

WHAT GETS COUNTED GETS DONE:  
A POLICY ANALYSIS OF THE BARRIERS AND OPPORTUNITIES  
FOR PROVINCIAL GOVERNMENTS TO COLLECT  
DISAGGREGATED RACE-BASED HEALTH DATA

by

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Submitted in partial fulfilment of the requirements  
for the degree of Master of Arts

at

Dalhousie University  
Halifax, Nova Scotia  
August 2018

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## **Dedication**

This project is dedicated to the scores of African-Canadian activists and advocates from across the diaspora whose tireless struggle inspired this work.

# **Table of Contents**

<i>List of Tables</i> .....	<i>vii</i>
<i>List of Figures</i> .....	<i>viii</i>
<i>Abstract</i> .....	<i>ix</i>
<i>List of Abbreviations Used</i> .....	<i>x</i>
<i>Acknowledgements</i> .....	<i>xi</i>
<b>Chapter 1: Introduction</b> .....	<b>1</b>
<b>Counterpoints</b> .....	<b>6</b>
Counterpoint 1: “Race is irrelevant in setting health policy.” .....	6
Counterpoint 2: “We have all of the information we need.” .....	6
Counterpoint 3: “If someone is sick, we look after them.” .....	7
Counterpoint 4: “It is technically complicated.” .....	7
Counterpoint 5: “Collecting health data by race will be divisive.” .....	8
<b>Definitions of racism:</b> .....	<b>8</b>
Structural racism: .....	8
Institutional racism: .....	9
Interpersonal racism:.....	9
<b>Methodology</b> .....	<b>9</b>
<b>Chapter Outline</b> .....	<b>16</b>
<b>Chapter 2: Literature Review</b> .....	<b>18</b>
<b>Introduction</b> .....	<b>18</b>
<b>The global context for racial health data</b> .....	<b>18</b>

<b>The Canadian context .....</b>	<b>19</b>
<b>Counter-arguments .....</b>	<b>23</b>
<b>Conclusion .....</b>	<b>25</b>
<b><i>Chapter 3: Racism and the mosaic.....</i></b>	<b>27</b>
<b>Introduction .....</b>	<b>27</b>
<b>Multiculturalism and the ‘mosaic’ .....</b>	<b>28</b>
<b>History of discrimination .....</b>	<b>36</b>
<b>Present day discrimination and health .....</b>	<b>39</b>
<b>Agenda setting and racial health inequities.....</b>	<b>43</b>
The Politics Stream .....	44
The Problem Stream .....	47
The Policy Stream.....	48
<b>Conclusion .....</b>	<b>49</b>
<b><i>Chapter 4: What data exists across federal, provincial and municipal jurisdictions?..</i></b>	<b>51</b>
<b>Introduction .....</b>	<b>51</b>
<b>Public health in Canada .....</b>	<b>52</b>
<b>The Federal Government.....</b>	<b>54</b>
The Census.....	54
Sample surveys .....	57
<b>Provincial governments.....</b>	<b>62</b>
Administrative Sources .....	62
<b>Municipal governments.....</b>	<b>68</b>

<b>Conclusion .....</b>	<b>69</b>
<b><i>Chapter 5: Race, genetics, and health.....</i></b>	<b>71</b>
<b>Introduction .....</b>	<b>71</b>
<b>UNESCO Statements on Race .....</b>	<b>72</b>
<b>Race and genetics.....</b>	<b>74</b>
<b>The BiDiI Controversy .....</b>	<b>79</b>
<b>Moving forward: the ecosocial approach .....</b>	<b>82</b>
<b>Conclusion .....</b>	<b>85</b>
<b><i>Chapter 6: Race, ethnicity, and methodology.....</i></b>	<b>87</b>
<b>Introduction .....</b>	<b>87</b>
<b>Introducing ethnicity.....</b>	<b>88</b>
<b>Ethnicity in the Canadian context.....</b>	<b>92</b>
<b>Multiple dimensions of race and mixed-race identification.....</b>	<b>93</b>
<b>Conclusion .....</b>	<b>97</b>
<b><i>Chapter 7: Indigenous peoples and data sovereignty.....</i></b>	<b>99</b>
<b>Introduction .....</b>	<b>99</b>
<b>Indigenous communities and health.....</b>	<b>100</b>
<b>Data sovereignty and OCAP® principles.....</b>	<b>103</b>
<b>Limitations .....</b>	<b>108</b>
<b>Conclusion .....</b>	<b>111</b>
<b><i>Chapter 8: Conclusion.....</i></b>	<b>112</b>

<b>Introduction .....</b>	<b>112</b>
<b>Opportunities .....</b>	<b>113</b>
Providing a basis for policy change .....	113
Increased efficiency in current program provision .....	114
Strengthening inter-governmental ties .....	115
Building trust with community members.....	115
<b>Limitations .....</b>	<b>116</b>
<b>Agenda for further research .....</b>	<b>117</b>
<b>Conclusion .....</b>	<b>118</b>
<b><i>Bibliography</i>.....</b>	<b>119</b>

## **List of Tables**

Table 1: Table comparing provincial race-based data collection approaches across Canada.....	66
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## **List of Figures**

Figure 1: Graph depicting perspectives on assimilation in the USA and Canada .....	32
Figure 2: Diagram of Multiple Streams Approach .....	44
Figure 3: Sample of ethnoracial identifier question in 2016 Census .....	56
Figure 4: Chart showing the prevalence of interviewees who perceive their health is fair or poor disaggregated by race, shown by crude rate.....	60
Figure 5: Chart showing the prevalence of interviewees who perceive their health is fair or poor disaggregated by race, shown by numerator .....	61
Figure 6: Racial identification survey questions utilized by the “We Ask Because We Care” project .....	68
Figure 7: Maps comparing the global distribution of the sickle cell trait (HbS) to the endemicity of malaria.....	77
Figure 8: A schematic illustration of ecosocial theory as it applies to racism.....	84
Figure 9: Matrix showing how racial dimensions are measured to produce different research results.....	95
Figure 10: A visual representation of the cultural framework used in the First Nations Regional Health Survey .....	106



## **Abstract**

An emerging aspect of public health research indicates that race operates as a factor in producing health inequities for racialized groups. Researchers have little ability, however, to demonstrate the extent of this impact in provinces across Canada because few provinces collect disaggregated race-based health data. This predicament prompts the research question: What are some of the barriers and opportunities that exist when provincial governments decide to collect disaggregated race-based health data?

This thesis uses discursive and historical institutionalism to demonstrate that difficulties of data coordination in a federal system, fears of causing stigma among patients, beliefs among policymakers and the public in Canada as a society free of racism, and confusion over the biological basis of race operate as barriers in collecting disaggregated data. Collecting data may provide opportunities to build trust with marginalized communities and assist advocates in placing racial health equity initiatives onto the policy agenda.

## **List of Abbreviations Used**

CIHI - Canadian Institute for Health Information

CCHS - Canadian Community Health Survey

CIC - Citizenship and Immigration Canada

DNA - deoxyribonucleic acid

FDA - Food and Drug Administration

IR - Indian Register

MSA - Multiple Streams Approach

OCAP - Ownership, Control, Access, Possession

NAACP - National Association for the Advancement of Colored People

NCCDH - National Collaborating Centre for Determinants of Health

NSHCC - Nova Scotia Home for Colored Children

PC - Progressive Conservative

TAVIS - Toronto Anti-Violence Intervention Strategy

UN - United Nations

UNDRIP - United Nations Declaration of the Rights of Indigenous People

UNESCO - United Nations Educational, Scientific and Cultural Organization

## **Acknowledgements**

I would first like to thank my supervisor, Dr. Katherine Fierlbeck, for her help and support throughout this project. Your feedback and guidance this year has been invaluable, and I really appreciate it. I would also like to thank Dr. Elizabeth McGibbon, Dr. Robert Huish and Dr. Lori Turnbull for their insights and contributions to this thesis. Receiving the benefit of your time and expertise has strengthened the final product, and my studies at Dalhousie, significantly.

I would also like thank my colleagues in the Department of Political Science's cohort of 2017-18. Your friendship and advice helped me to survive the barrage of work and late nights. It has been an honour to get to know each of you, and I wish great things for you in the future.

To my family, Ola, Ami, Joy and Adewale. Your encouragement and care shone through, despite the geographical distance between us. Your unending support means the world to me.

Most importantly, thank you to my wife, Heather. None of this would be possible without your love, your honesty and your kindness. You made incredible sacrifices to help me achieve this dream, and you did it all while being the best partner and friend I could ever ask for. I hope to care for you as much as you care for me every day of our lives together, but it would still never be enough to match the devotion you have shown to me. Thank you is not enough.

## **Chapter 1: Introduction**

Research in the disciplines of public health and social epidemiology shows that, despite being a socially constructed phenomenon, race may be a significant factor in health inequities for racialized minority groups such as African Canadians. Despite this general knowledge, researchers have little ability to show the extent of this impact. The reason they cannot make critical claims about the potential role of racism as a cause of health disparities in racialized communities is that many provinces do not collect disaggregated race-based data, despite one of the core functions of public health being to uncover and address inequities.

Governments are beginning to pick up on the incongruity of this position – the Ontario government has recently announced a three-year initiative to collect disaggregated race-based data,<sup>1</sup> after years of advocacy from community groups.<sup>2</sup> Meanwhile, the Nova Scotia government sets as an expectation in their Health Equity Protocol that “public health will conduct assessments and seek to understand and report on health inequities, which may include inequities in factors and conditions that may determine health.”<sup>3</sup> The Protocol goes on to mention race as one of the factors that act as a determinant of health, and then notes that the public health division will “identify gaps in data and develop a strategy to collect the data needed to demonstrate inequities and changes over time.”<sup>4</sup> The Nova Scotia Health Authority’s 2016 efforts to survey 1000 people across the province highlighted that community members desire race and ethnicity

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<sup>1</sup> Government of Ontario, “A Better Way Forward.”

<sup>2</sup> Ngabo, “Toronto Advocates Applaud Race-Based Data Collection Initiative | Metro Toronto.”

<sup>3</sup> Department of Health and Wellness, “Nova Scotia Public Health - Health Equity Protocol.”

<sup>4</sup> Department of Health and Wellness.

identifiers to be attached to their health data so that they can make culturally appropriate decisions about their health care.<sup>5</sup> Neither the Department's Business Plan for 2018-19 nor the Health Authority's Strategic Plan for 2016-2019 mention disaggregated data collection.<sup>6</sup> The Health Authority's Strategic Plan, meanwhile, only mentions improving culturally relevant care by increasing the number of positive responses to a survey question about access.<sup>7</sup>

The complexity of this proposition prompts the question: **What are some of the barriers and opportunities that exist when provincial governments decide to collect disaggregated race-based health data?**

By asking this question, I hope to demonstrate the dialectic nature of race as it relates to Canadian health policy. Conceptions of race shape, and are shaped by, the institutional, social and political arrangements that form the Canadian health policy context.

It is helpful first to unpack what is meant by race to demonstrate why this question is important, and what makes it so complicated to monitor as a determinant of health. Race, according to the National Collaborating Centre for Determinants of Health (NCCDH), is "an idea developed by societies to create and categorize differences among groups of people based on physical features like skin colour and hair texture and sometimes culture and religion."<sup>8</sup>

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<sup>5</sup> Nova Scotia Health Authority, "Talk about Health: The Story," 7.

<sup>6</sup> Nova Scotia Health Authority, "Healthier Together: 2016-19 Strategic Plan"; Department of Health and Wellness, "Business Plan 2018-19."

<sup>7</sup> Nova Scotia Health Authority, "Healthier Together: 2016-19 Strategic Plan."

<sup>8</sup> National Collaborating Centre for Determinants of Health, "Let's Talk: Racism and Health Equity," 2.

Given that race is created and maintained by societies, it is also malleable to contextual factors that shape those societies: to economics, to political institutions, to geography. As a social construct, the meanings of race are “neither fixed, nor essential.”<sup>9</sup> Race is also typically used in the context of hierarchy<sup>10</sup> – it is bound to power in the way that it is constructed, and the way that it affects the lives of individuals and communities. Therefore, race is inherently political, and thus should be studied with a political science lens. Moreover, racial hierarchies are based on human value, which means that they are particularly pertinent in discussions of health and healthcare. A significant number of epidemiological and public health studies demonstrate that experiences of racial discrimination negatively determine the health outcomes of racialized individuals.<sup>11</sup> Furthermore, new evidence is emerging from the United States, Brazil, and in Canada that draws a link between structural forms of racism like segregation and health inequities.<sup>12</sup> Despite this evidence, there is still doubt among many in medical and policymaking communities about how important race is as an indicator to determine the efficacy of medical care.<sup>13</sup>

What many often forget in this discussion is the insidious role that race plays in many aspects of our lives, including in shaping health policy. By collecting disaggregated

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<sup>9</sup> Lee, “‘Race’ and ‘Ethnicity’ in Biomedical Research,” 1184.

<sup>10</sup> National Collaborating Centre for Determinants of Health, “Let’s Talk: Racism and Health Equity,” 2.

<sup>11</sup> Brondolo et al., “Racism and Ambulatory Blood Pressure in a Community Sample”; Nelson, “Unequal Treatment”; The Working Group of Experts on People of African Descent, “Report of the Working Group of Experts on People of African Descent on Its Mission to Canada”; Veenstra and Patterson, “Black–White Health Inequalities in Canada”; Williams and Mohammed, “Racism and Health I.”

<sup>12</sup> Jacoby et al., “The Enduring Impact of Historical and Structural Racism on Urban Violence in Philadelphia”; Barber et al., “At the Intersection of Place, Race, and Health in Brazil”; Centre for Arctic Medicine, Thule Institute, University of Oulu et al., “Structural Racism and Indigenous Health”; Gee and Ford, “Structural Racism and Health Inequities”; Waldron, “Experiences of Environmental Health Inequities in African Nova Scotian Communities.”

<sup>13</sup> Braun et al., “Racial Categories in Medical Practice”; Chin and Humikowski, “When Is Risk Stratification by Race or Ethnicity Justified in Medical Care?”; Varcoe et al., “Harms and Benefits.”

race-based health data, provincial governments are committing themselves to confront many challenges, including misconceptions among health policy stakeholders about what race is, and how it can determine health outcomes.

The complexity of navigating many of these challenges for health policy-makers is key to the methodological approach of this project. Racial issues and processes of racialization are messy. Often, as Roth notes, the term race is a proxy for a host of concepts, including self-identity, observed race, classification on surveys and how one perceives others see them.<sup>14</sup> Aside from that conflation of terms, researchers, statisticians and policymakers also frequently combine race and ethnicity into a single variable. This combination can be problematic because, as Valdez and Golash-Boza explain, “race and ethnicity influence and reflect fundamentally different inter-/intra-group relationships and dynamics that contribute to the life chances of group members.”<sup>15</sup> Aside from *that* debate, policymakers may also need to consider the intersections of race, ethnicity, and race/ethnicity with gender, age, class, sexuality, disability, immigration status and other factors that may act as determinants of health.

It is essential to incorporate these concepts, inscrutable as they may appear to be, into any nuanced discussion about racialization and racism in Canada. Combining these concepts with the challenges of Canadian health policy, which is itself a complex study of interlocking systems, necessitates an approach that dispenses with unidirectional causality. The barriers to disaggregated race-based health data collection in Canada should be approached from many angles. These barriers appear intractable because they

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<sup>14</sup> Roth, “Methodological Pitfalls of Measuring Race,” 2347; Kaplan, “The Quality of Data on ‘Race’ and ‘Ethnicity,’” 230.

<sup>15</sup> Valdez and Golash-Boza, “Towards an Intersectionality of Race and Ethnicity,” 2257.

operate in tandem. Therefore, to figure out how to overcome them, policymakers need to be able to isolate what they are, and how they operate.

This project contends that the barriers to disaggregated race-based health data collection include, but are not limited to: difficulties of data coordination in a federal system, fears of causing social stigma among patients, beliefs among policymakers and the public in Canada as a society free of racism, and confusion over the biological basis of race. While these barriers may vary in strength, each contributes to a policy context that makes it easy for provincial governments to push the pursuit of racial health equity from the policy agenda. Beyond these challenges for provincial governments, however, lie opportunities: to build inter-governmental ties, to approach fighting health disparities from a position of evidence-based knowledge, and to build trust with marginalized communities.

My intent with this project is to set out an agenda for further research that is rooted in critical antiracist approaches. This thesis aims to inspire in interested parties, including policymakers and researchers, a determination to fight for racial equity in cities and provinces across Canada. By developing a complete picture of the politics of sociodemographic data collection, I hope to inform policymakers' approach to creating transferable, community-focused data collection regimes that aid in addressing health inequities. Most importantly, I hope to add more nuance to discussions of race as it relates to healthcare in Canada.



## Counterpoints

The discussion around racial health inequities is not straightforward to begin or to maintain. It is easy to imagine the rebuttals that might emerge, either tacitly or explicitly, from presumably well-meaning individuals who believe in the efficacy of the status quo, or in the absence of racial inequity in Canada. I condense the substance of these arguments below in a good faith attempt to address these concerns directly:

*Counterpoint 1: “Race is irrelevant in setting health policy.”*

There is no need to collect race-based health data because race is irrelevant to how we set health policy. Socially determined health problems are a manifestation of issues like poverty, education, and individual behavioural choices,<sup>16</sup> and as such we should be devoting our attention to fixing those issues. Collecting race-based health data would be an unnecessary distraction from the massive challenges that provincial governments face in setting effective health policy, particularly those in Atlantic Canada who are struggling with a demographic crisis and constrained budgets.<sup>17</sup>

*Counterpoint 2: “We have all of the information we need.”*

We already do a decent job of tracking how different social categories affect health. We ask questions related to race on the Census, and we have the Canadian Community Health Survey to work from as well. Do policymakers need another set of data and statistics to parse through to make effective decisions?

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<sup>16</sup> Public Health Agency of Canada, “What Makes Canadians Healthy or Unhealthy?”

<sup>17</sup> Pate, “Why Health Care Is a Ticking Time Bomb in Atlantic Canada | CBC News.”

*Counterpoint 3: “If someone is sick, we look after them.”*

We know that genetics is important to healthcare, but biologically speaking, race does not exist.<sup>18</sup> If someone is sick, we look after them. The Hippocratic oath does not change based on someone’s race – we must treat everyone in the same way. Clinicians who are tempted to use race to identify illnesses may make assumptions that can threaten a patient’s life.<sup>19</sup> Worse still, we might be exposing patients to significant harm by asking them about their race or their ethnicity in a clinical setting by stereotyping them and making them feel like outsiders.<sup>20</sup> It is safer to avoid these risks by not collecting the data.

*Counterpoint 4: “It is technically complicated.”*

Collecting this race-based health data is all well and good in theory, but in practice, it is complicated to achieve. Race is an imprecise proxy – we cannot even agree on its definition, much less create a cohesive data collection protocol to measure it.<sup>21</sup> Ethnicity is a more accurate and less offensive way to separate between populations, so we should be focusing on using that to measure disparities. Plus, the technical challenge that disaggregating this data by race might provide makes this proposal unfeasible.

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<sup>18</sup> Royal and Dunston, “Changing the Paradigm from ‘race’ to Human Genome Variation”; Bamshad et al., “Deconstructing the Relationship between Genetics and Race.”

<sup>19</sup> Moscou and Baker, “The Role of Race in Clinical Decision Making.”

<sup>20</sup> Varcoe et al., “Harms and Benefits.”

<sup>21</sup> Kaplan, “The Quality of Data on ‘Race’ and ‘Ethnicity’”; Moscou et al., “Validity of Racial/Ethnic Classifications in Medical Records Data.”

*Counterpoint 5: “Collecting health data by race will be divisive.”*

Canada is not a country like the United States – we do not have the same issues of racism that dominate national politics in that country. Focusing on race is divisive, and makes Canadians feel bad about themselves.<sup>22</sup>

These arguments, when taken at face value, present significant barriers to policy progress on disaggregated race-based health data collection. The chapters that follow are designed to address these arguments directly to give readers a clear understanding of the hypothesis that I present.

### **Definitions of racism:**

Before beginning, it is useful to establish some key definitions of terms that I will often utilize throughout this project:

#### *Structural racism:*

According to Bailey et al., structural racism (also referred to as systemic racism) involves “interconnected institutions, whose linkages are historically rooted and culturally reinforced. It refers to the totality of ways in which societies foster racial discrimination, through mutually reinforcing inequitable systems (in housing, education, employment, earnings, benefits, credit, media, health care, criminal justice, and so on) that in turn reinforce discriminatory beliefs, values, and distribution of resources, which together affect the risk of adverse health outcomes.”<sup>23</sup> One of the essential things to note about structural racism is that it does not necessarily require the active participation or

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<sup>22</sup> Ibbitson, “Liberal Investigation into Systemic Racism Should Keep a Low Profile.”

