. Butch had a profound respect for all living creatures, especially animals and birds, and had the ability to coax chickadees into his hand and have hummingbirds land on his shoulder. And creatures, be they his pets or in the wild seemed to know his special gifts. These included his beloved parrots and cockatoo, his

dog, guinea pig, pet rats, and even neighbourhood squirrels. He seemed to be a "whisperer" to all creatures. When he was 12, he made sure his family knew that he had firm plans to attend college to study avian veterinary medicine.

For most people, to know this young man was to love him. His specialness, intelligence, gentleness and kindness in the face of his awful suffering makes it even more difficult to comprehend the later years of his hospital care, but does make it possible to understand Butch and his family's anger, hurt, and immense sense of betrayal by the very people and institutions charged with his care.

As Butch grew older the disease took an ever-greater toll. His hospital stays became longer and by age 12 he had undergone more than 20 surgeries. He developed esophageal varices and cirrhosis of the liver and spleen. Around this time, he was sent to the Sick Kids hospital in Toronto to determine whether he should have a liver transplant. There was no immediate consensus on a transplant then, but the family's doctor in North Bay notified them that he had received a letter from Sick Kids asking for a follow-up visit for Butch every six months. For some reason never explained to Butch or his family that referral was never acted upon at CHEO, and he was not sent to Toronto again though the possibility of a liver transplant was held out to the family at various times.

By his teen years Butch's knowledge of his disease was encyclopedic. He knew his body and its warning signals, and he knew his medications by name, purpose and amounts, the respective benefits and often difficult side effects of each one. With such knowledge and by now lengthy experience living with CF, Butch expected and had a right to expect that he would have a voice in his own care and treatment path. He was also acutely aware and accepted from early on that he would never have the opportunity to live a long and healthy life, but he was determined to fight for his survival as long as he could and live every day to the fullest.

At fifteen his pain medication regimen no longer provided him reasonable comfort. An MRI had shown that Butch had two compression fractures in his spine and some bones were malformed resulting in chronic pain in addition to all the other problems as CF wracked his body. He was referred to a pain specialist to explore possible new avenues for relief. Accompanied by his Mom, Butch met with a new physician at the Roger Neilson House, a facility at CHEO “dedicated to loving and skilled palliative care to support children, youth and their families” according to their website.

Butch’s experience with the doctor there was anything but loving.

He had welcomed the meeting hoping for some support to make his days more bearable. Instead, this meeting marked one of the most hurtful experiences in his history with the health care system. Making no effort to get to know Butch, the Doctor opened the meeting by stating that he was unlikely to prescribe new pain medication for him because of addiction... “a condition you would know all about being native and living with addicts and alcoholics every day where you are from.” He continued in this vein for a time until Butch and his Mom walked out, stunned and now emotionally scarred by the doctor’s ugly words and the hateful assumptions upon which they were based.

His long stays at CHEO had their bright spots and as Butch never ceased to express, there were many good people who did their best to make his life bearable. One of those “bright spots” was the amazing, caring, friendship and advocacy of Michèle, who was the Child Life Specialist at CHEO that became very special to him. Michèle took a real interest in Butch and encouraged his love of learning and passion for his birds. She remained his good friend for much of his last years. Upon learning of his passing, she wrote the following in a heartfelt condolence to his family, “*BUTCH and family... The exceptional privilege was for me to accompany and support Butch throughout his journey at CHEO ... Brilliant walking encyclopedia, creative dreamer, nature and animal*

*lover, bacon and chocolate milk connoisseur...he taught many of us at CHEO lessons of courage, resilience, optimism, acceptance, caring and loving... Another adventurous journey is starting somewhere else Butch... Thanks for your contributions on CHEO’s Youth Forum and for your unique presence with all of us all these years...”*

There were others involved in his care who made his life a living hell. The treatment of Butch by a very senior nurse in the CF unit at The Ottawa Hospital - General Campus was nothing short of appalling. She waged a relentless campaign with Butch and, when she could, each of his parents, to force the signing of a Do Not Resuscitate order (DNR). When Butch challenged her in any way it became worse. She would lecture him on how much his care cost the hospital, the implication being as a terminal patient he was not worth the investment.

Butch made it clear he understood that he was dying but would fight for as long as he could for the right to treatment involving antibiotics, blood transfusions and other non - invasive measures that would prolong his life. Butch and his Dad took the time to have those very difficult conversations and his decision was to keep going on that basis... but if it was an emergency, he did not want extraordinary measures like the shock paddles, having his chest pounded or the use of other desperate actions used to revive him. When the Grim Reaper, as Butch aptly nicknamed this individual persisted the family complained of her harassment to the hospital administration. Even Butch’s aunt travelled to Ottawa to help advocate on his behalf. When Butch or members of his family complained, the vindictive nurse threatened and on occasion withheld snacks, TV and telephone privileges which Butch was entitled to. The hospital did nothing to reprimand the nurse but did finally agree to the family’s request to have her taken off his medical team.