<sup>23</sup> Bailey et al., “Structural Racism and Health Inequities in the USA,” 1454.

intention of individuals.<sup>24</sup> This definition will be crucial to this thesis because it showcases the subtle, yet powerful effects of discourses and institutions on maintaining health inequities.

*Institutional racism:*

Institutional racism refers to discrimination in service provision, behaviour or policies that occur on an organizational level.<sup>25</sup> It differs from structural racism insofar as it is concerned with meso-level interactions and mechanisms, such as the emergence of xenophobic political parties that normalize racist rhetoric.<sup>26</sup>

*Interpersonal racism:*

Interpersonal racism occurs when individuals utilize racist slurs, verbal or physical assaults or other discriminatory behaviours against another.<sup>27</sup> Examples of interpersonal racism include hate crimes and speech.

## **Methodology**

As noted above, the combination of Canadian health policy and issues of racialization create complex methodological terrain. My hypothesis – that various barriers to disaggregated race-based health data collection combine to create an institutional context that pushes racial health equity off the policy agenda – demands a holistic analysis of how these barriers intersect to create this context.

To achieve this goal, I will conduct an institutional analysis focusing primarily on

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<sup>24</sup> Gee and Ford, “Structural Racism and Health Inequities,” 116.

<sup>25</sup> Ontario Human Rights Commission, “Racism and Racial Discrimination.”

<sup>26</sup> The emergence of far-right political parties and their effect on European societies is explored in Rydgren, “Meso-Level Reasons for Racism and Xenophobia.”

<sup>27</sup> National Collaborating Centre for Determinants of Health, “Let’s Talk: Racism and Health Equity,” 3.

provincial governments, assessing the discursive, historical and political contexts that shape policy approaches to racial health inequities. This approach is adapted from the Three New Institutionalisms as discussed by Hall and Taylor,<sup>28</sup> as well as the extensive discussion of discursive institutionalism conducted by Schmidt.<sup>29</sup> The works of John Kingdon also inform this approach, whose multiple streams approach (MSA) offers a helpful framework for analyzing the agenda-setting process.

Hall and Taylor note that historical institutionalists define institutions as the “formal or informal procedures, routines, norms and conventions embedded in the organizational structure of the polity or political economy.”<sup>30</sup> When taking a cultural approach, historical institutionalists tend to emphasize worldview and routine over rational choice, noting that “the choice of a course of action depends on the interpretation of a situation rather than on purely instrumental calculation.”<sup>31</sup> The cultural approach stands in contrast to the calculus approach, which deems actors as strategic, seeking a particular set of goals that act toward their benefit.<sup>32</sup> This form of analysis is particularly helpful when analyzing how policymakers may utilize a social construct like race in setting health policy, as the imprecision of its definition combined with the assumptions that underpin lay perceptions of race expose the degree to which interpretation and historical context shape policy norms. It has, however, been criticized as forming too static an explanation for the structure of institutions, with the idea of path dependence operating as an impediment to parsimonious explanations of change within institutions.<sup>33</sup>

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<sup>28</sup> Hall and Taylor, “Political Science and the Three New Institutionalisms.”

<sup>29</sup> Schmidt, “Discursive Institutionalism.”

<sup>30</sup> Hall and Taylor, “Political Science and the Three New Institutionalisms,” 938.

<sup>31</sup> Hall and Taylor, 939.

<sup>32</sup> Hall and Taylor, 939.

<sup>33</sup> Schmidt, “Discursive Institutionalism,” 304.

To account for these changes, and to account for the effect of current discussions about race, multiculturalism and the social determinants of health, I will utilize discursive institutionalism. Discursive institutionalism seeks to account for the role of ideas and discourse in institutional contexts, showing how they shape and shift policy choices and political action.<sup>34</sup> Here, discourse at once means the “ideas represented in the discourse (which may come in a variety of forms as well as content) and the interactive processes by which ideas are conveyed (which may be carried by different agents in different spheres).”<sup>35</sup> Discourse, when applied to this context, does not just mean the debate around race as a relevant factor in shaping data collection policies, but the way in which that relevance is expressed or ignored (biomedical research, data collection protocols, organizations set up explicitly to address racial health equity). Because much of this discourse is about what is *unsaid*; about what is absent, discursive institutionalism is insufficient. Thus, historical institutionalism is useful in showing how this discourse is historically framed.<sup>36</sup> For instance, a history of discrimination against racialized peoples might create a discursive context that frames the discrimination as an outcome of individual attitudes, as opposed to structural harm. A policy response that seeks to frame these issues in a structural context would thus be prevented from reaching the policy agenda.

In trying to collect disaggregated race-based health data, provincial governments are presumably attempting to gather evidence to form a consensus about the scope of racial health inequities within their jurisdictions, with intent to alleviate them through

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<sup>34</sup> Schmidt, 304, 305.

<sup>35</sup> Schmidt, 309.

<sup>36</sup> Schmidt, 314.

targeted policy. The Government of Nova Scotia, for instance, cites both targeted and targeted-universal policies as potential tools to mitigate health inequities.<sup>37</sup> The very challenges that make racial health inequities intractable as a public health issue, however, operate when considering data collection. As highlighted by Hicken et al., the historical basis for the roots of inequality is often missing or have been erased.<sup>38</sup> Therefore, a conventional approach to policy change that follows from established historical precedents will not meaningfully contribute to the alleviation of such issues. Racial health inequities are also a product of shared cultural processes, which means that they are usually not associated with malicious intent on the part of individuals or groups.<sup>39</sup> Furthermore, those shared cultural processes are contextual – no ‘cookie-cutter’ approach will work to overcome these barriers. Discursive institutionalism may offer insights into how ideas about racial health inequities can be changed – how discourses may change as agents and interests do too.<sup>40</sup>

As Fierlbeck explains, epidemiologists often refer to a web of causality to indicate the interconnected nature of the numerous factors that can cause and exacerbate disease.<sup>41</sup> The concept of a ‘web of causality’ maps neatly onto studies of racism, which “is a dynamic process that endures and adapts over time, and...influences multiple mechanisms, policies, practices and pathways that ultimately affect health.”<sup>42</sup> By extending the ‘causal web’ metaphor to describe racial health inequities as a form of social disease, I intend to apply a similarly holistic understanding of the interrelated

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<sup>37</sup> Department of Health and Wellness, “Nova Scotia Public Health - Health Equity Protocol.”

<sup>38</sup> Hicken et al., “Racial Inequalities in Health,” 2.

<sup>39</sup> Hicken et al., 2.

<sup>40</sup> Schmidt, “Discursive Institutionalism,” 322.

<sup>41</sup> Fierlbeck, *Health Care in Canada*, 125.

<sup>42</sup> Came and Griffith, “Tackling Racism as a ‘Wicked’ Public Health Problem,” 1.

causes of those inequities as an epidemiologist applies to the etiology of whatever illness they are investigating. In this analogy, discursive and historical institutionalism operate as diagnostic tools to find a ‘cure’ that is useful to policymakers and supports racialized peoples in their quest for health equity.

To support my methodological approach, I will utilize a combination of published academic analyses that outline the difficulties of race-based data collection, government reports that contextualize how both federal and provincial agencies are grappling with these barriers, literature acquired from research institutions like the Canadian Institute for Health Information (CIHI), and grey literature from non-governmental organizations and media sources. Grey literature, which is published or unpublished information that is not peer-reviewed,<sup>43</sup> will be particularly useful in approaching the question of race-based data collection. As Enticott et al. highlight, grey literature is useful when researching marginalized populations as academic researchers often undersample those groups.<sup>44</sup> Grey literature also allows for a nuanced understanding of complex public health issues, as it provides much needed evaluative context to previous attempts at addressing policy challenges.<sup>45</sup> Furthermore, grey literature operates as part of the policy discourse by helping to shape how policy problems are framed, as well as by offering solutions to these issues.<sup>46</sup> One of the difficulties with utilizing this kind of literature, however, is that no overarching body evaluates its quality or veracity.<sup>47</sup> To mitigate this issue, I intend to reference literature from organizations with a clear track record of detailed, reliable work

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<sup>43</sup> Enticott, Buck, and Shawyer, “Finding ‘Hard to Find’ Literature on Hard to Find Groups,” 1.

<sup>44</sup> Enticott, Buck, and Shawyer, 2.

<sup>45</sup> Adams et al., “Searching and Synthesising ‘Grey Literature’ and ‘Grey Information’ in Public Health.”

<sup>46</sup> Crammond and Carey, “What Is Policy and Where Do We Look for It When We Want to Research It?,” 407.

<sup>47</sup> Enticott, Buck, and Shawyer, “Finding ‘Hard to Find’ Literature on Hard to Find Groups,” 1.



with governments and other stakeholders, including The Wellesley Institute, and the First Nations Information Governance Centre. Grey literature can also be challenging to find, as no single bibliographic source catalogues it.<sup>48</sup> To circumvent this obstacle, I intend to search databases and affiliated websites to gather as much information as I can.

As part of the methodology for this project, it is crucial for me to reflect on my positionality as a researcher, and to be explicit about how it informs my analysis of this issue. Walt et al. note in their paper on ‘doing’ health policy analysis in middle and low-income countries that researchers ought to demonstrate greater reflexivity on how their social and economic position might affect the research agendas they choose to pursue, as well as the data they might collect and analyze.<sup>49</sup> While Canada is not a low or a middle-income country, I believe that it is still necessary to disclose how my social position affects the direction of this thesis project given that it is pertinent to the content of the research.

I identify as a middle-class Black man of British-Nigerian descent. I have lived in Canada since I was 18, spending much of my time as a student, and I have lived in three different provinces. I have also worked in a provincial government in Atlantic Canada as a constituency assistant embedded within a Department of Health. These experiences, as well as my positionality, place me in a unique position as both an ‘insider’ and an ‘outsider.’ ‘Insider’ status, according to Merriam et al. (cited in Walt et al.) allows researchers to “project a more truthful, authentic understanding of the culture under study”, while outsider status allows them to “ask taboo questions, and [to be] seen as

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<sup>48</sup> Enticott, Buck, and Shawyer, 2.

<sup>49</sup> Walt et al., “‘Doing’ Health Policy Analysis,” 314, 315.

non-aligned with sub-groups.”<sup>50</sup> I am an ‘insider’ when it comes to health policy insofar as I worked alongside senior policymakers in a provincial government for nearly two years, and I, therefore, have a degree of insight and appreciation for the challenges they face in acting in the public interest. I am an outsider because I am not a Canadian and because I am Black. Some of the challenges that I discuss in this thesis pertain directly to my life experience, yet many others are far outside of what I have ever seen or felt. In this way, this thesis is not meant to speak for any community that I may subscribe to or any that I do not. My goal instead is to fuse accuracy with empathy to inspire policy change: to ask difficult questions of those in positions of authority, while being cognizant of the significant challenges that they face.

I will not be conducting any primary interviews to test my hypothesis. I will include graphs made with the Health Inequalities Data Tool offered by the Public Health Agency of Canada in this project. The Health Inequalities Data Tool contains “data on indicators of health status and health determinants, stratified by a range of social and economic characteristics (i.e. social stratifiers) meaningful to health equity.”<sup>51</sup> The Data Tool allows users to stratify by cultural or racial background on a limited number of indicators, with data that derives from the Canadian Community Health Survey (CCHS) among other surveys.<sup>52</sup> Aside from utilizing the Health Inequalities Data Tool, I intend to synthesize much of the secondary literature on this topic in a novel, engaging way that I hope will be useful to policymakers and interested citizens.

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<sup>50</sup> Walt et al., 314.

<sup>51</sup> Public Health Agency of Canada, “Health Inequalities Data Tool.”

<sup>52</sup> Public Health Agency of Canada.

## **Chapter Outline**

In Chapter 2, I will conduct a review of the relevant literature that outlines some of the core challenges that I will address throughout this project. Chapter 3 will then reflect upon how conceptions of the efficacy of multiculturalism affect perceptions of racism's impact on policy-making. It briefly reviews the history behind Canada's official claims to multiculturalism, and then draw contrasts between those claims and some of the historical and contemporaneous experiences of African-Canadians. I then utilize the multiple streams approach framework to discuss the barriers that African-Canadians have in setting the policy agenda.

After establishing some of the historical and discursive contexts behind racial health inequities in Canada, Chapter 4 turns to a discussion of the current state of race-based health data collection in federal, provincial and municipal jurisdictions across Canada. It will touch on the complexities of data coordination in a federal system while also exploring the degree to which the marginalization of public health in Canadian health policy presents barriers to the implementation of disaggregated race-based health data.

Chapter 5 turns to analyze some of the conceptual barriers that may affect attempts to collect race-based health data. It details the tensions between biological explanations of the role that race may play in health and the stance that race is socially constructed. Building upon that debate, it uses the development of biomedical ideas about race, as well as the recent advent of personalized medicine to illustrate the dangers of attempting to fix social problems with biomedical solutions. Chapter 6 then attempts to

parse the differences between race and ethnicity and discusses the dangers of discursive conflation by researchers and policymakers.

Chapter 7 turns towards analyzing the opportunities that policymakers have for overcoming these barriers. It discusses how the data collection regime for Indigenous peoples differs from the data collected about racialized peoples in Canada. It gives a brief history of Indigenous peoples' relationships to the Canadian health system and then discusses the OCAP® data standard that could act as a model for other communities to have ownership over their health information. This discussion is expanded in Chapter 8 to include the broader implications of surmounting the barriers discussed previously for policymakers and researchers, while also outlining an agenda for further research.

## **Chapter 2: Literature Review**

### **Introduction**

Racial data is collected by institutions to inform healthcare practices – from the clinician-patient level to population-level analyses. While this data is collected in different nations across the globe, there is no global standard or transferability to data collection or results. There is no uniform process to collect racial health data in Canada, and most provincial governments do not collect data disaggregated by race (a notable exception being in correctional facilities).<sup>53</sup> The way that racial data is categorized and utilized shifts based on societal context. While there is some disagreement about best practices in utilizing this data for health policy and clinicians, there is agreement among many scholars that racial health data may be useful to policymakers when presented on a population level. There is little discussion in the literature, however, of the policy context that influences governments' ability to collect this data. This literature review utilizes peer-reviewed articles, as well as grey literature, to interrogate how racial health data can be utilized to inform health practices.

### **The global context for racial health data**

Much of the literature highlights that racial health data, when collected for the right purposes and on a population-level, can be useful in identifying and ameliorating health disparities. There are, as Beckfield and Krieger highlight, significant gaps in global data that might inform health disparities, particularly in developing nations.<sup>54</sup> Much of the existing data does not transfer across national contexts and does not exist

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<sup>53</sup> Owusu-Bempah and Wortley, "Race, Crime, and Criminal Justice in Canada," 428.

<sup>54</sup> "Epi + Demos + Cracy," 168.

longitudinally, meaning that policymakers cannot account for health outcomes that emerge over long periods of time.<sup>55</sup> Health plans in the United States, from which the bulk of the research utilizing racial health data emerges, only began to systematically collect data on race and ethnicity after the Institute of Medicine called for action to address health disparities in 2002.<sup>56</sup> Since that time, however, there has been an extensive amount of research from the United States that interrogates the linkage between race and health outcomes.<sup>57</sup> Sixty percent of health plans surveyed by Escarce et al. collected data on race and ethnicity, and 65% of those who collected that data did so to address health disparities.<sup>58</sup>

### **The Canadian context**

Conversely, there is little data, and a small body of research, about the role race might play in creating health inequities in Canada. A study by Khan et al. noted that only five out of the 99 studies they reviewed utilized nationally representative data to compare ‘visible minorities’ to White people.<sup>59</sup> The nationally representative data that the studies highlight is mostly cross-sectional, and includes the Canadian Community Health Survey (CCHS) as administered by Statistics Canada.<sup>60</sup> The CCHS does collect data

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<sup>55</sup> Beckfield and Krieger, 168.

<sup>56</sup> Escarce et al., “Collection Of Race And Ethnicity Data By Health Plans Has Grown Substantially, But Opportunities Remain To Expand Efforts,” 1984.

<sup>57</sup> Brondolo et al., “Racism and Ambulatory Blood Pressure in a Community Sample”; Harrell et al., “Multiple Pathways Linking Racism To Health Outcomes”; Krieger et al., “Racial Discrimination & Cardiovascular Disease Risk”; Walker, Williams, and Egede, “Impact of Race/Ethnicity and Social Determinants of Health on Diabetes Outcomes”; Wynia, Ivey, and Hasnain-Wynia, “Collection of Data on Patients’ Race and Ethnic Group by Physician Practices.”

<sup>58</sup> “Collection Of Race And Ethnicity Data By Health Plans Has Grown Substantially, But Opportunities Remain To Expand Efforts,” 1986, 1988.

<sup>59</sup> Khan et al., “(In) Visible Minorities in Canadian Health Data and Research,” 2.

<sup>60</sup> Khan et al., 21.

disaggregated by race.<sup>61</sup> As Krieger et al. note in their study of racial discrimination and cardiovascular disease risk, cross-sectional data limits the ability for researchers to make causal inferences about the outcomes of their studies.<sup>62</sup> Moreover, datasets like the CCHS may undersample ‘visible minorities.’<sup>63</sup> Given that most of the existing data in Canada exist in this form, there is a significant gap in the Canadian policy landscape about racial health inequities.

Much of the data produced by Statistics Canada uses the term ‘visible minorities’ as a proxy for racialization. Statistics Canada defines ‘visible minorities’ as “persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour.”<sup>64</sup> This definition emerges from the Employment Equity Act but is utilized in much of the Canadian statistical literature. As De Maio and Kemp note, the term conflates heterogeneous groups with divergent histories and confuses race, ethnicity, and nationality.<sup>65</sup> Roth argues that the term is somewhat effective for its original purpose, as employment discrimination typically occurs because of racial appearance as opposed to racial self-classification.<sup>66</sup> What presents a challenge to researchers is the methodological blurriness that accompanies the term’s translation into different contexts, including health care. Roth notes that in a self-identification study of university students at the University of British Columbia, “some Asian students – specifically, fractions of those who

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<sup>61</sup> Siddiqi et al., “Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada,” 137.

<sup>62</sup> “Racial Discrimination & Cardiovascular Disease Risk,” 10.

<sup>63</sup> Khan et al., “(In) Visible Minorities in Canadian Health Data and Research,” 21; Siddiqi et al., “Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada,” 140.

<sup>64</sup> Statistics Canada, “Visible Minority Immigrant Definition.”

<sup>65</sup> “The Deterioration of Health Status among Immigrants to Canada,” 466.

<sup>66</sup> Roth, “Methodological Pitfalls of Measuring Race,” 2349, 2350.

identified as Chinese (9 per cent), Korean (8 per cent), South Asian (8 per cent), and Southeast Asian (5 per cent) – did not identify as visible minority.”<sup>67</sup> The students may not have perceived themselves to be in the minority at their institution because Chinese, South Asian and Korean students make up 47 percent of its first-year student population.<sup>68</sup> The term ‘visible minorities’ is, in this context, unhelpful in describing the students’ social position. Instead, it alludes to the notion that they are not White – a racial distinction that may shift the meaning of the data that is collected and produced.

While Roth’s article does not speak specifically about measuring race in a healthcare context, it effectively highlights the political nature of how institutions measure race in Canada. The original utility of a term like ‘visible minority’ is lost, and the term becomes a normative, aggregating force that shapes perceptions about the experiences of heterogenous racialized groups in Canada. This kind of discursive conflation is criticized throughout much of the literature. Thompson argues that although the tendency to combine race and ethnicity may stem from a realization that racial categories are arbitrary social constructions, the effect of this conflation is that claims of discrimination from racial minorities are ignored or downplayed.<sup>69</sup> Lee argues that the conflation of race and ethnicity in biomedical research without interrogation may assist in the reification of race as a biological reality.<sup>70</sup> Given that these social categories have different relationships to power,<sup>71</sup> conflating them to assess health inequities means making demonstrably misleading claims about certain racialized peoples. Disaggregating

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<sup>67</sup> Roth, 2352.

<sup>68</sup> Roth, 2352.

<sup>69</sup> Thompson, “Is Race Political?,” 527.

<sup>70</sup> Lee, “‘Race’ and ‘Ethnicity’ in Biomedical Research,” 1184.

<sup>71</sup> Thompson, “Is Race Political?,” 528.



health data by race thus requires a clarity of purpose about *what* is being measured as much as an understanding of *how* this task might be undertaken.