There were other horrific incidents as the challenges of the disease increased. Butch’s attacks became more severe and each time he spiralled downwards it seemed that it would be his last. Yet he would

rally and challenge his treatment with his Mom advocating passionately on behalf of her very sick son when they knew his fragile body was not responding well. During one of these times, Butch was fed a regimen of strong laxatives for two solid weeks to try and flush his system. Not surprisingly, he lost weight. Hospital personnel said it was not the laxatives and suggested there was a possibility that Butch's Mom was starving him, eating his hospital food and probably had Munchausen syndrome, a mental disorder where the caretaker of a child, often the mother makes up fake symptoms or causes real symptoms to make it look like the child was sick as a desperate ploy for attention.

Another time Butch's Mom was accused of being a drug addict based on absolutely no evidence except as far as the family was concerned, negative assumptions they made because she was rake thin, had some bad teeth and was part of an Indigenous family going through hard times. To fight back Butch's Mom took a drug test, and when it showed absolutely no evidence to confirm the accusation there was never an apology nor an end to the routine rudeness and disrespect both Butch's parents were subjected to during these many months as they held vigil over their son during his long weeks in hospital.

One can only imagine what the family went through dealing with such madness and absurd judgements raining down because of who they were. The worst part was that all of this misinformation and innuendo, the family believes became permanent entries in Butch's hospital record and charts. Once information went into his records his parents were told it could be redacted but never removed and the Butler family was always discouraged, indeed prevented, from gaining access to his medical records including as a reason, the enormous cost to photocopy the information of a now heavy file. These records in a very real sense 'travelled' with Butch and were the first thing seen by unfamiliar medical personnel every time he landed in the Emergency room. It never took long after a cursory review of his file for initial concern and caring bedside manners to turn into something else.

On Butch's 18th birthday, without any warning, discussion or explanation Butch was moved to the General campus. His charts, of course, followed him. He was told abruptly that from now on he would receive adult care and any consultations with Sick Kids hospital including the possibility of a liver transplant were no longer an option. For Butch and the family, weeks turned into months at the General. The quality of Butch's care did not improve nor did the attitudes towards his family. Palliative care, intended as a pathway to bring some relief and comfort to a dying patient, seemed the opposite to Butch... it was more like a cold and uncaring shortcut to hasten his death. So much so that a few months before he died, he insisted that his family take him home no matter what, where at least he could spend his last days with them and tend to his beloved birds. And so, he came home.

While at home, his bleeds happened more frequently, and vomiting was a daily fact of his existence. Still Butch battled for some time every day to feel, to laugh and to love and be loved by his family and friends dear to him. He had had an IV pick inserted in his arm in order to allow him to have IV medicine at home. There were several trips to the Emergency and on one occasion both he and his Mom fought to prevent the removal of the permanent pick having been advised by his palliative Doctor that given the condition of his veins it was very likely the last one they could give him. In other words, the pick was his remaining life line for transfusions and medicines. Their pleas were not being heeded, so in fear they left the hospital for home. The hospital called the police saying Butch was a danger to himself and others. When the police arrived at the family's home and the situation was explained, they were embarrassed, apologetic and angry at such treatment by the hospital and their own part in adding to his misery. Butch did not survive long after that horrible night.

As a postscript, this brave young man fought as long as he could. But his last hours were spent in excruciating pain, a victim of hallway medicine and dreadfully absent palliative care, this time at the Montfort Hospital. Some hospital staff seemed not to care about easing Butch's suffering at the end of his journey or helping a very frightened and

grieving family to understand what was happening. Although the Butlers had tried to prepare for this inevitable moment since Butch came into the world, that knowledge did not soothe or make coping with the death of their beloved son the slightest bit easier. Butch passed away at 4:35 am on April 30, 2018 in the arms of his Mom.

A long sought-after meeting with senior hospital personnel was finally granted with Butch's parents almost four months after he died. Apologies were made for what had happened, but it was expected that the family would share the hospital's view that whatever disciplinary measures and corrective actions they had taken (details of which were not shared) as a result of what happened, were adequate and enough to satisfy the family. In addition, the parents were advised that the experience would be useful as a "teaching opportunity" moving forward. For the Butlers, the real truth of their son's last hours however difficult to hear and understand, remains out of reach. They have been denied that face-to-face conversation with the doctor actually responsible for his care that night. For them, not getting to the hard truths of that night no matter how difficult to hear or admit has left them with an unshakeable and profound feeling that even in his final hours, everything and everyone quit on Butch. And in their grief, sometimes that feeling gets misdirected to themselves as parents and they worry they could have done more to protect their son as his best and long-time advocates.