The Government of Ontario has undertaken the process of collecting data that is disaggregated by race with its 3-year anti-racism strategic plan, “A Better Way Forward,” launched in March 2017. The Government identified collecting disaggregated race-based data as a core part of their goal to address racial inequities.<sup>72</sup> Community stakeholders in Toronto, including the Wellesley Institute and Black Lives Matter - Toronto, have been advocating for this kind of data collection for years. The report itself acknowledges the work of community groups repeatedly and frames the shift as “hearing the call for change.”<sup>73</sup> It also notes that there are “decades of research, reports and recommendations” that advocate for government to do more to combat systemic, or structural racism.<sup>74</sup> Yet health information custodians, defined in the *Personal Health Information Protection Act, 2004* as “a person or organization...who has custody or control of personal health information as a result of or in connection with performing the person’s or organization’s powers or duties,”<sup>75</sup> are excluded from the mandate to collect disaggregated race-based health data in the *Anti-Racism Act, 2017*.<sup>76</sup> This exclusion was heavily criticized by the Association of Ontario Health Centres and The Wellesley Institute among other organizations as negating the government’s stated goals of achieving health equity.<sup>77</sup> By excluding health information custodians from the

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<sup>72</sup> Government of Ontario, “A Better Way Forward,” 17.

<sup>73</sup> Government of Ontario, 9.

<sup>74</sup> Government of Ontario, 9.

<sup>75</sup> Government of Ontario, Personal Health Information Protection Act, 2004.

<sup>76</sup> Government of Ontario, Anti-Racism Act, 2017.

<sup>77</sup> The Wellesley Institute, “Wellesley Institute Submission in Response to the Proposed Regulation under the Anti-Racism Act on Data Standards for the Identification and Monitoring of Systemic Racism”; Association of Ontario Health Centres, “Submission to the Standing Committee on General Government Regarding Bill 114, An Act to Provide for Anti-Racism Measures.”

requirement to collect race-based data, the Ontario provincial government may have undermined attempts at addressing racial health inequities in the province.

“Colour Coded Health Care,” a 2012 report written by Nestel but commissioned by the Wellesley Institute, effectively synthesizes the existing evidence that shows how race affects health outcomes in Canada. Nestel concludes by speculating that a uniquely Canadian challenge to the collection of racial data in the health care system is “a belief in the absence of racial inequalities.”<sup>78</sup> Nestel’s comment, while given short shrift in her treatment of this issue, is illuminating. It alludes to the notion that the lack of racial data collection in Canada is an issue of belief, as opposed to an issue of resources or ability. When placed at the end of the report with little explication, however, it does not develop into an actionable item for policymakers to change. A structured, detailed account of this belief is necessary to understand the nuances that may exist within such a statement.

### **Counter-arguments**

Some researchers do not agree that the racial health data is the most important type of data to improve health system performance. Du Mont and Forte, in a study linking perceived discrimination to self-rated health in Canada, found that those who perceive discrimination based on their physical appearance other than skin colour, as well as those who have a disability, suffer poorer health outcomes than those who were discriminated against because of their race.<sup>79</sup> Du Mont and Forte utilized Statistics Canada’s General Social Survey for their study. Respondents were asked a specific question about discrimination and race but were aggregated as visible minorities.<sup>80</sup> While their

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<sup>78</sup> Nestel, “Colour Coded Health Care: The Impact of Race and Racism on Canadians’ Health,” 23.

<sup>79</sup> “Perceived Discrimination and Self-Rated Health in Canada,” 5,6.

<sup>80</sup> Du Mont and Forte, 2, 3.

conclusion that other forms of discrimination apart from racism are worth studying is valid, Du Mont and Forte also fall into the trap of conflating the experiences of all racialized peoples by using Statistics Canada's 'visible minority' classification. The aggregation of these groups in Statistics Canada's metrics is changing, as seen by the Canadian Community Health Survey. Until a shift to collecting disaggregated data happens in more of Statistics Canada's surveys, researchers run the risk of reducing the validity of their conclusions about members of those groups.

A strong argument against the collection of demographic data (in this case, ethnicity data) comes from Varcoe, Browne, Wong and Smye. Their qualitative study focused on data collection at the point of care and found that participants had significant concerns about being discriminated against because of the data collection.<sup>81</sup> The patients, particularly those who might be identified as 'visible minorities' by Statistics Canada, may undergo a process of racialization due to their self-identification, which would expose them to differential treatment by clinicians.<sup>82</sup> The patients' concern exposes a deeper issue: they perceive that their ethnicity already exposes them to differential clinical treatment, and that self-identifying will only heighten experiences of discrimination.<sup>83</sup> Varcoe et al. conclude that to justify data collection, healthcare organizations must prove that ethnicity data is of significant benefit to combat health inequities in a clinical setting.<sup>84</sup>

Varcoe et al.'s study adds nuance to the discussion of data collection, and tempers notions that data collection will be a quick fix to entrenched issues of inequity. The

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<sup>81</sup> "Harms and Benefits," 1664.

<sup>82</sup> Varcoe et al., 1664.

<sup>83</sup> Varcoe et al., 1663.

<sup>84</sup> 1665.

setting of the study in a clinical context, however, shifts the discussion from structural inequity to interpersonal discrimination. While still a significant issue and a contributor to institutional racism, the treatment of a patient by a clinician is just one contributing factor to health outcomes. Fear of harming patients may present a barrier to disaggregated race-based data collection, and Varcoe et al.'s analysis adds some useful context about the implementation of data collection policies. This account rebuffs, in part, Nestel's assertions, and points to the contradictions inherent in race-based data collection.

Notably, provincial governments in Canada do partner with Indigenous peoples and the federal government to collect specific health data. The Nova Scotia government, which does not currently collect data disaggregated by race, nonetheless partnered with five First Nations on Cape Breton and Health Canada to create the Nova Scotia First Nations Client Registry.<sup>85</sup> The CCHS has, in recent years, also added questions about Aboriginal identity for First Nations, Métis and Inuit.<sup>86</sup> The capability to collect racial health data exists in Canada, and as evidenced by "A Better Way Forward," there has been a recent uptick in initiatives aiming to collect it. Without a keen analysis of the political questions that underpin this kind of data collection, however, it could become a misunderstood, onerous task for policy-makers and clinicians alike.

## **Conclusion**

The literature is lacking in nuanced investigations of the barriers for provincial governments to collect disaggregated race-based health data. There is little holistic analysis of political factors that may shape data-collection policies. Some of the literature

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<sup>85</sup> Government of Nova Scotia, "Health Data Sharing Agreement Will Improve Health Care in First Nations Communities."

<sup>86</sup> Gionet and Roshanafshar, "Select Health Indicators of First Nations People Living off Reserve, Métis and Inuit."

does hint at potential barriers that might affect policymakers' decisions, including a lack of belief that racial health inequities exist, and a reticence to racialize patients in a clinical setting. Broader discussions of other barriers that push racial health equity from the policy agenda are necessary to develop an accurate account of the current policy context.

The first and most important discussion to have is about how structural racism operates in the Canadian context. I intend to highlight the insufficiency of the national discourse of multiculturalism when framing policy responses to racial health inequities. Here, I will examine Nestel's claim of a "belief in the absence of racial inequalities," elaborating on how that belief may affect African-Canadians' ability to set the policy agenda on addressing health equity.

## **Chapter 3: Racism and the mosaic**

### **Introduction**

Canada has a legacy and maintains a reality of racial discrimination on interpersonal, institutional and structural levels against racialized peoples.<sup>87</sup> Canada is perceived internationally and domestically, however, as a society where racism either does not proliferate widely or is a problem of extremist individuals. This discourse is supported by Canada's official policy of multiculturalism, which codifies into law "[the] management of diversity through formal initiatives in the federal provincial and municipal domains."<sup>88</sup> This discourse and its attendant policy imprint renders the negative experiences of racialized peoples as invisible and undermines their attempts at influencing both provincial and federal policy discourses towards racial equity. This policy context thus impedes progress on quantifying the health impacts of racism.

This process is best characterized by the phrase "democratic racism," defined by Henry et al. as:

an ideology in which two conflicting sets of values are made congruent to each other. Commitments to democratic principles such as justice, equality, and fairness conflict but coexist with attitudes and behaviours that include negative feelings about minority groups, differential treatment, and discrimination against them.<sup>89</sup>

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<sup>87</sup> Maynard, *Policing Black Lives*.

<sup>88</sup> Hyman, Meinhard, and Shields, "The Role of Multiculturalism Policy in Addressing Social Inclusion Processes in Canada," 3.

<sup>89</sup> Henry et al., "The Ideology of Racism," 114.

The result of “democratic racism” is that it increases marginality and oppression, which contributes to racial health inequities, while also undermining the ability that members of marginalized communities have to influence policymakers, set a new policy agenda, and make health inequities visible. Core injustices like overrepresentation in the prison population, underrepresentation in the labour market and positions of governance and authority, and discriminatory treatment in health and social care settings among others all amplify that marginality. The core challenge for policymakers posed in this project – substantively developing strategies to ameliorate racial health inequities by collecting disaggregated race-based health data – will be far more successful if policymakers engage with broader policy networks of invested actors, organizations and community members who can guide and shape policy proposals. There must be a substantial effort to devote the resources (financial, intellectual and social) necessary to make sure that Canada's actions live up to its rhetoric. This legacy of democratic racism and the marginality that it breeds in racialized communities is one of the most significant barriers that policymakers will face in collecting race-based health data.

This chapter will focus specifically on African Canadian experiences with anti-black racism and discrimination and is a response to Counterpoint 1 as detailed in Chapter 1. This focus is not intended to exclude the experiences of other racialized peoples, but instead to emphasize the connection between the silencing that emerges from democratic anti-Black racism and the impact on policy discourses across the country.

### **Multiculturalism and the ‘mosaic’**

As noted above, one of Canada’s key national policy discourses is that of multiculturalism. The federal government instituted an official multiculturalism policy in

1971, which recognized multiculturalism as a fundamental characteristic of Canadian society, and encouraged equal treatment and respect for all regardless of race, ethnic origin, religion or skin colour.<sup>90</sup> This policy was subsequently entrenched into the Charter of Rights and Freedoms in 1982 and followed up by the Canadian Multiculturalism Act of 1988.<sup>91</sup> Each province has some form of multiculturalism policy, with some like Nova Scotia also retaining a Cabinet committee on multiculturalism and a separate advisory council.<sup>92</sup>

These policies provided for “state funding to ethnocultural groups for cultural maintenance, removal of cultural barriers to participation in Canadian society, cultural interchange, and official language training for immigrants.”<sup>93</sup> Kymlicka explains that the initial impetus for the multiculturalism policy of 1971 was Québécois nationalists agitating for change during the 1960s.<sup>94</sup> As the federal government scrambled to find a way to make “Quebecers feel more at home” in Canada by enhancing the status of the French language in official government services and emphasizing Canada’s “duality,” they found that other longstanding ethnic groups like Ukrainians and Poles felt ignored and undermined.<sup>95</sup> Thus, multiculturalism became somewhat of an afterthought – a way to secure political support among other things for bilingualism, which the government of the time felt was the real issue.<sup>96</sup>

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<sup>90</sup> Hyman, Meinhard, and Shields, “The Role of Multiculturalism Policy in Addressing Social Inclusion Processes in Canada,” 5.

<sup>91</sup> Hyman, Meinhard, and Shields, 6.

<sup>92</sup> For a comprehensive look at provincial policies regarding multiculturalism, please see Brosseau and Dewing, “Canadian Multiculturalism,” 16.

<sup>93</sup> McElhinny, “Reparations and Racism, Discourse and Diversity,” 51.

<sup>94</sup> Kymlicka, “The Three Lives of Multiculturalism,” 18.

<sup>95</sup> Kymlicka, 18.

<sup>96</sup> Kymlicka, 19.



Notably, however, neither racialized peoples nor Indigenous groups were included in these early attempts at entrenching multiculturalism.<sup>97</sup> Subsequent attempts were made by the federal government and by organized advocacy groups to implement anti-racism as a part of multiculturalism but critics claimed that anti-racism ran contrary to the original spirit of the policy.<sup>98</sup> Moreover, as McElhinny explains, the government's pivot towards focusing on race relations in the 1980s was criticized as being poorly funded and unable to cope with the institutional factors that promote racial discrimination.<sup>99</sup> The foundations of Canada's multiculturalism policy were ill-suited to engaging with racial discrimination. Kymlicka points out that racialized peoples are often not discriminated against because of their country of origin, but rather because of their skin tone (their observed race).<sup>100</sup> Moreover, as Ku et al. note, official multicultural policy has been criticized as "essentializing cultures, endorsing "song and dance" difference while depoliticizing resistance and diverting attention from racism."<sup>101</sup> Finally, this discourse often presumes the recent immigrant status of most of the people that it targets, which does not adequately represent the experiences of racialized peoples.

Nevertheless, this policy discourse has affected the way that Canadians see themselves. Prime Minister Trudeau, for instance, noted that multiculturalism is "as synonymous with Canada as the Maple Leaf."<sup>102</sup> Winter notes that multiculturalism has allowed White Canadians to "develop a national identity that enables them to distinguish

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<sup>97</sup> Leung, "Canadian Multiculturalism in the 21st Century," 108.

<sup>98</sup> Kymlicka, "The Three Lives of Multiculturalism," 22.

<sup>99</sup> McElhinny, "Reparations and Racism, Discourse and Diversity," 52.

<sup>100</sup> Kymlicka, "The Three Lives of Multiculturalism," 22.

<sup>101</sup> Ku et al., "'Canadian Experience' Discourse and Anti-Racism in a 'Post-Racial' Society," 2.

<sup>102</sup> Rt. Hon. Justin Trudeau, Prime Minister of Canada, "Statement by the Prime Minister of Canada on Multiculturalism Day."

their nation from the alleged melting-pot model in the United States and to take pride in a presumably more tolerant and “caring” approach to minorities.”<sup>103</sup> This support can be seen in a Nanos Research survey conducted in October 2016 found that multiculturalism, diversity and bilingualism were one of the values that Canadians seemed to prize the most, behind equity and social justice and Canada’s history of peacekeeping.<sup>104</sup>

Other recent public opinion polls, however, show a mixed outlook for pluralism.<sup>105</sup> A 2017 poll conducted by Corporate Research Associates noted that two-thirds of Atlantic Canadians supported screening immigrants for “Canadian values,”<sup>106</sup> though a follow-up survey determined that those “Canadian values” include respect for cultural differences.<sup>107</sup> Another well-publicized survey conducted by the Angus Reid Institute shows that while 67% of Canadians believe that immigrants are integrating well into their community, 68% also believe that minorities should do more to integrate into Canadian society.<sup>108</sup> As Figure 1 demonstrates, they are also more likely to say that minority groups should assimilate compared to Americans:

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<sup>103</sup> Winter, “Rethinking Multiculturalism After Its ‘Retreat,’” 640.

<sup>104</sup> Nanos Research, “Exploring Canadian Values - Values Survey Summary.”

<sup>105</sup> For a historical perspective, see EKOS Politics and iPolitics.ca, “Attitudes to Immigration and Visible Minorities - A Historical Perspective.” Their 2013 poll showed that 37% of respondents believed that there were too many visible minorities coming into Canada – the highest level since 1993.

<sup>106</sup> Pruss, “2/3 of Atlantic Canadians Support ‘values’ Screening of Immigrants, Poll Suggests | CBC News.”

<sup>107</sup> Brown, “The Silent Majority and the Issue of Canadian Values.”

<sup>108</sup> Angus Reid Institute, “What Makes Us Canadian?”

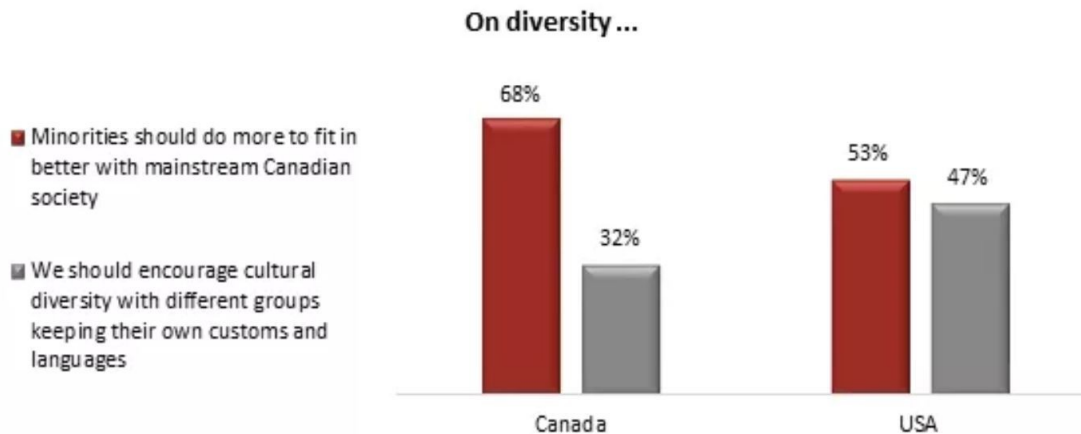


Figure 1: Graph depicting perspectives on minority assimilation in the USA and Canada<sup>109</sup>

Critics claimed that the survey was methodologically flawed for conflating minorities and immigrants, for identifying a specious mainstream society, and for presenting too stark a choice between assimilation and diversity that does not exist on a policy level.<sup>110</sup> When placed in context, however, it does provide insight into the central tensions that multiculturalism presents to Canadian society. The conflation of terms aside, the choice provided between fitting in and expressing diversity may not be one that any government asks explicitly of racialized peoples but may be implied by policy proposals and discourses. Such sentiments might have been insinuated by legislation introduced by the former Conservative-led federal government, including the *Zero Tolerance for Barbaric Cultural Practices Act* and the attendant tip line designed to report marriage “fraudsters” to the government,<sup>111</sup> and attempted provincial legislation like the Charter of Quebec Values.<sup>112</sup> In both cases, these pieces of legislation represent attempts to define a

<sup>109</sup> Angus Reid Institute.

<sup>110</sup> Jedwab, “Opinion | How Angus Reid, CBC Got It Wrong about Multiculturalism.”

<sup>111</sup> Gaucher, “Monogamous Canadian Citizenship, Constructing Foreignness and the Limits of Harm Discourse.”

<sup>112</sup> Hassan et al., “Impact of the Charter of Quebec Values on Psychological Well-Being of Francophone University Students.”

normative national or provincial culture – thus engaging in a project of nation-building – by expressing the “barbaric” nature of others who are primarily racialized.<sup>113</sup> While the exact question asked by the Angus Reid Institute may not be a feasible choice for individuals to make, the underlying discourse around that choice – i.e. the construction and maintenance of a mainstream Canadian society – is one that may push policy proposals aimed at supporting marginalized peoples off of the agenda.

Moreover, the discourse of multiculturalism is predicated on the idea of tolerance, but tolerance does not presuppose understanding or addressing injustice. Henry et al. summarize these fundamental issues with the policy discourse of multiculturalism:

“The concepts of tolerance, accommodation, sensitivity, harmony and diversity lie at the core of multicultural ideology and are firmly embedded in multicultural policy and discourse... The emphasis on tolerance and sensitivity suggests that while one must accept the idiosyncrasies of the ‘others,’ the underlying premise is that the dominant way is superior.”<sup>114</sup>

The dominant way referred to by Henry et al. found resonance during Stephen Harper’s tenure as Prime Minister and Leader of the Conservative Party of Canada.<sup>115</sup> As Ryan points out, the Conservative party subsumed multicultural rhetoric into social conservatism, rhetorically supporting multiculturalism while stripping its attendant policy responses of their equity seeking attempts.<sup>116</sup>

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<sup>113</sup> Gaucher, “Monogamous Canadian Citizenship, Constructing Foreignness and the Limits of Harm Discourse,” 533; Winter, “Rethinking Multiculturalism After Its ‘Retreat,’” 648.

<sup>114</sup> Henry et al., “The Ideology of Racism,” 117.

<sup>115</sup> Ryan, “Does Canadian Multiculturalism Survive through State Repression?,” 347.

<sup>116</sup> Ryan, 347.

For example, the federal government implemented *Canada's Action Plan Against Racism* in 2005 under the leadership of Prime Minister Paul Martin, which provided a five-year, \$56 million plan to combat racism that included initiatives to improve the integration of immigrants into the labour market and to develop a nationally standardized data-collection strategy on hate crimes.<sup>117</sup> An evaluation of the plan conducted by the Government in 2010 concluded that while anti-racism was a priority in the early-to-mid-2000s, the “priorities of the GoC [Government of Canada] have evolved, with an increased focus on social cohesion and equal access to economic opportunity.”<sup>118</sup> Citizenship and Immigration Canada (the department in charge of the *Action Plan* at the time) responded to these comments by noting that “approaches developed at CIC to addressing racism and discrimination now focus on commonalities rather than differences.”<sup>119</sup> They subsequently let settlement and integration programs lapse while scattering expertise and programming on multiculturalism throughout the Department.

This response from CIC is characteristic of what Henry et al. term as the discourse of equal opportunity, or the idea that we all exist on a “level playing field.”<sup>120</sup> By offering rhetorical support to multiculturalism while stripping the term itself of any equity-seeking meaning, they obscured the inequities that existed in favour of promoting an agenda that focused on “commonalities” – i.e. focusing on the dominant discourse described above. Winter notes, when conducting a discourse analysis of 130 speeches conducted by former Minister of Immigration, Citizenship and Multiculturalism Jason Kenney, that

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<sup>117</sup> Department of Canadian Heritage, “A Canada for All,” 25, 49.

<sup>118</sup> Department of Canadian Heritage, iv, v.

<sup>119</sup> Department of Canadian Heritage, ix.

<sup>120</sup> Henry et al., “The Ideology of Racism,” 116.

multiculturalism under the Conservatives became “about them” as opposed to “about us” – a distinction that paints Canada as a tolerant, White, Anglo-Saxon and Christian nation that newcomers may threaten with extremism and hatred.<sup>121</sup> The effect of this shift in focus is that it undermined future efforts aimed at addressing structural racism in Canada, and shaped an ongoing discourse of denial and suspicion of the “other.”<sup>122</sup> An example of a similar shift can be seen in Quebec which started, but ultimately cancelled, a consultation on systemic racism last year, choosing instead to focus on “immigration, employment and francization.”<sup>123</sup> By constructing a national discourse that ignores anti-racism efforts, as well as defunding provincial organizations that sought to advocate for human rights,<sup>124</sup> the federal government may have made it more difficult for those efforts to emerge on provincial policy agendas.

There are signs, however, that a focus on anti-racism efforts has been renewed by the federal government. Budget 2018 set aside \$23 million over two years for a nationwide consultation on a new anti-racism initiative that would be part of the Multiculturalism Program at the Department of Canadian Heritage.<sup>125</sup> Though criticized for “making people feel bad about themselves,”<sup>126</sup> this consultation offers a chance for racialized peoples in Canada to be direct in expressing how profoundly racism may affect

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<sup>121</sup> Winter, “Rethinking Multiculturalism After Its ‘Retreat,’” 650.

<sup>122</sup> A recent example of this discourse can be seen in the controversy over an advertisement that the Conservative Party of Canada released depicting a Black man walking over the Canadian border with a suitcase: The Canadian Press, “Conservative Party Pulls Attack Ad Showing Black Man Walking over Trudeau Tweet | CBC News.”

<sup>123</sup> Commission des droits de la personne et des droits de la jeunesse, “The Commission Des Droits de La Personne et Des Droits de La Jeunesse to Continue Its Reflection on Systemic Discrimination and Racism.”

<sup>124</sup> Gergin, “Silencing Dissent.”

<sup>125</sup> Government of Canada, “Budget 2018.”

<sup>126</sup> Ibbitson, “Liberal Investigation into Systemic Racism Should Keep a Low Profile.”

their lives. The section below provides the readers of this project with a small excerpt from a litany of injustices.

### **History of discrimination**

Nova Scotia is home to the oldest Black community in Canada. There is a complex and important historical context that continues to underpin current efforts to collect African Nova Scotian health data, and in turn, efforts to use this data for anti-racist policy intervention. African-Canadians have been marginalized in Canada from the earliest days of colonial settlement. This marginalization, however, takes place in different ways over nearly 400 years of history depending on factors such as immigrant status (or lack thereof). Slavery was practiced in Canada for 200 years, with Quebec City, Montreal and Halifax playing key roles as “transatlantic network ports” that received boatloads of enslaved African men and women.<sup>127</sup> While slavery in Canada differed from plantation-style slavery in the United States in its style and scope, slave-owners in Canada came from all social classes, and slaves were often placed in a form of extreme isolation that entrenched an anti-Black racial logic in the minds of white settlers that eventually became codified into law.<sup>128</sup>

Free Black migrants also fared poorly during this period. The migration of over 3500 Black Loyalists from 1782-84 into Nova Scotia brought initial promises of 500 acres of land per family in exchange for loyalty to the British cause in the American War of Independence, but settlers reneged on this promise, giving loyalists as little as one acre of non-arable scrubland.<sup>129</sup> After North America’s first race riot in Shelburne was caused

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<sup>127</sup> Maynard, *Policing Black Lives*, 18, 23, 24.

<sup>128</sup> Maynard, 23.

<sup>129</sup> Saney, “The Black Nova Scotian Odyssey: A Chronology,” 80.

by Black labourers being paid below scale by White employers, 1,200 Loyalists elected to sail back to Sierra Leone despite attempts by colonial authorities to keep them in Nova Scotia.<sup>130</sup> These incidences belie the near-utopian conception of Canada as the terminus of the Underground Railroad. As author Robyn Maynard notes, those who did make it to Canada via the Underground Railroad also faced significant challenges in Canada:

Indeed, freedom runners often experienced the same anti-Black racism north of the border that they sought to flee in the U.S. For example, in 1891, in Chatham, a town where many of the freedom runners had settled, a band of armed whites tried to force an elderly Black couple from their land...Black lives, whether recent Black Americans or Canadian-born, while nominally free, were relegated to a separate and unequal status in all realms of society.<sup>131</sup>

As the 20<sup>th</sup> Century began, Black people moved across Canada, aided by the railroads and by available farmland in areas of Saskatchewan, Alberta, and British Columbia.<sup>132</sup> As the population size and distribution of Black people increased across the country, however, communities were segregated from accessing public services. In Nova Scotia, schools were segregated *de jure* from 1918 to 1954 as part of the Nova Scotian Education Act.<sup>133</sup> These schools were often in a dilapidated condition, with few resources or teachers, and many did not open at all.<sup>134</sup> The last segregated school in the province closed in 1983.<sup>135</sup> In Ontario, meanwhile, the last segregated school closed in 1965.<sup>136</sup>

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<sup>130</sup> Saney, 81.

<sup>131</sup> Maynard, *Policing Black Lives*, 30.

<sup>132</sup> Winks, "Negro School Segregation in Ontario and Nova Scotia," 24.

<sup>133</sup> Winks, 26.

<sup>134</sup> Winks, 26, 27.

<sup>135</sup> Historica Canada, "Black History Canada - End of Segregation in Canada."

<sup>136</sup> Winks, "Negro School Segregation in Ontario and Nova Scotia," 29.



Housing was also heavily segregated, with landowners like the Canada Land Company refusing to sell to Black people in Canada West, segregated housing in Hamilton and Winnipeg,<sup>137</sup> and restrictive real estate covenants preventing the sale of houses to Black people (among other racialized peoples) in Vancouver and Victoria.<sup>138</sup> Hotels and hospitals often refused to serve Black people;<sup>139</sup> Black people fought in segregated battalions in both World Wars,<sup>140</sup> and traditionally Black neighbourhoods like Africville in Nova Scotia were bulldozed in the pursuit of ‘urban renewal.’<sup>141</sup>

Black people were perceived as “unassimilable” and were barred from immigrating into Canada by the *Immigration Act, 1910*, which allowed the federal government to restrict immigration for any race “deemed unsuited to the climate or requirements of Canada.”<sup>142</sup> In fact, in 1938, the German government sought advice from Canada to introduce and implement racially discriminatory legislation.<sup>143</sup> The federal government largely rebuffed the request, in part because civil rights were a provincial jurisdiction and as such there was no nationally coordinated strategy of racial policy.<sup>144</sup> The federal government finally removed the race-based restrictions for immigration and permanent residency in Canada in 1967, which paved the way for increased migration from across the African and Caribbean diaspora.<sup>145</sup>

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<sup>137</sup> Maynard, *Policing Black Lives*, 37.

<sup>138</sup> CBC News, “Vancouver’s Racist Real Estate Titles Reveal City’s Dark History | CBC News.”

<sup>139</sup> Maynard, *Policing Black Lives*, 38.

<sup>140</sup> Saney, “The Black Nova Scotian Odyssey: A Chronology,” 87; Maynard, *Policing Black Lives*, 38.

<sup>141</sup> LOO, “Africville and the Dynamics of State Power in Postwar Canada,” 23.

<sup>142</sup> Maynard, *Policing Black Lives*, 35; Walker, “Race and the Law,” 7.

<sup>143</sup> Walker, “Race and the Law,” 13.

<sup>144</sup> Walker, 13.

<sup>145</sup> Branker, “Labour Market Discrimination,” 204.

This history is relevant to the health status of African Canadians today because one of the core features of the discrimination that many of these communities face is the way that this legacy is rendered invisible by discourses of tolerance.<sup>146</sup> As Wane notes in her exploration of the erasure of African Canadian women in school curricula, “[s]eparation from one’s past has a direct correlation to one’s ability (or inability) to relate to the present. The silence around our histories is instructive, reinforcing the message that our histories are neither relevant nor valid.”<sup>147</sup> As we will see below, this history profoundly affects the health and wellbeing of African-Canadians today, regardless of whether their families have been present in Canada for generations, or they have just arrived in the country.

### **Present day discrimination and health**

The history of social exclusion and discrimination discussed above has shaped how African Canadians exist in Canadian society. It has undermined the impact of multicultural policy discourses on the health and wellbeing of African Canadian communities. Communities with a long history of citizenship in this country are often bestowed a racialized outsider status that removes them from Canadian society,<sup>148</sup> despite 10 percent of Black Canadians having ancestry in Canada for three generations or more.<sup>149</sup> These communities suffer from high levels of poverty and unemployment,<sup>150</sup>

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<sup>146</sup> Wane, “African Women and Canadian History: Demanding Our Place In The Curriculum,” 159; Henry et al., “The Ideology of Racism,” 115.

<sup>147</sup> Wane, “African Women and Canadian History: Demanding Our Place In The Curriculum,” 159.

<sup>148</sup> Wane, 163.

<sup>149</sup> Maynard, *Policing Black Lives*, 77.

<sup>150</sup> Maynard, 77, 78.

housing discrimination,<sup>151</sup> and a higher likelihood of proximity to waste and landfill facilities, toxic dumps and pollution.<sup>152</sup>

Recent immigrants from across the African diaspora, meanwhile, battle exclusion from the labour market because of a lack of ‘Canadian experience’ – itself a racialized term,<sup>153</sup> consistent deskilling despite high levels of education,<sup>154</sup> and the attendant underemployment that comes with skills (both in terms of credentials and knowledge) going unrecognized.<sup>155</sup> Despite these heterogeneous experiences, Black Canadians of all backgrounds are subject to some common injustices including racial profiling by police and overrepresentation in the prison system among many others.<sup>156</sup>

I provide this list, which is by no means exhaustive, to demonstrate the profound challenges that African Canadians face in Canada today. On their visit to Canada, the United Nations Working Group of Experts on People of African Descent addressed the impact of these injustices on the wellbeing of African Canadians:

The cumulative impact of anti-Black racism and discrimination faced by African Canadians in the enjoyment of their rights to education, health, housing and employment, among other economic, social and cultural rights, has had serious consequences for their overall well-being. Anti-Black racism continues to be

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<sup>151</sup> Novac et al., “Housing Discrimination in Canada: What Do We Know About It?,” 2.

<sup>152</sup> Waldron, “Experiences of Environmental Health Inequities in African Nova Scotian Communities,” 11.

<sup>153</sup> Ku et al., “‘Canadian Experience’ Discourse and Anti-Racialism in a ‘Post-Racial’ Society.”

<sup>154</sup> Guo, “The Colour of Skill,” 241.

<sup>155</sup> Guo, 241.

<sup>156</sup> The Working Group of Experts on People of African Descent, “Report of the Working Group of Experts on People of African Descent on Its Mission to Canada,” 10.

systemic, leaving African Canadians among the poorest communities in Canada.<sup>157</sup>

The key here is that the *accumulation* of these structural injustices alters the health and wellbeing of African Canadian communities across Canada. Other social determinants of health such as gender, housing and employment all intersect with the impact of race and racism on racialized communities' lives.<sup>158</sup> The health effects of this racism are significant: from statistically higher rates of breast cancer in Black women who experience frequent everyday discrimination,<sup>159</sup> to elevated rates of hypertension based on experiences of discrimination,<sup>160</sup> and mental health struggles resulting from the chronic stress of discrimination.<sup>161</sup> Daily experiences of subtle discrimination, also known as microaggressions, are a significant culprit of the poor health outcomes that African Canadians suffer.<sup>162</sup>

These results are consistent with the storied impact of racial discrimination on the lives of African-Americans,<sup>163</sup> though different institutional structures and social policies mitigate them to an extent.<sup>164</sup> Galabuzi notes that race, when by combined with other social determinants like poverty, structures how some health disparities are spatially

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<sup>157</sup> The Working Group of Experts on People of African Descent, 12.

<sup>158</sup> McGibbon and Etowa, "Race and Racism as Determinants of Health," 73.

<sup>159</sup> McGibbon and Etowa, 75.

<sup>160</sup> Siddiqi et al., "Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada," 139.

<sup>161</sup> Corneau and Stergiopoulos, "More than Being against It," 264, 265.

<sup>162</sup> For a deeper discussion of the effects of microaggressions, check out Nadal et al., "The Injurious Relationship Between Racial Microaggressions and Physical Health."

<sup>163</sup> Brondolo et al., "Racism and Ambulatory Blood Pressure in a Community Sample"; Walker, Williams, and Egede, "Impact of Race/Ethnicity and Social Determinants of Health on Diabetes Outcomes"; Gee and Ford, "Structural Racism and Health Inequities"; Ben et al., "Racism and Health Service Utilisation."

<sup>164</sup> Siddiqi et al., "Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada," 140.

distributed. Neighbourhoods with high concentrations of immigrant and racialized populations are more likely to report depression, and are also more likely to suffer from chronic diseases like diabetes.<sup>165</sup> There is substantive evidence of racism at the point-of-care in health fields, including the complex pathways that lead clinicians to withhold care, and to discriminate in their care.<sup>166</sup> Decades of research, mostly from the United States, has found that stereotyping and racial bias also means that racialized patients are consistently less likely to be given medications for pain across all major medical specialties.<sup>167</sup>

Given that Canada's system of public health insurance necessitates that patients incur costs for ancillary medical products and equipment (with exceptions depending on provincial coverage), the underemployment and poverty that many African-Canadians face amplifies the likely negative health outcomes that discrimination produces.<sup>168</sup> McGibbon and Etowa note that patients' lack of compliance in treatment based in part on these barriers allows medical professionals to blame illness on the attitudes of these patients rather than attending to the structural challenges that they may face.<sup>169</sup> The shifting of culpability for adverse health outcomes onto marginalized patients worsens

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<sup>165</sup> Galabuzi, "Social Exclusion as a Determinant of Health," 110.

<sup>166</sup> Maina et al., "A Decade of Studying Implicit Racial/Ethnic Bias in Healthcare Providers Using the Implicit Association Test"; Calabrese et al., "The Impact of Patient Race on Clinical Decisions Related to Prescribing HIV Pre-Exposure Prophylaxis (PrEP)"; Attanasio and Kozhimannil, "Patient-Reported Communication Quality and Perceived Discrimination in Maternity Care."

<sup>167</sup> Hoffman et al., "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites"; Singhal, Tien, and Hsia, "Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse"; Hampton, Cavalier, and Langford, "The Influence of Race and Gender on Pain Management"; Hollingshead et al., "A Comparison of Race-Related Pain Stereotypes Held by White and Black Individuals."

<sup>168</sup> McGibbon and Etowa, "Race and Racism as Determinants of Health," 83.

<sup>169</sup> McGibbon and Etowa, 86.

perceptions of racial profiling and insensitivity in health care settings, alienating people from accessing the services they need in the ways that they need them.<sup>170</sup>

These profound challenges to the health of African-Canadians cannot be overcome when tolerance and conflict aversion are used to undermine policy progress. If the dominant policy discourse is one that believes “paying unnecessary attention to ‘differences’ leads to division, disharmony and disorder in society,”<sup>171</sup> those that are the recipients of harmful treatment due to those ‘differences’ will be unable to prompt policy change. The barriers that make it difficult for African-Canadians to improve their health are, in effect, the same barriers that make it difficult for communities to influence policy change.

### **Agenda setting and racial health inequities**

A core topic of interest in much of the public policy literature is how decisionmakers prioritize policy decisions and set policy agendas. John Kingdon’s Multiple Streams Approach (MSA) is a well-known and intuitive framework (consistent with discursive institutionalism)<sup>172</sup> that I will utilize here to describe the challenges that African-Canadians face in influencing the agenda-setting process. Figure 2 is a diagram of the Multiple Streams Approach created by Jones et al.:

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<sup>170</sup> McGibbon and Etowa, 84, 85.

<sup>171</sup> Henry et al., “The Ideology of Racism,” 116.

<sup>172</sup> Schmidt, “Discursive Institutionalism,” 307.

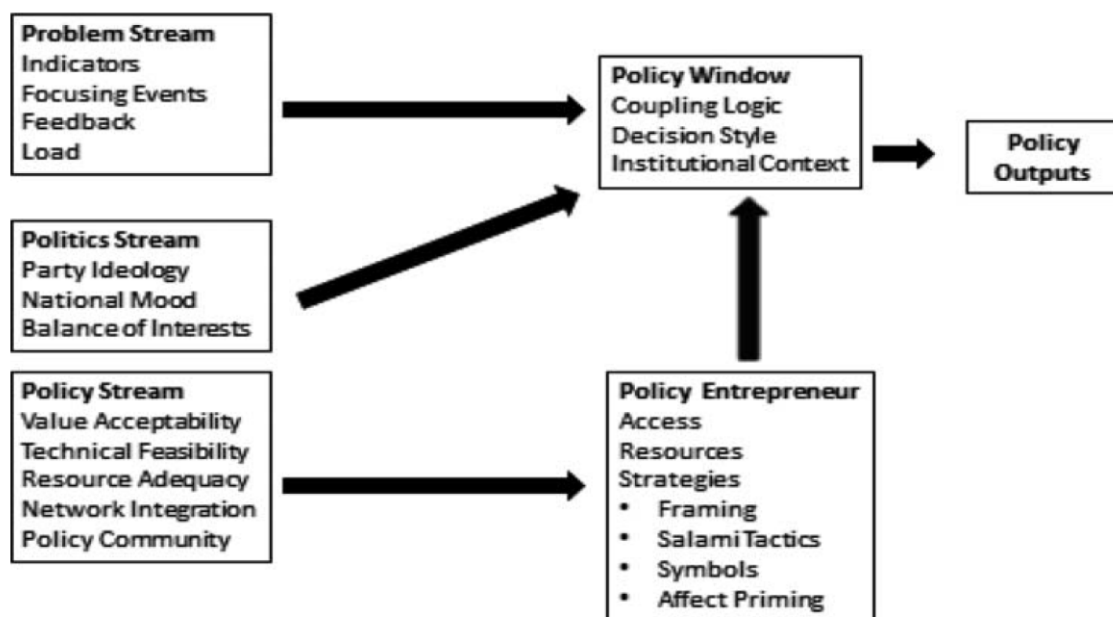


Figure 2: Diagram of Multiple Streams Approach<sup>173</sup>

As the diagram above shows, the MSA has three independent streams (problems, politics, and policies) that converge at opportune times in ‘policy windows’ when coupled by ‘policy entrepreneurs.’<sup>174</sup> These independent streams offer insights into the barriers that African-Canadians face in influencing policies oriented at dismantling health inequities, which I will briefly touch upon below.

### *The Politics Stream*

The politics stream is comprised of national mood, party ideology, and balance of interests. The discussion above details elements of the national mood, with multiculturalism being the relevant policy discourse that frames much of the discussion about race in Canada. Unfortunately, that discourse may have suppressed a public appetite for change. A June 2017 poll conducted by Ipsos Public Affairs shows that 21%

<sup>173</sup> Jones et al., “A River Runs Through It,” 15.

<sup>174</sup> Jones et al., 16, 17, 18.

fewer Canadians believe that racism is a serious problem compared to those surveyed in 1992, despite more Canadians than ever before having been a victim of racism.<sup>175</sup>

Ironically, the same poll also shows that Canadians have become less ‘tolerant’ in the past 12 years, with fewer participants willing to live next to a neighbour of a different race and 16% of people who would never marry or have a relationship of a different race.<sup>176</sup> While it is important to note that the majority of Canadians polled do not subscribe to these views, the seeming regression in anti-racist sentiment combined with the increase in experiences of racism among Canadians augurs poorly for advocates of racial equity that include Black Lives Matter chapters across the country.

Party ideology varies from province to province, and of course between federal and provincial governments. The Liberal Party of Canada currently shapes the federal context. Their 2015 policy platform “A New Plan for a Strong Middle Class” contains no references to multiculturalism, racism, or health equity,<sup>177</sup> but Budget 2018 does devote \$23 million over two years towards a national consultation on anti-racism issues.<sup>178</sup> As noted above, the former Conservative government mostly pushed anti-racism efforts from the policy agenda. The provincial picture is varied. Nova Scotia, for instance, does not have a province-wide anti-racism plan. The province is, however, conducting an inquiry into the abuse conducted at the Nova Scotia Home for Colored Children (NSHCC), and is using the inquiry as a platform to explore systemic and institutionalized racism.<sup>179</sup>

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<sup>175</sup> Ipsos Public Affairs and Global News, “Canada’s 150th Anniversary,” 19, 20.