In the time that has passed since Butch's death, enormous love, respect and admiration has flowed from far and wide to this incredible family. There are many, many people who are missing and grieving for this special young man. For his family and for some time to come there is only the indescribable pain of loss, and their broken hearts. As a baby, Butch's Dad wanted him to have a 'strong' name to see him through life. So 'Butch' was added to the wee boy's already chosen handle of Steven Michael Butler. Butch certainly lived up to that name. And for his Mom, Dad, brothers and sister their comfort and ours comes from knowing his spirit is now finally free to soar without pain and suffering like the birds he loved so much.

It was hard for Butch and his family to share their private journey. It was not done for reasons of revenge or recriminations. Butch never allowed himself to wallow in pity or be driven by resentments of all the things he missed of a normal childhood. He was able to attend school only for short periods, but his learning was deep and unique, and he was wise beyond his years...an old soul. For Butch his sharing was instead a call to action that we must strive to build a more caring world and as human beings never give up on efforts to bring about reconciliation based always on kindness and respect, patience and understanding for each other.

The determined young man wanted his story told and he asked that the world listen, acknowledge and stand up to the ugly realities he and his family endured at the hands of a health care system and too many professional caregivers who could provide not a single credible excuse for such treatment. Butch wanted to know and be convinced that his city and his community will not tolerate this happening to another Indigenous person. Unlike cystic fibrosis, an illness with no known cause or cure, the racist attitudes and treatment, disrespect and downright ugliness of too many of his experiences can and must be dealt with, ended and never allowed to regain a foothold to victimize another Indigenous child or family.

This work, the dedication and determination seemingly Olympic in size, is not beyond the citizens of this city. The task to reform and rebuild a health system on a foundation of love, tolerance and kindness with no cracks in the foundation to permit the terrible sickness of hate and prejudice in, will for Butch and his family, finally be an acknowledgement... an acknowledgement of his short time among us and his contribution as a human being. To contemplate anything less as a legacy for this young hero and his incredible struggle, is to ignore our difficult truths and perpetuate them.

**Recorded and Written by Melody Morrison**



# Endnotes

# Endnotes

1. First Nations Health Authority, Framework for Cultural Safety and Humility. [Cultural Safety and Humility \(fnha.ca\)](http://www.fnha.ca)
2. The Champlain region covers most of eastern Ontario—Ottawa, Renfrew, and Cornwall—Champlain Local Health Integration Network (LHIN) had a mandate to ensure health services are well-organized, appropriately funded, and meet the health needs of the region's residents. It works with approximately 125 health service providers offering 240 health programs and/or services in hospitals, community support services, mental health and addiction service agencies, community health centres, and long-term care homes. See: <http://www.champlainlhin.on.ca/AboutUs/Intro.aspx>.
3. The Circle members represent a range of Indigenous-specific political and health services and wellness organizations including Wabano Centre for Aboriginal Health, the Health Department for the Mohawk Council of Akwesasne, Algonquins of Pikwàkanagàn First Nation, Métis Nation of Ontario, Ontario Inuit Children's Centre, Akausivik Inuit Family Health team, Tungasuvvingat Inuit, Odawa Native Friendship Centre, Renfrew and County District Aboriginal Friendship Centre, and Minwaashin Lodge. See: <http://www.champlainlhin.on.ca/GoalsandAchievements/IndigenousHealthCircleForum.aspx>
4. See, for instance: Naomi Adelson, "The Embodiment of Inequity: Health Disparities in Aboriginal Canada," *Canadian Journal of Public Health*, 96(2): S45-S61; National Collaborating Centre for Aboriginal Health, "An Overview of Aboriginal Health in Canada." 2013. <https://www.ccnca-nccah.ca/docs/context/FS-OverviewAboriginalHealth-EN.pdf>; Patel S, Paulsen C, Heffernan C, et al. Tuberculosis transmission in the Indigenous peoples of the Canadian prairies. *PLoS One*. 2017; 12 (11): e0188189; Health Canada. A Statistical Profile on the Health of First Nations in Canada: Self-rated Health and Selected Conditions, 2002 to 2005. Available: [http://www.hc-sc.gc.ca/fniah-spnia/alt\\_formats/pdf/pubs/aborig-autoch/2009-stats-profil-vol3/2009-stats-profil-vol3-eng.pdf](http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdf/pubs/aborig-autoch/2009-stats-profil-vol3/2009-stats-profil-vol3-eng.pdf); T. Kue Young, "Review of Research on Aboriginal Populations in Canada: Relevance to their Health Needs." *BMJ*. vol. 327, (2003): 419-422; and Peter Bjerregaard, T. Kue Young, Eric Dewailly, and Sven OE Ebbesson, "Indigenous Health in the Arctic: An Overview of the Circumpolar Population." *Scand J Public Health*, vol. 32(2004): 390-295; and Billie Allan & Janet Smylie, "First Peoples, Second Class Treatment: The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada." (Toronto: The Wellesley Institute, 2015), p. 1. Available at, <https://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf>;
5. See for example Paul Sylvestre, Heather Castledan, Jeff Denis, Debbie Martin, & Amy Bombay, "The Tools at their Fingertips: How Settler Colonial Geographies Shape Medical Educations Strategies for Grappling with Anti-Indigenous Racism." *Social Science and Medicine* 237(2019): 112363. <https://www.sciencedirect.com/science/article/pii/S027795361930348X?via%3Dihub>; Sarah de Leeuw, Nicole Marie Lindsey, Margo Greenwood, "Rethinking Determinants of Indigenous Peoples Health in Canada" *Introduction to Determinants of Indigenous Peoples Health in Canada: Beyond the Social*. Margo Greenwood, Sarah de Leeuw, Nicole Marie Lindsay, & Charlotte Reading eds. (Toronto: Canada Scholar's Press, 2015): xi-xxix; Charlotte Reading, "Structural Determinants of Aboriginal Peoples Health." In *Introduction to Determinants of Indigenous*

*Peoples Health in Canada*. Greenwood, de Leeuw, Lindsay, & Reading eds. pp. 3-15; Billie Allan & Janet Smylie, “First Peoples, Second Class Treatment: The Role of Racism in the Health and Well-Being of Indigenous Peoples in Canada.” (Toronto: The Wellesley Institute, 2015).

6. RCAP was tasked with addressing many of the issues about Aboriginal rights that had been highlighted during the Oka Crisis of 1990. The final, five-volume, 4,000-page report was released in 1996 and laid out a twenty-year agenda for implementing changes.
7. RCAP, “Gathering Strength.” vol. 3, pg. 99. Accessible at: <http://data2.archives.ca/e/e448/e011188230-05.pdf>.
8. RCAP, “Gathering Strength,” vol. 3, pg. 186 accessible at: <http://data2.archives.ca/e/e448/e011188230-03.pdf>.
9. RCAP, Renewal: A Twenty-Year Commitment.” vol. 5, pg. 82. Accessible at: <http://data2.archives.ca/e/e448/e011188230-05.pdf>. They also attributed this to a media culture that generally devoted little effort to providing accurate or reliable information on Aboriginal issues
10. Truth and Reconciliation Commission of Canada, Honouring the Truth, Reconciling for the Future, 2015. <https://nccdh.ca/resources/entry/honouring-the-truth-reconciling-for-the-future>
11. Truth and Reconciliation Commission of Canada: Calls to Action, 2015. [http://trc.ca/assets/pdf/Calls\\_to\\_Action\\_English2.pdf](http://trc.ca/assets/pdf/Calls_to_Action_English2.pdf). The health specific calls to action are numbered 18-24.
12. National Inquiry Into Missing and Murdered Indigenous Women and Girls, “Reclaiming Power and Place: Exec Summary of the Final Report.” 2019 [https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Executive\\_Summary.pdf](https://www.mmiwg-ffada.ca/wp-content/uploads/2019/06/Executive_Summary.pdf); Hon. Jacques Viens, “Public Address” & “Summary Report of Public Inquiry Commission on Relations Between Indigenous Peoples and Certain Public Services in Québec: Listening, Reconciliation, and Progress,” 30 Sept 2019, [www.gouv.qc.ca](http://www.gouv.qc.ca) accessed 15 Oct 2019; Leilani Farha , Report of the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context. United Nations, October 2019 <https://undocs.org/en/a/74/183>
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- 63.** SYS Advisory Committee consisted of representatives from Wabano Centre for Aboriginal Health, Minwaashin Lodge, Tungasuvvingat Inuit, Inuugatigiit Centre for Inuit Children, Youth and Families, the Health Department for the Mohawk Council of Akwesasne, Algonquins of Pikwàkanagàn First Nation, Métis Nation of Ontario, Children’s Hospital of Eastern Ontario, Ottawa Public Health, Algonquin Traditional Teacher, Albert Dumont, and late Métis Elder, Jo MacQuarrie.
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