<sup>176</sup> Ipsos Public Affairs and Global News, 21.

<sup>177</sup> Liberal Party of Canada, “A New Plan for a Strong Middle Class.”

<sup>178</sup> Government of Canada, “Budget 2018.”

<sup>179</sup> Government of Nova Scotia, “Reflection and Action Task Group Report to Legislature.”



Ontario, a province that does have an explicit anti-racism plan that includes disaggregated race-based data collection, recently changed government from the Liberal Party to the Progressive Conservatives. While there has been no official announcement from Premier Ford about the status of the Anti-Racism Directorate or implementation of the *Anti-Racism Act, 2017*, a spokesperson for the Progressive Conservatives has already confirmed that the government will be restoring funding for TAVIS, a controversial violence-suppression program that utilized carding in heavily policed areas that critics called racial profiling.<sup>180</sup> Moreover, as Morgan notes, the previous Progressive Conservative regime led by Mike Harris in the 1990s dismantled core anti-racism policy efforts including the *Employment Equity Act* and the Ontario Anti-Racism Secretariat.<sup>181</sup> The new PC government has already moved the Anti-Racism Directorate (formerly a standalone agency) into the mandate of the Minister of Community Safety and Correctional Services, which implies a link between Black people and criminality.<sup>182</sup> It seems plausible, therefore, that the progress made under the leadership of Kathleen Wynne and the Liberal Party of Ontario could be halted or reversed.

Balance of interests, or the aggregate position of relevant interests,<sup>183</sup> again varies based on provincial jurisdiction. A critical mass of advocates and activists can prompt governments to introduce policy aimed at addressing racial health inequities as evidenced by Ontario's introduction of the *Anti-Racism Act, 2017* after pressure from community groups including Black Lives Matter-Toronto.<sup>184</sup> It is, therefore, possible for advocates

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<sup>180</sup> White, "Doug Ford Plans to Restore Controversial Measures after Toronto Shootings."

<sup>181</sup> Morgan, "Populism and Racism in Two Ontario Elections."

<sup>182</sup> Government of Ontario, "News from the Secretary | Ontario.Ca"; Abdillahi et al., "Black Community Reps Pen Open Letter to John Tory and Doug Ford on Gun Violence."

<sup>183</sup> Jones et al., "A River Runs Through It," 16.

<sup>184</sup> Ngabo, "Toronto Advocates Applaud Race-Based Data Collection Initiative | Metro Toronto."

and interest groups to influence policy change when they are cohesive and vociferous in their demands for transformation. This method, however, seems difficult to replicate on a national stage. The Federation for Black Canadians, which was founded at the beginning of 2018, is the first national organization representing African-Canadians for decades.<sup>185</sup> Many organizers and activists, however, are suspicious of the group's intentions because of its connections to the federal Liberal Party, and because the chair of the group is a sitting judge in Ontario.<sup>186</sup> This suspicion (and the cause for the suspicion itself) may undermine attempts at building coalitions to develop advocacy initiatives that aim to tip the balance of interests towards addressing racial health inequities.

### *The Problem Stream*

Indicators for action on racial health inequities are relatively scarce in Canada, as many jurisdictions do not collect disaggregated race-based health data. As discussed elsewhere in this thesis, the data that does exist indicates that there is a problem but does not provide much of a platform for policy action. It is impossible to rely on focusing events because they are, by definition, “jarring and sudden.”<sup>187</sup> There may be some feedback generated by initiatives like the Health Inequalities Data Tool, and by the antiracism consultations that the Department of Canadian Heritage will undertake, as well as by the recent report by the United Nations Working Group of Experts on People of African Descent, but those outcomes remain to be seen at the time of writing.

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<sup>185</sup> Nanji, “Black Canadians Mobilize Nationally for the First Time in Decades.”

<sup>186</sup> Mussa, “Activists Question Federation of Black Canadians’ Leadership, Ties to Liberals | CBC News.”

<sup>187</sup> Jones et al., “A River Runs Through It,” 15.

### *The Policy Stream*

If both the politics stream and the problem stream remain unavailable as potential drivers of policy change, the policy stream is, therefore, the most likely avenue for policy change that currently exists for African-Canadians. The policy stream, according to Jones et al., consists of five subcategories through which policy proposals might be successful:

Proposals likely to survive conform to existing value constraints (value acceptability), the technical ability to actually create and/or implement the proposal is at least a possibility (technical feasibility), and the needed resources for the proposal are obtainable (resource adequacy). Finally, there are the policy communities (Kingdon, 1984) or policy networks (Zahariadis, 1999) associated with the ideas that shape how dissemination along dimensions of size, mode, capacity, and access influence an idea's proliferation or, in some cases, its extinction.<sup>188</sup>

Ontario's data collection protocol has demonstrated the feasibility of disaggregated race-based data collection.<sup>189</sup> The value constraints of such a policy are well within the mandate of public health professionals and policymakers, for whom data surveillance to eliminate health inequities is a well-established practice.<sup>190</sup> Policy networks of actors interested in addressing racial health inequities exist across Canada, from larger organizations like the Wellesley Institute or the National Collaborating Centre for Determinants of Health to smaller organizations like the Health Association of African

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<sup>188</sup> Jones et al., 16.

<sup>189</sup> Government of Ontario and Anti-Racism Directorate, "Data Standards for the Identification and Monitoring of Systemic Racism."

<sup>190</sup> Hicken et al., "Racial Inequalities in Health," 1.

Canadians. These networks and the communities that they represent are more than aware of the issues discussed in this chapter. Disaggregated health data collection would likely not reveal unforeseen information about the health inequities that these communities face. Data collection operates as a tacit acknowledgement by policymakers of once-ignored policy discourses well understood by those affected by racism. It may, therefore, offer a platform for policy entrepreneurs to open a policy window for concrete action on racial health inequities.

### **Conclusion**

Discourses of multiculturalism obscure the history of racial discrimination in Canada, masking the extent of the inequities that racialized communities have faced and continue to face. It is essential for policymakers committed to addressing racial health inequities to recognize Canada's history of discrimination and to understand the links between that history and the racial health inequities that people currently face.

Policymakers cannot adequately address the issues of racism that emerge from Canada's history by using colourblind approaches – an explicit engagement with anti-racist approaches is necessary to address these existing inequities. By using the Multiple Streams Approach, I demonstrated that the most viable option for change in the present policy context is by utilizing policy networks as a platform for shaping data collection policies, which thus provide indicators for contextualizing the shape and extent of racial health inequities.

To directly address Counterpoint 1, it is clear that race is a relevant factor in discussions of health policy within provincial governments because race plays a role in determining the health of racialized Canadians. Given the profound impact of structural

and institutional racism on the health and wellbeing of African-Canadians in particular, any policy interventions designed to improve their health outcomes necessarily ought to address one of the significant causes behind the adverse outcomes in the first place.

Without data to support interventions and to galvanize support to open policy windows, however, placing policies designed to achieve racial health equity onto the policy agenda will be difficult to achieve. Disaggregated race-based health data operates, then, as a foundation and guide for future policy action.

Now that I have established why these indicators are so important to track, I will now outline how we track them in Canada. Unpacking the patchwork of data collection policies on a federal, provincial and municipal levels of governance will help in illustrating the scope of the challenges for interested policymakers in developing a cohesive approach to these issues.

## **Chapter 4: What data exists across federal, provincial and municipal jurisdictions?**

### **Introduction**

The current regimen for collecting race-based health data spreads out over municipal, provincial and federal jurisdictions. It is patchwork, and it has significant gaps when it comes to population-level disaggregated data collection. Both federal and provincial bodies across Canada are starting to develop disaggregated data collection capacity, but the success of their efforts on addressing racial health inequities is largely unknown.

Much of the health data that policymakers use in health services planning comes from three primary sources: the Census, sample surveys (especially the Canadian Community Health Survey) and administrative sources like health insurance registries. The federal government issues the Census, and many of the most prominent sample surveys. Provincial governments tend to rely on administrative data like insurance registries to plan health services and deliveries. Large municipalities like the City of Toronto also have the capacity and flexibility to engage in surveillance and have been acting as test sites for larger data collection initiatives. The decentralized and diffuse nature of a federal system like Canada means that there is little standardization in data collection protocols between different levels of government, or between jurisdictions on the same level of government. Ontario's *Data Standards for the Identification and Monitoring of Systemic Racism* may act as a useful template for provincial governments keen on establishing common ground with their counterparts. This chapter corresponds with Counterpoint 2: "*We have all of the data we need.*"

Before outlining the different types of data collection that occur on federal, municipal and provincial levels, it is important to give some context for the broader governance arrangements that structure public health in Canada.

### **Public health in Canada**

Public health, like other aspects of healthcare in Canada, is primarily a provincial responsibility (with some important caveats). Each province has a different political and economic climate that affect their engagement with policies aimed at addressing the social determinants of health (racial health equity included). The uneven application of public health interventions is a nationwide issue, particularly as it pertains to the social determinants of health. As Frank and Di Ruggiero note, health promotion initiatives are far less effective nationally if implemented according to each province's ability and willingness to pay for programming.<sup>191</sup>

The spatially-oriented nature of public health governance means that there are also both federal and municipal public health agencies like the Public Health Agency of Canada and Toronto Public Health that exist to address issues that arise within their various jurisdictions. These agencies are coordinated by the Pan-Canadian Public Health Network, which itself is governed by the Pan-Canadian Public Health Network Council that comprises policymakers from federal, provincial and territorial jurisdictions. The Council is accountable to the Conference of Federal, Provincial and Territorial Deputy Ministers of Health.<sup>192</sup> The upshot of this complex governance arrangement is that as the Network's *Blueprint for a federated system of public health surveillance in Canada*:

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<sup>191</sup> "Public Health in Canada," 191.

<sup>192</sup> Pan-Canadian Public Health Network, "About the Pan-Canadian Public Health Network."

*vision and action plan* notes, decision-making processes within the Network are cumbersome, and do not always include relevant partners.<sup>193</sup> Moreover, the fact that the Council is accountable to the F/P/T Deputy Ministers of Health means that they have little authority to implement policy without the sanction of another body that has its own internal negotiations to manage. This lack of decision-making authority for public health officials includes the Chief Public Health Officer of Canada, who no longer has organizational responsibilities over the Public Health Agency of Canada, and thus cannot set priorities or compel the government to act on their suggestions.<sup>194</sup> This lack of authority, combined with a network-based method of governance, presents difficulties to the coordination of nationwide efforts to collect race-based health data.

Public health agencies are also constrained by a continued stretch of budgetary freezes or cuts that hamper their ability to make progress on issues about the social determinants of health, including their data surveillance capacity.<sup>195</sup> Quebec's regional public health services, for instance, received a 33% cut in funding in 2015 that led to over a hundred job losses, despite public health only accounting for 2% of the provincial health care budget.<sup>196</sup> These cuts came despite Quebec's long-held reputation as the gold standard in public health delivery.<sup>197</sup> Nova Scotia, meanwhile, spent 1.9% of its provincial health budget on public health in 2017 – the same proportion as in the year

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<sup>193</sup> Public Health Agency of Canada and Pan-Canadian Public Health Network, *Blueprint for a Federated System for Public Health Surveillance in Canada*, 20.

<sup>194</sup> Potvin, "Canadian Public Health under Siege," 401.

<sup>195</sup> Dutt, "How Public Health Is Funded in Canada and Why That Needs to Change."

<sup>196</sup> Guyon and Perreault, "Public Health Systems under Attack in Canada," 326; Potvin, "Canadian Public Health under Siege," 402.

<sup>197</sup> Frank and Di Ruggiero, "Public Health in Canada," 191; Guyon and Perreault, "Public Health Systems under Attack in Canada," 326.



2000.<sup>198</sup> These cuts are symptomatic of what Louise Potvin terms as a Canadian public health sector “under siege.”<sup>199</sup> Chronic underfunding, combined with a complicated and disempowered intergovernmental decision-making process, only serves to make public health interventions into the social determinants of health less effective, which in turn contributes to justifying why public health initiatives receive less funding. This fragmented governance structure impacts the data collection framework that exists nationwide, creating a similarly scattered patchwork of initiatives and policies on federal, provincial and municipal levels. I have detailed the initiatives that exist within each jurisdiction below.

### **The Federal Government**

The federal government plays a significant role in health data surveillance. Among other data analyses, bodies such as Statistics Canada, the Public Health Agency of Canada, and the Canadian Institute for Health Information leverage federal resources to create snapshots of citizens’ perceived health and experiences within health systems across the country. This information is used by both federal and provincial governments to set public policy.

#### *The Census*

The Census, conducted by Statistics Canada, is meant to capture a 5-year snapshot of Canada's demography in a single day.<sup>200</sup> The short-form of the Census is sent out to every Canadian household, while the long-form of the Census is sent to approximately

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<sup>198</sup> Canadian Institute for Health Information, “Health Expenditures in the Provinces and Territories: Provincial and Territorial Chartbook, 2017,” 22.

<sup>199</sup> Potvin, “Canadian Public Health under Siege,” 402.

<sup>200</sup> Government of Canada, “Census of Population.”

25% of households.<sup>201</sup> The short-form version of the Census collects information like addresses, language spoken and marital status.<sup>202</sup> The long-form Census is different – it is the preeminent survey instrument used to guide social policy, including health policy. It speaks to issues of demography and measures differential outcomes in ways that the short-form Census cannot.<sup>203</sup>

The long-form Census was the centre of controversy in the early part of this decade. Statistics Canada, under the direction of Prime Minister Stephen Harper, replaced it in 2011 with the National Household Survey – a voluntary survey instrument.<sup>204</sup> The move was deeply unpopular within the public health community as well as more broadly among researchers and other civil society groups.<sup>205</sup> The Canadian Public Health Association claimed that, over the long term, the cancellation of the mandatory survey would “contribute to an increase in the overall health burden within our society, especially for the more vulnerable and marginalized members of our society.”<sup>206</sup> Despite initial claims from the former Chief Statistician of Canada that the data collection process for the National Household Survey mitigated the effects of removing the mandatory long-form survey, participation in the National Household Survey dropped 16.8% from 2006<sup>207</sup>.

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<sup>201</sup> Government of Canada.

<sup>202</sup> Government of Canada.

<sup>203</sup> The Wellesley Institute, “Socio-Demographic Data and Equity in Health Services in Ontario: Building on Strong Foundations,” 7.

<sup>204</sup> Government of Canada, “Statistics Canada.”

<sup>205</sup> The Wellesley Institute, “Socio-Demographic Data and Equity in Health Services in Ontario: Building on Strong Foundations,” 7; Ontario Council of University Libraries, “Cancellation of the Mandatory Long-Form Census - Background and Impact | Ontario Council of University Libraries.”

<sup>206</sup> Canadian Public Health Association, “The Impact of Cancelling the Mandatory Long-Form Census on Health, Health Equity and Public Health,” 3.

<sup>207</sup> Government of Canada, “The 2011 National Household Survey—the Complete Statistical Story,” para. 4.

Statistics Canada, under the direction of Prime Minister Trudeau, reinstated the mandatory long-form Census for the 2016 survey. It includes information about income, immigration, marital status, and visible minority status<sup>208</sup>. The long-form Census also asks some self-reported health questions that seek to establish whether the respondent is disabled, whether they are suffering from a long-term illness, or whether they manage a long-term emotional or psychological health issue<sup>209</sup>. One of the questions in the long-form Census explicitly asks participants to identify by disaggregated ethnoracial identifiers:

This question collects information in accordance with the *Employment Equity Act* and its Regulations and Guidelines to support programs that promote equal opportunity for everyone to share in the social, cultural, and economic life of Canada.

**19** Is this person:

Mark "X" more than one circle or specify, if applicable.

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai, etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Korean
- Japanese

Other — specify:

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Figure 3: Sample of ethnoracial identifier question in 2016 Census<sup>210</sup>

As sociologist Wendy Roth explains, Statistics Canada calculates racial identity with the understanding that non-visible minority status is proscribed to “people who (1)

<sup>208</sup> Government of Canada, “2016 Census of Population Questions, Long Form (National Household Survey).”

<sup>209</sup> Government of Canada.

<sup>210</sup> Roth, “Methodological Pitfalls of Measuring Race,” 2350.

mark themselves White or Aboriginal (in a separate question), (2) mark Latin American, Arab, or West Asian together with White, or (3) mark Latin American, Arab, or West Asian and provide a European write-in response (e.g. English).”<sup>211</sup> Selecting any other category determines an individual as a visible minority. While this approach does work in the context of the Employment Equity Act, Roth notes that we have no evidence that suggests the accuracy of these categories in measuring racial appearance.<sup>212</sup> Moreover, the health-related information that the long-form Census collects is limited in scope, and thus needs to be supplemented by other surveys that focus more specifically on how Canadians utilize and interact with their health system.

### *Sample surveys*

The most relevant survey for population health study is the Canadian Community Health Survey (CCHS), which is also conducted by Statistics Canada. It collects information about health status, utilization and determinants on a health region (or sub-provincial) level.<sup>213</sup> The CCHS is cross-sectional – it has a sample size of 65,000 people across the nation, but excludes:

persons living on reserves and other Aboriginal settlements in the provinces; full-time members of the Canadian Forces; the institutionalized population, children aged 12-17 that are living in foster care, and persons living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James.

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<sup>211</sup> Roth, 2349.

<sup>212</sup> Roth, 2350.

<sup>213</sup> Government of Canada, “Canadian Community Health Survey - Annual Component (CCHS).”

Altogether, these exclusions represent less than 3% of the Canadian population aged 12 and over.<sup>214</sup>

Statistics Canada conducts the voluntary survey annually, and in 2013, underwent an extensive overhaul that included disaggregated racial demography questions similar in structure to those on the Census and that also includes questions that adhere to the Everyday Discrimination Scale.<sup>215</sup> This survey is an important tool for policymakers on federal and provincial levels, and is “used to monitor, plan and evaluate programs to improve the health of Canadians.”<sup>216</sup>

Despite the benefits of the CCHS as a robust snapshot of Canadian health systems, the survey does have significant gaps. Some researchers have concerns about undersampling both in the CCHS and in the Census. Siddiqi et al. acknowledge that, though the CCHS has the largest sample of Black and Asian Canadians of any national health survey, sample sizes were still small enough to have potentially affected their study’s results, which suggests that “it is important to attend to sample size adequacy and representativeness.”<sup>217</sup> Rotondi et al. also found, utilizing a respondent-driven sampling method, that Toronto's Indigenous population (First Nations, Inuit & Métis) was significantly underrepresented in the 2011 Census – a conservative estimate of 55,000 people as opposed to the 19,270 noted in the Census.<sup>218</sup>

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<sup>214</sup> Government of Canada.

<sup>215</sup> Government of Canada, “Canadian Community Health Survey - Annual Component (CCHS) - 2013 Questionnaire.”

<sup>216</sup> Government of Canada, “Canadian Community Health Survey - Annual Component (CCHS).”

<sup>217</sup> Siddiqi et al., “Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada,” 140.

<sup>218</sup> Rotondi et al., “Our Health Counts Toronto,” 6.

Moreover, the CCHS acknowledges that they do not survey the institutionalized population. Given that African Canadians and Indigenous peoples are disproportionately represented in the prison system compared to the general population,<sup>219</sup> neglecting to sample those in prisons may reduce the validity of CCHS findings about racialized groups. The CCHS acknowledges that these exclusions represent less than 3% of the population, yet they also represent some of the most marginalized people in Canada. Those that are in prison are more likely to have poor health outcomes, but a lack of data prevents researchers from being able to track key indicators like mortality after release and prevalence of chronic disease.<sup>220</sup> Furthermore, offenders in Canada tend to stay for short stints in prison.<sup>221</sup> Therefore, the health status of prisoners is likely to play a role in the overall health of marginalized groups and thus may be relevant information for health system planning.

The CCHS is just one of the surveys included in the Public Health Agency of Canada's Health Inequalities Data Tool. The tool, a response to Canada's pledges to the Rio Political Declaration on the Social Determinants of Health, collates a host of national health-related surveys as well as Census information and information from Vital Statistics to allow interested researchers to manipulate a range of health outcomes by social stratifiers.<sup>222</sup> PHAC's goal in developing this tool is to illustrate the numerous ways in which health inequalities exist across the nation, and are amplified by social, ecological and economic contexts. Because one of the key sources for this tool is the CCHS,

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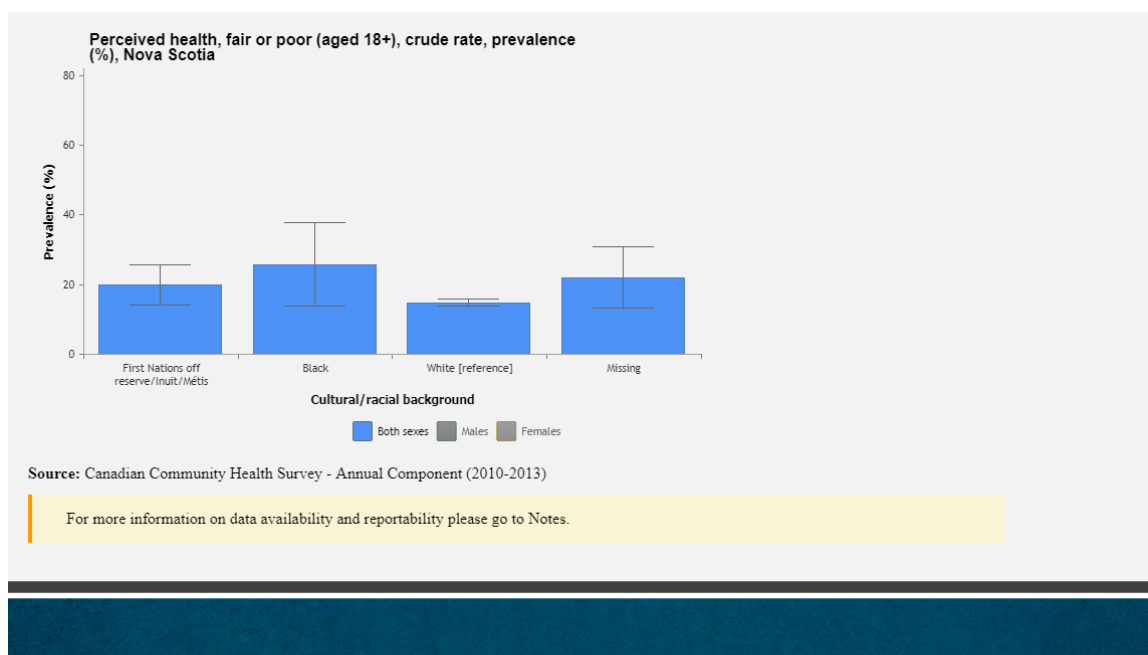
<sup>219</sup> Government of Canada, "Adult Correctional Statistics in Canada, 2015/2016."

<sup>220</sup> Kouyoumdjian et al., "Health Status of Prisoners in Canada," 218.

<sup>221</sup> Government of Canada, "Adult Correctional Statistics in Canada, 2015/2016."

<sup>222</sup> Public Health Agency of Canada, "Health Inequalities Data Tool."

however, it is hamstrung by the same issues of undersampling that potentially affect the validity of the CCHS. Figure 4 shows a graph of self-reported perceived health (fair to poor) in Nova Scotia, disaggregated by race and presented as a crude rate of persons who rated their health as poor relative to the total population of people in each racial category sampled from 2010-2013:



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

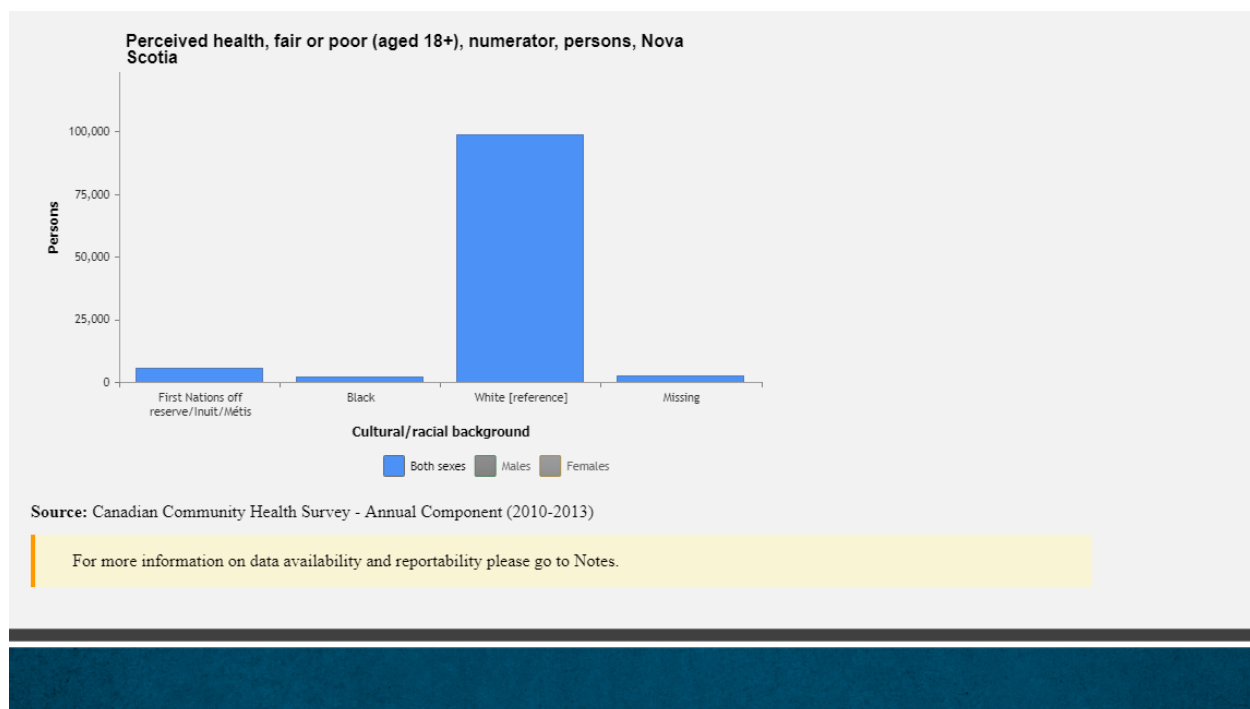
Canada

Figure 4: Chart showing the prevalence of interviewees who perceive their health is fair or poor disaggregated by race, shown by crude rate<sup>223</sup>

The figure demonstrates that more Black people and First Nations people who live off-reserve, as well as Inuit and Métis populations, perceive their health to be fair or poor relative to the White population. It is a helpful depiction of the underlying challenges that face marginalized groups in Nova Scotia when compared to White people.

<sup>223</sup> Public Health Agency of Canada.

The impact of this graph is lessened when one sees these figures presented as numerators instead of as comparative rates:



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

Canada

Figure 5: Chart showing the prevalence of interviewees who perceive their health is fair or poor disaggregated by race, shown by numerator<sup>224</sup>

This graph shows the drastic numeric difference between populations who rated their health as fair or poor. For reference, 98,950 people who self-identify as White responded in this fashion, as opposed to 2,370 Black people and 5,660 First Nations people. The differences in these numbers illustrate the statistical challenges of relying on these numbers as a basis for health system planning. The minimal numbers of Black and First Nations individuals identified in Nova Scotia as part of the CCHS illustrate the challenge of utilizing cross-sectional data sources as representative of larger populations.

<sup>224</sup> Public Health Agency of Canada.



The margin for error within each of these datasets is significant enough to warrant concern about their larger applicability to the lives of marginalized communities.

Provincial governments, therefore, might be wary about relying on such a data source to act as a foundation for addressing health inequities.

### **Provincial governments**

Services provided by provincial governments are the primary access point for Canadians into the health system, and therefore are the primary repositories for data about the ways that Canadians access and navigate health services.

#### *Administrative Sources*

Administrative data sources are typically under the purview of provincial governments and are usually connected to service utilization, or insurance billing data. These sources are often more cost-effective and easier to administrate than surveys.<sup>225</sup> This data covers all residents within a province who may have utilized health services, and thus it provides a great deal of information about healthcare experiences, access and diagnosis of patients.<sup>226</sup> This data often does not include any demographic identifiers except date of birth, sex and location of patient access.<sup>227</sup> Table 1 lists where each province stands regarding collecting disaggregated race-based health data as of April 2018. Each category referenced in the table below is derived from the long-form version

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<sup>225</sup> The Wellesley Institute, “Socio-Demographic Data and Equity in Health Services in Ontario: Building on Strong Foundations,” 8.

<sup>226</sup> The Wellesley Institute, 8.

<sup>227</sup> The Wellesley Institute, 8.

of the 2016 Census, which asks specific questions about racial or ethnic background, First Nations/Inuit/Métis status, and immigration status<sup>228</sup>.

Province	Disaggregated collection by racial or ethnic group	Disaggregated collection by First Nations/Inuit/Métis status	Disaggregated collection by immigrant status
<b>British Columbia</b>	Intent to collect, but data is too sparse <sup>229</sup>	Operates the Tripartite Data Quality and Sharing Agreement between the First Nations Health Authority, the Ministry of Health and regional health authorities <sup>230</sup>	Intent to collect, but no data available <sup>231</sup>
<b>Alberta</b>	No data	Partnership between Alberta Assembly of Treaty Chiefs and province ongoing via the Alberta First Nations Information Governance Centre <sup>232</sup>	Maintains Alberta Immigrant Registry; covers primary immigration to the province only; last available data from 2008 <sup>233</sup>

<sup>228</sup> Government of Canada, “2016 Census of Population Questions, Long Form (National Household Survey).”

<sup>229</sup> Provincial Health Services Authority, “Priority Health Equity Indicators for British Columbia: Selected Indicators Report,” 1.

<sup>230</sup> Bruhn, “Identifying Useful Approaches to the Governance of Indigenous Data,” 19.

<sup>231</sup> Provincial Health Services Authority, “Priority Health Equity Indicators for British Columbia: Selected Indicators Report,” 1.

<sup>232</sup> McBride, “Data Resources and Challenges for First Nations Communities,” 16.

<sup>233</sup> Government of Alberta, *Immigrant Health in Alberta*.

Province	Disaggregated collection by racial or ethnic group	Disaggregated collection by First Nations/Inuit/Métis status	Disaggregated collection by immigrant status
<b>Saskatchewan</b>	Data collected on a health region (municipal) level about HIV/AIDS – visible minorities listed as “other” <sup>234</sup>	Data collected on a health region (municipal) level – no data on reserve <sup>235</sup>	No data
<b>Manitoba</b>	Ethnicity data collected about HIV/AIDS – self-reported and collected by follow-up interview with patient <sup>236</sup>	Data collected about population, within the Drug Program Information Network, and referring to HIV/AIDS <sup>237</sup>	No data
<b>Ontario</b>	Implemented Anti-Racism Act (2017) which calls for disaggregated race-based data collection across the public service, but excludes health information custodians <sup>238</sup>	Institute for Clinical and Evaluative Studies maintains data linkage agreements with the Chiefs of Ontario, the Métis Nation of Ontario and is working on a partnership with Tungasuvvingat Inuit <sup>239</sup>	About to implement Anti-Racism Act (2017) which calls for disaggregated race-based data collection across the public service that will include questions about immigrant status but excludes health information custodians <sup>240</sup>

<sup>234</sup> Saskatoon Health Region, “Social Determinants of HIV and AIDS - Ethnicity.”

<sup>235</sup> Saskatoon Health Region, “Better Health for All: Advancing Health Equity in Health Care.”

<sup>236</sup> Manitoba Health, Healthy Living, and Seniors, “Annual Statistical Update: HIV and AIDS 2014.”

<sup>237</sup> Manitoba Health, Seniors and Active Living, “Annual Statistics 2015-2016.”

<sup>238</sup> Government of Ontario, “Data Standards for the Identification and Monitoring of Systemic Racism.”

<sup>239</sup> Piper et al., “Walking the Path Together,” 7.

<sup>240</sup> Government of Ontario, “Data Standards for the Identification and Monitoring of Systemic Racism.”

Province	Disaggregated collection by racial or ethnic group	Disaggregated collection by First Nations/Inuit/Métis status	Disaggregated collection by immigrant status
<b>Québec</b>	No data	Issues <i>Avis sur Qanuilirpitaa?</i> (a health survey of Nunavik Inuit peoples <sup>241</sup> , as well as a reference document about the diet of First Nations and Inuit peoples <sup>242</sup> )	The Québec Population Health Survey and the HIV surveillance report collects information on immigrant status as well as language spoken <sup>243</sup>
<b>Nova Scotia</b>	No data	Established First Nations Client Linkage Registry in 2016 to improve surveillance of health outcomes for First Nations groups in the province <sup>244</sup>	No data
<b>New Brunswick</b>	No data	No data	No data
<b>Prince Edward Island</b>	No data	No data	No data

<sup>241</sup> Comité d'éthique de santé publique, "Avis sur Qanuilirpitaa? 2017 – How are we now? Enquête sur la santé des Inuits du Nunavik."

<sup>242</sup> Bergeron et al., "L'alimentation Des Premières Nations et Des Inuits Au Québec."

<sup>243</sup> Institut de la statistique Québec, "Enquête québécoise sur la santé de la population, 2014 – 2015 Questionnaire"; Bitera et al., "Programme de surveillance de l'infection par le virus de l'immunodéficience humaine (VIH) au Québec : rapport annuel 2016."

<sup>244</sup> Government of Nova Scotia, "Health Data Sharing Agreement Will Improve Health Care in First Nations Communities."

Province	Disaggregated collection by racial or ethnic group	Disaggregated collection by First Nations/Inuit/Métis status	Disaggregated collection by immigrant status
<b>Newfoundland and Labrador</b>	No data	Instituted the Indigenous Administrative Data Identifier to improve surveillance of health outcomes for First Nations groups in the province <sup>245</sup>	No data

Table 1: Table comparing provincial race-based data collection approaches across Canada

The table above illustrates significant gaps in data collection regimes across Canada. None of these datasets are standardized, which means that it is difficult to develop a systematic and comprehensive understanding of the issues that racialized groups in Canada face. Without standardization, policymakers may find it challenging to make informed interventions that holistically address extant health inequities.

With standardization in mind, Ontario’s draft data standards for disaggregated data collection may offer a template for adaptation in other jurisdictions that intend to begin race-based data collection, though a caveat must be made about the exclusion of health information custodians from the *Anti-Racism Act, 2017*. The standards explicitly state that the purpose of data collection is to “identify and monitor systemic racial disparities for the purpose of eliminating systemic racism and advancing racial equity.”<sup>246</sup> Being explicit about the anti-racism goals that underpin race-based data collection helps to clarify how these standards may be structured and how the data may be utilized. They

<sup>245</sup> Government of Newfoundland and Labrador, “Newfoundland and Labrador Indigenous Administrative Data Identifier Standard.”

<sup>246</sup> Government of Ontario and Anti-Racism Directorate, “Data Standards for the Identification and Monitoring of Systemic Racism,” 5.

also offer examples of racial categories and structured questions that might be utilized by other jurisdictions across Canada. While racial categories are contextually dependent, choosing a standardized set of choices for people to self-report may offer the comparability that policymakers may need to engage in meaningful policy interventions. Finally, the standards emphasize intersectionality as a core unit of analysis:

It is important to understand the complexities and differences in experiences of systemic racism. This may mean examining potential intersections between race, and religion or ethnic origin, for example, to identify whether Middle Eastern Muslims experience unique barriers compared to non-muslims, or Muslims who are described as “White.”<sup>247</sup>

Policymakers who seek to engage in disaggregated data collection should be aware that race, and racism, do not occur in a vacuum. Contextual factors magnify or lessen the impact of structural inequities, and change how individuals or communities experience them. Intersectionality is particularly salient as it relates to healthcare. As epidemiologist Greta Bauer notes, intersectionality can be useful for population health research as it offers precision and relevancy to the experiences of community members.<sup>248</sup> A data collection regime that takes this into account may, therefore, be more effective at delivering the kind of information that would be effective in mitigating health inequities.

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<sup>247</sup> Government of Ontario and Anti-Racism Directorate, 18.

<sup>248</sup> Bauer, “Incorporating Intersectionality Theory into Population Health Research Methodology,” 11.

## Municipal governments

Major census metropolitan areas and health regions like the City of Toronto, or the Saskatoon Health Region sometimes conduct sample surveys to monitor health inequities in their jurisdictions. An example of this is the “We Ask Because We Care” project conducted by Toronto Public Health, in conjunction with three area hospitals. The project issued a demographic survey to 2242 patients in five pilot sites about key socioeconomic indicators, including race and ethnicity, and their relation to their current health outcomes.<sup>249</sup> This project had a participation rate of 80%, and the report noted that patients were generally comfortable when approached by clinical staff who were well-trained and knowledgeable, as opposed to volunteers.<sup>250</sup> As seen in Figure 6, the survey asked participants to select a single racial category while utilizing the same racial categorizations utilized by the Toronto District School Board.<sup>251</sup>

6. Which of the following <b>best</b> describes your race? <b>CHECK ONE ONLY.</b>	
<input type="radio"/> Aboriginal (e.g., Inuit, First Nations, Non-status Indian, Métis, Aboriginal person from outside Canada)	<input type="radio"/> Latin American (e.g., Argentinean, Chilean, Salvadoran)
<input type="radio"/> Asian - East (e.g., Chinese, Japanese, Korean)	<input type="radio"/> Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
<input type="radio"/> Asian - South (e.g., Indian, Pakistani, Sri Lankan, Indo-Caribbean)	<input type="radio"/> Mixed heritage (Please specify) _____
<input type="radio"/> Asian - South East (e.g., Malaysian, Filipino, Vietnamese)	<input type="radio"/> White/ European (e.g., English, Italian, Portuguese, Russian)
<input type="radio"/> Black - Africa (e.g., Ghanaian, Kenyan, Somali)	<input type="radio"/> Other(s) (Please specify) _____
<input type="radio"/> Black - North America	<input type="radio"/> Prefer not to answer
<input type="radio"/> Black - Caribbean Region (e.g., Barbadian, Jamaican)	<input type="radio"/> Do not know

Figure 6: Racial identification survey questions utilized by the “We Ask Because We Care” project<sup>252</sup>

<sup>249</sup> Agic et al., “We Ask Because We Care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report.”

<sup>250</sup> Agic et al., 28, 32.

<sup>251</sup> Agic et al., 31.

<sup>252</sup> Agic et al., 45.

This project shows the flexibility that larger municipalities and health regions have in innovating in data collection methods and standards. Provincial governments can monitor the outcomes of pilot projects like “We Ask Because We Care” without taking on the cost burden and potential political fallout created by province-wide implementation. As governments begin to interrogate the feasibility of race-based data collection in their jurisdictions, it may be worth engaging with the public health units within these municipalities and health regions to discover creative ways of gathering this information.

## **Conclusion**

The current state of race-based health data collection in federal, provincial and municipal governments across Canada is a patchwork of measures that lack comparability and comprehensiveness. Responding directly to Counterpoint 2, there is much that we do not know about the state of racial health inequities in Canada, and the policies necessary to alleviate them. The decentralized nature of health governance in Canada, combined with the underfunding of public health departments across the country, contribute to the significant gaps in knowledge that we have about racial health inequities. There are several promising initiatives, including the Ontario provincial government’s data standards as mandated by the *Anti-Racism Act, 2017*, and the Public Health Agency of Canada’s Health Inequalities Data Tool, but it remains to be seen whether these initiatives have a substantive impact on shifting racial health equity onto the policy agenda.

Before policymakers can engage in a conversation about changing the current state of data collection protocols across Canada, they must confront more in-depth,



theoretical debates within the biomedical community about how to approach race. The advent of genomics and biomedicine has rendered these debates as crucial in forming policy approaches to health inequities that exist among racialized peoples.

## **Chapter 5: Race, genetics, and health**

### **Introduction**

Now that I have outlined the current state of health data collection regimes across Canada, I will now turn my attention to some of the underlying theoretical debates within the biomedical community that could be used as evidence to suggest that collecting race-based health data might be an invalid approach to ameliorating health inequities.

One such debate is about what some call the ‘concept of race,’ which asks whether race is a useful scientific identifier between human beings, or whether it has no biological basis, and thus should be excised from scientific discourse. This debate is particularly fervent in the context of genomics and personalized medicine.

Some researchers believe that race, as a social construction, has a limited place (or no place at all) in assessing clinical outcomes or in creating medicines to address disease.<sup>253</sup> There are others who believe that race is biologically grounded, and that differential health outcomes are the result of the genetics of different races.<sup>254</sup> A third perspective, espoused by social epidemiologists like Nancy Krieger, notes that our social and ecological contexts are embodied through expressions and distributions of disease.<sup>255</sup> One side of this debate approaches, at its extreme, medicine as ‘colourblind,’ while the other side risks engaging in scientific racism and discussions of eugenics. Researchers face challenges of assumption and bias which are transmitted to policymakers by the assumption of the neutrality of scientific research. The challenge for policymakers is,

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<sup>253</sup> Kaplan, “The Quality of Data on ‘Race’ and ‘Ethnicity’”; Marks, “The Realities of Races”; Moscou and Baker, “The Role of Race in Clinical Decision Making.”

<sup>254</sup> Shiao et al., “The Genomic Challenge to the Social Construction of Race”; Reich, “Opinion | How Genetics Is Changing Our Understanding of ‘Race.’”

<sup>255</sup> Krieger, “Methods for the Scientific Study of Discrimination and Health,” 936; Brondolo, Gallo, and Myers, “Race, Racism and Health.”

therefore, to challenge those assumptions and to think critically about what is said (and unsaid) in seemingly apolitical discussions. This chapter corresponds with Counterpoint 3, and contends that biomedical research on race is a contested site of knowledge that produces racial differences in treatment and care.

### **UNESCO Statements on Race**

To understand the difficulty of navigating the confluence of race, genetics and medicine, it is important to understand the historical context that produced these debates. After scientific racism was used throughout much of the 19<sup>th</sup> Century to justify the oppression and murder of marginalized communities, the genocide committed by the Nazi regime, as well as events such as the Tuskegee experiments led to a push in the 20<sup>th</sup> Century for scientists and for anthropologists to disavow race as a biological category. As Reardon notes, after World War II, the “canonical narrative of race and science” was that the scientific study of race was “replaced by studies of population and culture.”<sup>256</sup> UNESCO released two separate statements on race, each of which were designed to clarify the proper usage of race as it pertained to scientific inquiry.<sup>257</sup> These documents only prompted further debate. The first statement made the case that race, though more “social fact” than “biological myth” had some scientific meaning, but was unable to distinguish meaningful social traits or to determine a hierarchy of populations.<sup>258</sup> As Brattain observes, however, this stance was controversial:

Project directors discovered that little consensus existed beyond agreement about the wrongness of Nazism, and scholars who had begun to challenge the scientific

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<sup>256</sup> Reardon, *Race to the Finish*, 22.

<sup>257</sup> Reardon, 26.

<sup>258</sup> Brattain, “Race, Racism, and Antiracism,” 1387; Reardon, *Race to the Finish*, 29.

basis of the race concept itself proved to be in an increasingly embattled minority [...] The second statement recanted the first group's social constructivist position, returned to a biological definition of race, and, significantly, also affirmed older scientific traditions (and languages) by noting differences between "non-literate" and "more civilized" people on intelligence tests.<sup>259</sup>

The first statement reflects an antiracist stance that, given the political context, was a marked departure from scientific orthodoxy. The controversy generated by the statement reflected both political and ideological concerns with nations like South Africa and the United States reacting poorly to a document that undermined the racially segregated structure of their societies at that time<sup>260</sup>.

UNESCO's attempt to remove ideology from the scientific study of race ironically exposed the reluctance of many in the scientific community to eschew racial hierarchies from their work. As Brattain notes when explaining how the UNESCO statements connected to integration efforts in the United States: "The assumption that biological "difference" existed, common to scholars and nonscholars, racists and antiracists, was handily conscripted by segregationists to provide scientific-sounding arguments against integration."<sup>261</sup> The debate over UNESCO's statements on race presaged some of the debates over genomics that came after it, despite being largely forgotten by mainstream scientific discourses. Both racist and anti-racist (or anti-racist within the context of the 1950s) perspectives in this debate ended up perpetuating narratives that worked against a push for equity by racialized peoples all over the world,

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<sup>259</sup> "Race, Racism, and Antiracism," 1387, 1388.

<sup>260</sup> Brattain, 1398.

<sup>261</sup> 1408.

all while claiming objectivity and truth as their core motivation. The antiracist perspective did not account for the entrenched reality of racism in science, nor the resonance of those ideas within the public,<sup>262</sup> and thus served to give cover to the very ideologies it attempted to dismantle.

After the Statements on Race, the scientific community essentially split into two camps: those who aligned with social scientists in determining race as a social construct, and those who believed that race has a genetic basis worth investigating.<sup>263</sup> As technology improved and the idea of sequencing a human genome became achievable, initiatives like the Human Genome Diversity Project that sought to collect DNA from populations all over the world became profoundly controversial flashpoints in which narratives of scientific racism eventually ended up scuppering the project.<sup>264</sup>

### **Race and genetics**

As defined earlier, race is a social construction based on physical features like skin colour, malleable to different cultural and political contexts.<sup>265</sup> Some researchers conversely argue that there is significant overlap between lay conceptions of race and discrete genetic populations based on ancestral origins<sup>266</sup>. Shiao et al. argue that recent advances in sequencing the human genome have allowed geneticists to “identify an empirical structure within human genetic variation that at a certain scale resembles the continentally based racial classifications of the U.S. federal government.”<sup>267</sup> They claim

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<sup>262</sup> Brattain, 1406, 1410.

<sup>263</sup> Hunt and Megyesi, “The Ambiguous Meanings of the Racial/Ethnic Categories Routinely Used in Human Genetics Research,” 351.

<sup>264</sup> Hunt and Megyesi, 351; Reardon, *Race to the Finish*.

<sup>265</sup> National Collaborating Centre for Determinants of Health, “Let’s Talk: Racism and Health Equity,” 2.

<sup>266</sup> Lee, “‘Race’ and ‘Ethnicity’ in Biomedical Research,” 1184.

<sup>267</sup> Shiao et al., “The Genomic Challenge to the Social Construction of Race,” 68.

that the notion that race is socially constructed establishes a biological threshold for difference as so high that not even the concept of different biological species would be sufficient,<sup>268</sup> and suggest that “clinal classes” ought to be used alongside race in a manner akin to the distinction between biological sex and socially constructed gender.<sup>269</sup>

There is significant pushback to this line of inquiry in the literature. In a direct response to Shiao et al., HoSang disputes the notion that race is the most logical level of division between populations:

Geneticists and evolutionary biologists have discerned these population clusters (or more precisely, the geographic patterns of clinal variation) at many different scales—hemispheric, continental, subcontinental, regional, and so on... Put another way, if “African” is a “biological” category with explanatory power, then so might be every other grouping inferred in a population structure analysis.<sup>270</sup>

HoSang goes on to convincingly target the idea that by separating populations into ‘clinal classes,’ researchers are letting the data define the groups, noting that such a separation demands an *a priori* definition of race.<sup>271</sup> He notes that the contested alignment between self-reported race or ethnicity and genetic populations is not necessarily biological, but simply a reflection of established histories of migration: “At the most quotidian level, the findings suggest that a statistical analysis of genetic ancestry informative markers of a population in the United States that self-identifies as “black” is likely to bear a relationship to an analysis of populations sampled in some region of sub-Saharan Africa. And a population that self-identifies as Chinese is likely to be statistically related with a

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<sup>268</sup> Shiao et al., 70.

<sup>269</sup> Shiao et al., 72.

<sup>270</sup> HoSang, “On Racial Speculation and Racial Science,” 231.

<sup>271</sup> HoSang, 231.

population in China.”<sup>272</sup> HoSang’s emphatic response to Shiao et al.’s claims of the statistical validity of race reflects unease among researchers of a creeping sense of biological determinism. As Bamshad et al. note, designations of race and ethnicity capture some of the genetic information necessary to determine ancestry, but are incomplete and malleable estimations of a host of biological and environmental factors.<sup>273</sup> Claims that race or ethnicity are genetically correct distinctions matter because they affect the way that genetic diseases like sickle-cell anemia are researched and treated.

Sickle-cell anemia is a life-threatening hereditary disease of the blood that affects the shape of red blood cells, causing pain, infections and strokes among other symptoms<sup>274</sup>. It is common among people of sub-Saharan African descent both in diaspora and on the continent, affecting up to 3% of births in some parts of the continent<sup>275</sup> and approximately 8% of African-Americans<sup>276</sup>. This prevalence among people of African descent has led to an assumption of sickle-cell as a “black” disease<sup>277</sup>. The disease is also prevalent, however, in people whose ancestors come from “Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.”<sup>278</sup> Sickle cell trait (where one carries the sickle cell gene but does not present with the disease) is typically associated with areas where malaria is prevalent,<sup>279</sup> and the trait

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<sup>272</sup> HoSang, 233.

<sup>273</sup> Bamshad et al., “Deconstructing the Relationship between Genetics and Race,” 608.

<sup>274</sup> American Society of Hematology, “Sickle Cell Disease.”

<sup>275</sup> Grosse et al., “Sickle Cell Disease in Africa.”

<sup>276</sup> American Society of Hematology, “Sickle Cell Disease.”

<sup>277</sup> Lee, Mountain, and Koenig, “The Meanings of Race in the New Genomics,” 35.

<sup>278</sup> Centers for Disease Control and Prevention, “Data and Statistics | Sickle Cell Disease.”

<sup>279</sup> Piel et al., “Global Distribution of the Sickle Cell Gene and Geographical Confirmation of the Malaria Hypothesis.”

is linked with increased resistance to contracting malaria<sup>280</sup>. Moreover, as Figure 7 shows, the distribution of sickle cell is not uniform across the African continent:

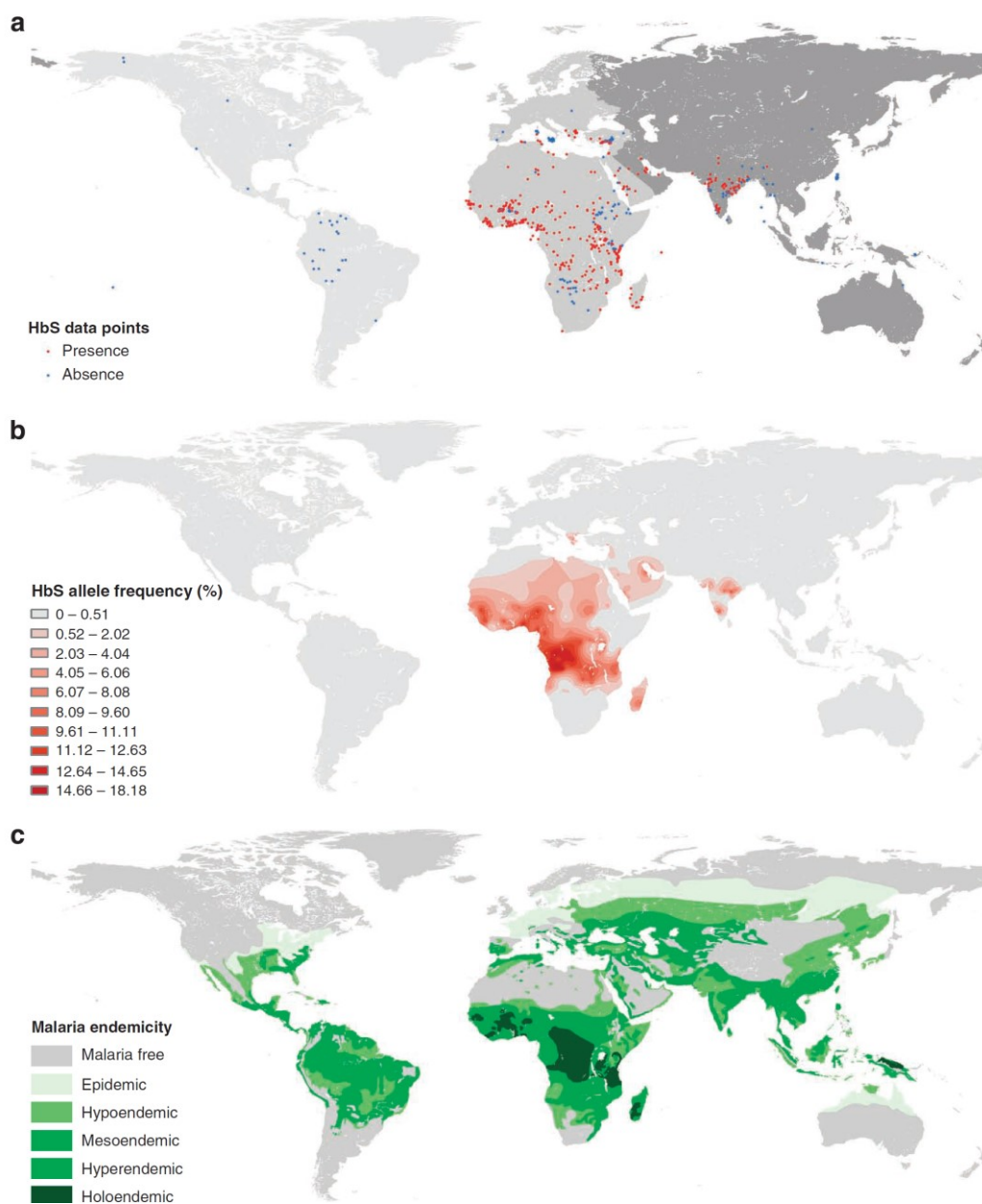


Figure 7: Maps comparing the global distribution of the sickle cell trait (HbS) to the endemicity of malaria<sup>281</sup>

<sup>280</sup> Serjeant, “The Natural History of Sickle Cell Disease.”

<sup>281</sup> Piel et al., “Global Distribution of the Sickle Cell Gene and Geographical Confirmation of the Malaria Hypothesis,” 3.



The map indicates that sickle cell is prevalent in western and central Africa, but non-existent in southern and eastern parts of the continent. Descendants of people from each of these regions would likely be considered Black in North America, yet they may have markedly different ancestries. Moscou and Baker illustrate the danger of these assumptions in a clinical setting, providing a case example of a Sierra Leonian man who was misdiagnosed with sickle cell anemia because he was Black (and misidentified as being African-American).<sup>282</sup> In actuality, the patient was suffering from schistosomiasis, a disease caused by parasites common to people in sub-Saharan Africa that can present as asymptomatic for years while causing damage to the bladder, organs and liver.<sup>283</sup> The disease is hard to detect in any circumstance, but the diagnosis was made more challenging by the assumptions that clinicians made about the patient's heritage and background.<sup>284</sup>

Moscou and Baker's case study illustrates the challenge of translating complex genetic notions of population and heredity into clinical assessments. While there is a clear relationship between genetic diseases like sickle cell and genetic populations that include people of African descent, reducing that relationship to race as observed by clinicians flattens many of the nuances that are necessary to make an informed judgement about disease. Knowing a patient's *self-identified* race or ethnicity may be helpful to clinicians in placing individuals in context, but this must be done with care, as Varcoe et al. have illustrated the significant harm that might be caused by this form of data collection.<sup>285</sup> Without a complete understanding of proximate relationships between genetic ancestry

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<sup>282</sup> Moscou and Baker, "The Role of Race in Clinical Decision Making," 43.

<sup>283</sup> Moscou and Baker, 45.

<sup>284</sup> Moscou and Baker, 45.

<sup>285</sup> Varcoe et al., "Harms and Benefits," 1665.

and social constructs like race and ethnicity, a clinician is in effect playing a biomedical game of ‘telephone,’ with misstatement after misstatement leading to potentially dangerous outcomes.

### **The BiDil Controversy**

Debates over the biological validity of race have continued with the advent of personalized medicine as a viable means of treatment. The introduction of drugs like BiDil into the marketplace marks a shift within the biomedical community towards medicalizing health inequalities. If these shifts were fully realized, they would undermine the central premise of collecting race-based health data – to map the social and ecological inequities that affect the health of racialized peoples. These debates expose how far the biomedical community is from a consensus on how to navigate biological and social realities in a way that acknowledges race as a social construction while also advancing genomic technology. This lack of consensus should inspire policymakers to be cautious about the assumptions that may influence the research they use to inform their work.

BiDil, a heart disease medication introduced in the United States in 2005, claimed to be the first tailor-made drug for African-Americans.<sup>286</sup> The drug combined two generic medicines that were previously on the marketplace into a single tablet, and trial results found that when added to standard therapy, BiDil reduced mortality in advanced heart failure patients who self-identified as Black<sup>287</sup>. These claims came despite the fact that, according to Roberts, there was “little evidence that race mattered to its [BiDil’s] efficacy.”<sup>288</sup>

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<sup>286</sup> Collier, “A Race-Based Detour to Personalized Medicine,” 351.

<sup>287</sup> Bibbins-Domingo and Fernandez, “BiDil for Heart Failure in Black Patients,” 52, 53.

<sup>288</sup> Roberts, “What’s Wrong with Race-Based Medicine?: Genes, Drugs, and Health Disparities,” 2.

The launch of BiDil was controversial, despite the medication having the endorsement of the National Association for the Advancement of Colored People (NAACP) as well as the Black Congressional Caucus and the Association of Black Cardiologists.<sup>289</sup> The drug's approval by the Food and Drug Administration was based in part on the belief that "nitric oxide uptake is different in blacks than whites,"<sup>290</sup> even though the researchers used a trial with only self-identified Black patients as proof that the medication was effective.<sup>291</sup> Moreover, subsequent testing of the drug could not definitively determine that the treatment did not work for patients of other races, undermining the implication that African-Americans should solely utilize BiDil.<sup>292</sup>

The researchers behind the development of BiDil contended that they utilized race as the "best available proxy" for a more precise form of genetic care.<sup>293</sup> Its advocates claimed that the drug would help to alleviate health disparities suffered by African-Americans, emphasizing that drugs like BiDil might help to encourage African-Americans to participate in health trials instead of avoiding them.<sup>294</sup>

Roberts argued that marketing BiDil as a race-specific medication renders its approval a political issue as opposed to a biomedical one, and states that this form of marketing may worsen racial inequities instead of alleviating them.<sup>295</sup> Reverby placed BiDil in a broader historical context, noting that the racial logic that underpins BiDil echoes the biological determinism that spurred the infamous Tuskegee study.<sup>296</sup> The drug

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<sup>289</sup> Roberts, 13.

<sup>290</sup> Reverby, "Special Treatment," 479.

<sup>291</sup> Bibbins-Domingo and Fernandez, "BiDil for Heart Failure in Black Patients," 53.

<sup>292</sup> Bibbins-Domingo and Fernandez, 53.

<sup>293</sup> Reverby, "Special Treatment," 478.

<sup>294</sup> Reverby, 479.

<sup>295</sup> Roberts, "What's Wrong with Race-Based Medicine?: Genes, Drugs, and Health Disparities," 2.

<sup>296</sup> Reverby, "Special Treatment," 479.

is an example of how the reification of race as a biological entity undermines attempts to deal with the social realities of discrimination, despite the good intentions of researchers. BiDil was offered as a panacea for health disparities among African Americans, despite the extensive evidence that suggests that those disparities are in fact a function of structural racism. Bibbins-Domingo and Fernandez place much of the responsibility for BiDil upon the FDA:

In more general terms, by invoking the rhetoric for health disparities and applying it to the drug approval process when no direct evidence exists, while ignoring the evidence that health disparities are driven by disparities in health care and a wide range of social conditions, the FDA reframes the debate on addressing health disparities without scientific basis... Reframing health disparities as a pharmacologic phenomenon distorts existing evidence and may lead to less evidence-based care.<sup>297</sup>

The transference of social issues into the biomedical realm creates a troubling precedent. As Braun (cited in Roberts) explains, the determination that disease is rooted in racial difference, whether that difference is about resistance or susceptibility to disease, is part of the foundational logic of beliefs that Black people are inferior.<sup>298</sup> Furthermore, the focus on personalized medicine may distract from efforts to address health inequities by diverting much-needed money and attention away from the social determinants of health.<sup>299</sup> Finally, there is evidence to suggest that there is significant undersampling of

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<sup>297</sup> “BiDil for Heart Failure in Black Patients,” 55.

<sup>298</sup> Roberts, “Race, Gender and the Political Conflation of Biological and Social Issues,” 239.

<sup>299</sup> Khoury and Galea, “Will Precision Medicine Improve Population Health?,” 1357; Bayer and Galea, “Public Health in the Precision-Medicine Era,” 500.

racial minorities in genomic databases, which reduces the validity of personalized medicines based upon results garnered from them.<sup>300</sup>

### **Moving forward: the ecosocial approach**

The policy implications of the approval of medicines like BiDil may make policymakers reticent to approach race in any sense when setting health policy. As Kahn notes when cited in Collier, the collection of health data that corresponds to socially acknowledged racial categories is paramount in addressing health disparities, as that is the only way to track how these disparities are maintained.<sup>301</sup> This reality leaves policymakers in a challenging position – by tracking race, they run the risk of reifying it as a biological reality. Yet by ignoring race, they risk turning an eye to sites of discrimination. Epidemiologist Nancy Krieger captures this tension when discussing the necessity of research that infers racism as the causal factor behind racial health inequities:

Knowledge of racial discrimination in wages, for example, can be obtained only if one knows what others are paid. Similarly, knowledge of racial inequality in the provision of medical care, above and beyond disrespectful interpersonal interactions, can be obtained only by comparing the types of treatment offered to groups that exhibit equivalent morbidity rates but differ in regard to their race/ethnicity.<sup>302</sup>

To understand disparities, in other words, we must have points of comparison: we cannot abstractly presume the existence (or lack thereof) of discrimination without data to support such a proposition. Therefore, tracking data about self-identified race as it

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<sup>300</sup> Landry et al., “Lack Of Diversity In Genomic Databases Is A Barrier To Translating Precision Medicine Research Into Practice.”

<sup>301</sup> “A Race-Based Detour to Personalized Medicine,” 352.

<sup>302</sup> Krieger, “Does Racism Harm Health?,” S22.

pertains to population health outcomes does not presuppose the biological reality of race. Instead, it aims to map how social relations affect biology. Ecosocial theory, as pioneered by Krieger, is a comprehensive model aiming to capture the relationship between biology and society without making essentializing claims about race.

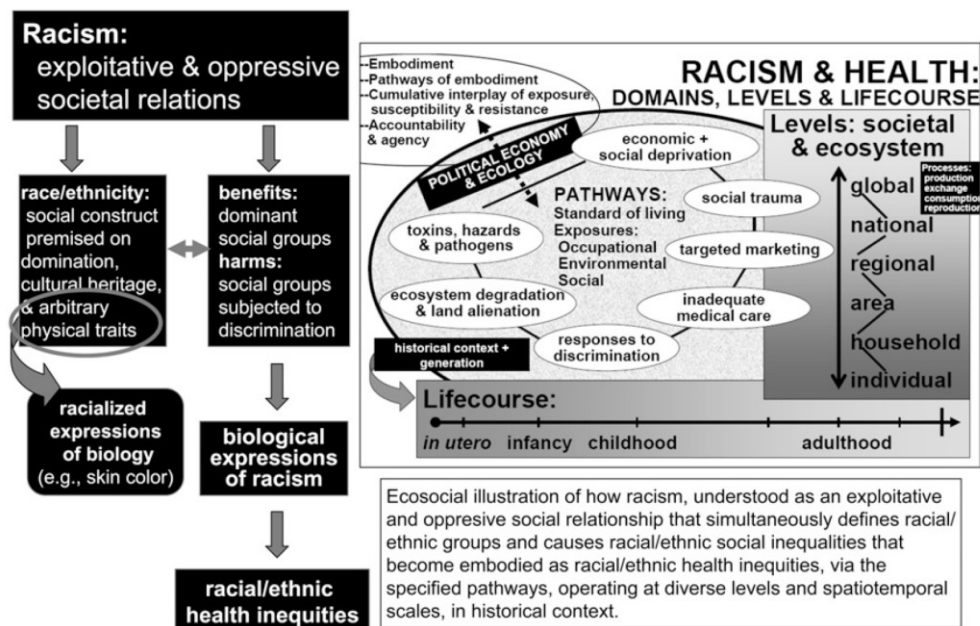
The core premise of ecosocial theory is that people embody (or biologically incorporate and express) the social and environmental contexts that they inhabit.<sup>303</sup> This embodiment occurs in “diverse, concurrent, and interacting pathways” that include environmental hazards, social deprivation and social trauma.<sup>304</sup> This context combines with biological susceptibilities and resistances to shape gene expression in individuals.<sup>305</sup> This theoretical approach is elegant insofar as it accounts for biological differences without reifying them as racial absolutes. Instead, the social realities of discrimination are shown to have a profound effect on the health of marginalized populations. Ecosocial theory tracks how these social realities have an impact across the lifecourse, with historical context shaping exposure to many of the pathways listed above. Figure 8 is a visual representation of how ecosocial theory functions:

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<sup>303</sup> Krieger, “Methods for the Scientific Study of Discrimination and Health,” 937.

<sup>304</sup> Krieger, 937.

<sup>305</sup> Krieger, 937.



Source: Krieger.<sup>7,17,18</sup>

Figure 8: A schematic illustration of ecosocial theory as it applies to racism<sup>306</sup>

The challenge with the illustration, and with the theory, is that it is complicated to understand, and harder still to operationalize in policy. The temporal and social scope of an ecosocial analysis requires proxies to translate the enormity of such a proposition into functional data. As Krieger notes, tests like the Everyday Discrimination Scale and the Implicit Association Test can be useful in gathering meaningful self-reported data about experiences of discrimination when placed in a broader context that includes nativity and domains of discrimination.<sup>307</sup> Ultimately, these methods of research require significant attention and resources, which must be supported by governments and communities to have a chance at being successful.

<sup>306</sup> Krieger, 938.

<sup>307</sup> Krieger, 939, 940.

## Conclusion

The complexity of debates around the role of race in biomedical research may act as a significant barrier to policymakers looking to begin collecting disaggregated race-based health data. Beliefs in race as a biological reality can lead to adverse clinical outcomes when uninterrogated, while the advent of personalized medicine and genomics creates unhelpful assumptions about potential biomedical solutions to social issues. The lack of consensus about the role race plays in genetics places policymakers in an uncomfortable position that requires an innovative, yet complicated, solution in ecosocial theory to help navigate potential pitfalls in collecting race-based health data. To paraphrase Krieger, the saying ‘no data, no problem’ will not suffice in a context fraught with misunderstanding, and with elevated stakes.<sup>308</sup>

Responding directly to Counterpoint 3, it is evident that clinicians do not necessarily treat patients in the same way when they are sick – that there are a host of uninterrogated assumptions about the biological basis of race that emerge in the process of treatment. These assumptions are best combatted with information – the kind of information that disaggregated race-based data collection would provide. By contextualizing racial health inequities in their social contexts, policymakers have an opportunity to provide evidence to challenge some of those assumptions while assisting clinicians in more accurately diagnosing and treating patients.

Even when armed with a parsimonious theory like ecosocial theory, policymakers may still be challenged by a legacy of neglect and discrimination by their predecessors, as

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<sup>308</sup> Krieger, 942.



well as by the challenges of discursive conflation and choosing precisely what social category to measure if they choose to collect data. The next chapter will unpack some of the difficulties in defining and measuring race as a data variable while exploring how ethnicity as a related, yet different variable is sometimes used euphemistically in research.

## **Chapter 6: Race, ethnicity, and methodology**

### **Introduction**

Discursive conflation is a significant challenge for researchers and policymakers when attempting to facilitate conversations about the links between social processes such as racism and health. As noted above, it is important for policymakers and for researchers to know exactly what they are measuring, and why they are measuring it if they decide to collect disaggregated race-based health data.

In the face of being perceived as entrenching racial bias by collecting race-based health data, researchers and policymakers may choose to utilize ethnicity to group populations. Researchers may perceive ethnicity as being “group-defined and voluntaristic,” with ethnicity being “achieved” and race being “ascribed.”<sup>309</sup> In other words, people can opt into, or out of ethnicity to some degree, but cannot do the same with race, which is chosen by others. That perceived choice thus provides researchers cover from the perception that they may be ascribing race to someone, which research subjects could interpret as a harmful form of stereotyping. This euphemistic approach to health data collection may, however, obscure the purpose of data collection, which is to observe and monitor inequalities that manifest as a form of societal discrimination, by choosing to avoid conflict.

Figuring out whether to collect health data based on race, ethnicity, or some combination of both is more complicated than it initially appears to be. Far from a simple question of technical accuracy, this decision also encapsulates ethical and methodological issues that include: whether measuring differences is the same as measuring inequities,

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<sup>309</sup> Lee, “‘Race’ and ‘Ethnicity’ in Biomedical Research,” 1184.

which version of racial identification is appropriate for data collection, and whether collecting this data at all might racialize people and cause them harm. Clarity about the explicit goals of data collection in provincial governments may assist policymakers in deciding what they want to measure, and whether disaggregating by race, by ethnicity or by both might assist them in doing so. This chapter corresponds to Counterpoint 4 and contends that the technical difficulty of collecting disaggregated race-based data is magnified by a lack of clarity about the goals of data collection.

### **Introducing ethnicity**

Ethnicity can be defined in two ways – as self-identified membership of defined social groupings, or as an externally imposed category based on nativity or ancestry, regardless of how a person might identify themselves.<sup>310</sup> Wimmer describes the second conception of ethnicity as emerging from the works of the German philosopher Johann Gottfried Herder:

In brief, according to Herder's social ontology, the world is made up of peoples each distinguished by a unique culture (1), held together by communitarian solidarity (2), and bound by shared identity (3). They thus form the self-evident units of observation and analysis (4) for any historical or social inquiry—the most meaningful way of subdividing the population of humans.<sup>311</sup>

While the insights of an eighteenth-century philosopher may not seem immediately applicable to a modern policy problem, Herder's conception of ethnicity is perhaps closest to the lay definition of shared ancestry or cultural background.<sup>312</sup>

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<sup>310</sup> Aspinall, "Operationalising the Collection of Ethnicity Data in Studies of the Sociology of Health and Illness," 830.

<sup>311</sup> Wimmer, "Herder's Heritage and the Boundary-Making Approach," 246.

<sup>312</sup> Merriam-Webster, "Definition of ETHNIC."

According to Wimmer, Herder's 'social ontology' can be applied to assimilation theory, with the idea being that eventually ethnic groups would assimilate into the 'mainstream' and thus become meaningless.<sup>313</sup> Multiculturalism also relies on the essential characteristics of ethnic groups, with the idea that those essential differences should be respected and preserved, as opposed to deconstructed as in the assimilationist milieu.<sup>314</sup> Both Winant and Wimmer note that Herder's definition, which slots people into essential characteristics, can be unhelpful and stereotypical.<sup>315</sup>

The challenge is, however, how to proceed from that point. Wimmer cites boundary theory as a possible *explanans*, which states that ethnicity is formed by a reversible process of boundary-making – a way for actors to differentiate themselves from others with specific cultural markers that they deem to be relevant.<sup>316</sup> In essence, it frames race as a form of ethnicity – another way that actors in one social group define themselves against another. Wimmer's definition of ethnicity is aligned with notions of colourblindness in biomedical research. It frames race as a 'folk' taxonomy (or one not rooted in scientific knowledge) which only adds a "somatic," or physical, element to other cultural markers of difference.<sup>317</sup> This approach, however, undermines the profound impact that race has on structuring the political and social processes of societies across the world, even though it transforms in different contexts.<sup>318</sup> It assumes that one can

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<sup>313</sup> Wimmer, "Herder's Heritage and the Boundary-Making Approach," 247.

<sup>314</sup> Wimmer, 248.

<sup>315</sup> Winant, "Race, Ethnicity and Social Science," 2178; Wimmer, "Herder's Heritage and the Boundary-Making Approach," 248.

<sup>316</sup> Wimmer, "Herder's Heritage and the Boundary-Making Approach," 250, 251, 254.

<sup>317</sup> Winant, "Race, Ethnicity and Social Science," 2180.

<sup>318</sup> Winant, 2181.

explain away political realities with parsimonious theory – that one can ignore the values and norms that dictate how power is distributed in our society.<sup>319</sup>

The apolitical nature of Wimmer’s explanation of ethnicity may be tempting for policymakers and researchers keen on avoiding stoking conflict and harm by asking people to identify by race. As Varcoe et al. showed in their study of ethnicity data collection in a clinical context in Western Canada, however, this categorization is not immune to fears of stereotyping and differential treatment.<sup>320</sup> Lee argues that the distinction between race and ethnicity in such a context is far less pronounced than some researchers might believe, that separating between chosen identity and assigned identity in the context of ethnicity is more challenging than researchers would expect and that non-members of an ethnic group can prohibit others from identifying with their chosen ethnicity.<sup>321</sup> The benefits of using ethnicity for analytical clarity are, therefore, reduced. The fact that non-members of an ethnic group can proscribe, or prohibit, membership (notwithstanding the potential tensions of membership within ethnic groups) demonstrates that ethnicity is as contested and imprecise of a metric as race may be.

Given the imprecise and contested nature of ethnicity, using it as an apolitical replacement for race in research does little to solve the problems that proponents claim that it will solve. Hunt and Megyesi are concrete about their position on using race or ethnicity in biological research: “It is our position that, despite claims to scientific neutrality, we do in fact live in a racialized society, and the prevalent notions of group

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<sup>319</sup> As Winant puts it on page 2178: “social facts in the Durkheimian sense...given by politics.”

<sup>320</sup> Varcoe et al., “Harms and Benefits,” 1663.

<sup>321</sup> “[a] strictly achieved versus ascribed distinction may suggest falsely that there is greater analytical difference between the two than there really is. Furthermore, research on ethnic identity suggests that non-members may categorically proscribe ethnicity,” found in Lee, “‘Race’ and ‘Ethnicity’ in Biomedical Research,” 1184.

differences will drive interpretations of racialized data, no matter what labels are used, or what additional variables are included.”<sup>322</sup> Using ethnicity as a euphemistic means of differentiating between populations then, offers many of the same pitfalls of categorizing populations by race as similar processes of reification and imprecision are present in both.

The usefulness of Wimmer’s definition of ethnicity for policymakers is thus dependent on the goals of data collection. Measuring difference is not the same as measuring inequity, and as such, it is necessary for policymakers to directly address the social and political roots of why data ought to be collected in the first place. The irony of using ethnicity as a data-gathering category as opposed to race is that in attempting to craft a more accurate or less offensive description of population groups than race, researchers may introduce a whole new set of assumptions about who is included and excluded in particular groups. There is nothing wrong with using ethnicity as a category to collect data, but it is important that policymakers and researchers are clear about why they are using it as opposed to race, lest they gather data that does not apply to the needs of the communities they are researching.

Understanding the goals of research about the population groups whose data they seek to gather may assist in making research feasible and applicable for policymakers and community groups. As we will see further below, clarifying those research goals is more of a challenge than it may initially appear.

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<sup>322</sup> “The Ambiguous Meanings of the Racial/Ethnic Categories Routinely Used in Human Genetics Research,” 359.

### **Ethnicity in the Canadian context**

The use of ethnicity as a kinder, gentler demarcation of populations is particularly prevalent in Canada. Hinterberger highlights, when discussing the CARTaGENE biobank project based in Quebec, that ethnicity is often used in the Canadian health context to describe multicultural diversity while race is avoided as a potentially stigmatizing term: “The disclaimer itself (that the project will not deal with race) suggests that race is important insofar as it is kept separate from the project so as not to arouse “certain sensitive subjects” (though these are not explicitly articulated).”<sup>323</sup> Here, we see that the use of ethnicity by CARTaGENE researchers is based, in part, on avoiding perceptions of racism by not discussing those issues at all.

Hinterberger notes that the project’s slogan, “the world within *you*,” is particularly important in this context as it is misleading: the attraction for many genomics researchers to Quebec is its population’s perceived homogeneity, despite the fact that said homogeneity overlooks the complex relationship between colonial settlers and Indigenous peoples in the past.<sup>324</sup>

Other genomics researchers working in Quebec have, in fact, decried the recent presence of other ethnicities in this previously homogenous gene pool, stating: “it is becoming difficult to find recruits for GWAS [the genomic study] because interracial marriages have increased more than 30% from 2001 to 2006.”<sup>325</sup> This statement illuminates the need for researchers in the Canadian context to understand and confront how both race and ethnicity may affect the shape and the outcomes of their work. The

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<sup>323</sup> “The Genomics of Difference and the Politics of Race in Canada,” 155.

<sup>324</sup> 156.

<sup>325</sup> Hinterberger, 157.

term “interracial marriage” invokes a history of separation by race which is present in Canada as well as in the United States. It is, therefore, a highly political term – one that is being used to signify a biologically significant difference in a province’s makeup. Such a claim deserves interrogation and clarity. As Hinterberger explains, “discourses of multicultural difference appear to be far from dead or failing and, if anything, are finding renewed vigor in the molecular intersections between health, difference, and disease.”<sup>326</sup>

The proliferation of these discourses signifies the need for an assessment of the role that race and ethnicity might play in biomedical and genomic research. The assumptions of the researchers quoted above play a direct role in the direction of their research. These assumptions are rooted in the notion that to identify race is to be offensive, despite a stated belief that race is having an impact on the ability for their research to be conducted appropriately. Allowing these assumptions to go unchecked, therefore, may undermine the clarity and validity of research.

### **Multiple dimensions of race and mixed-race identification**

The issues described above about the definitions of race and ethnicity take on further complexity when the actual process of data collection is underway. Lay understandings of concepts like race and ethnicity introduce a level of fluidity and imprecision to research as both concepts change from person to person and from context to context.<sup>327</sup> As Roth notes, perceptions of race may change based on how a person identifies their race, how others may perceive them, how they may perceive how others may see them, their ancestry, and the options presented to them based on surveys like

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<sup>326</sup> 161.

<sup>327</sup> Hunt and Megyesi, “The Ambiguous Meanings of the Racial/Ethnic Categories Routinely Used in Human Genetics Research,” 358.



censuses.<sup>328</sup> Measuring each of these perceptions may give researchers divergent results for the same question. Figure 9, a matrix created by Roth to demonstrate this complexity, shows how these different racial dimensions produce different research outcomes:

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<sup>328</sup> Roth, "The Multiple Dimensions of Race," 1310.

Dimension of Race	Description	Typical Measurement	Also described as	Outcomes it may be appropriate for studying
RACIAL IDENTITY	Subjective self-identification, not limited by pre-set options.	Open-ended self-identification question	“Internal race” (Roth 2010); “Self-ID” (Scholler 2013); “racial identification” (Newby and Dowling 2007)	Political mobilization; assimilation; social networks; voting; residential decision-making; attitudes
RACIAL SELF-CLASSIFICATION	The race you check on an official form or survey with constrained options (e.g. the Census, college financial aid form, the GSS, etc.)	Closed-ended survey question	“Expressed race” (Roth 2010); “expressed internal race” (Harris and Sim 2002); “Census race” (Bailey 2008); “self-reported race” (Saperstein 2006); “racial identification” (Saperstein and Penner 2012)	Demographic change; vital statistics; disease and illness rates  <i>*Often used as a proxy for Racial Identity</i>
OBSERVED RACE	The race others believe you to be	Interviewer classification	“External racial identity” (Harris and Sim 2002); “racial classification” (Saperstein and Penner 2012); “racial identification” (Xie and Goyette 1997)	Discrimination; socioeconomic disparities; residential segregation; criminal justice indicators; health care/service provision
- Appearance-Based	Observed race based on readily observable characteristics	Interviewer classification with instructions to classify on first observation		- Racial profiling; discrimination in public settings
- Interaction-Based	Observed race based on characteristics revealed through interaction (e.g. language, accent, surname)	Interviewer classification with instructions to classify after interaction or survey		- Workplace discrimination; housing discrimination; language/accent-based discrimination
REFLECTED RACE	The race you believe others assume you to be	“What race do most people think you are?”	“Perceived” race (Vargas 2015)	Self-identification processes, perceived discrimination  <i>* Often used as a proxy for Observed Race</i>
PHENOTYPE	Racial appearance	Usually interviewer classification		Discrimination; socioeconomic disparities; residential segregation; criminal justice indicators; health care and service provision
- Color	Skin color	Usually interviewer classification on a likert scale or color palette		
- Other features	Hair texture or color, nose shape, lip shape, eye color	Usually interviewer classification on a series of categorical variables		
RACIAL ANCESTRY	The compiled racial groups of your ancestors			
- Known	What you believe your racial ancestry to be based primarily on family history	Self-report, often open-ended		Assimilation; racial boundary formation; social closure; disease and illness rates
- Genetic	Deep ancestry indicated by genetic testing	Analysis of ancestry informative markers by researchers or direct-to-consumer companies	“Genetic ancestry” (Royal et al. 2010); “Genome-wide ancestry” (Perez et al. 2013); “Ancestry inference” (Bolnick 2008)	Self-identification processes

Figure 9: Matrix showing how racial dimensions are measured to produce different research results<sup>329</sup>

<sup>329</sup> Roth, 1313.

Figure 9 demonstrates that many of these racial dimensions might be useful in the context of health policy but might provide differing insights for policymakers. For example, understanding reflected race, or what race a person thinks others perceive them to be, might be a great way of assessing the impact of interpersonal discrimination on health outcomes by measuring indicators like ambulatory blood pressure. It might not be useful, however, in understanding the potential drivers of residential segregation, which are more likely to be understood by using racial identity that could act as a proxy to understanding social networks and residential choice.

There are, however, risks to using some of these racial dimensions: the racial self-identification category (akin to tick boxes on a Census form) may restrict the capacity for mixed-race people to express what they perceive their racial identity to be by forcing them to ‘choose’ a race that best suits them.<sup>330</sup> Canada allows individuals to mark more than one ‘box’ on the Census, which provides for granularity in the data that is not found across much of the rest of the world.<sup>331</sup> This approach may not account for the context that might prompt an individual’s answers to these questions, creating uncertainty about whether their answers are an accurate reflection of their racial identity.<sup>332</sup> Moreover, as Kaplan notes, the wording of racial self-identification questions on census forms may have a significant effect on the kinds of answers that people may provide: “For example, when respondents are asked to choose one or more categories that “best describe” their race, they may be biased toward an answer reflecting external appearance because the

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<sup>330</sup> Roth, 1314; Aspinall, “What Kind of Mixed Race/Ethnicity Data Is Needed for the 2020/21 Global Population Census Round,” 1; Mihoko Doyle and Kao, “Are Racial Identities of Multiracials Stable?,” 418.

<sup>331</sup> Aspinall, “What Kind of Mixed Race/Ethnicity Data Is Needed for the 2020/21 Global Population Census Round,” 12.

<sup>332</sup> Roth, “The Multiple Dimensions of Race,” 1313.

word “describe” carries visual connotations.”<sup>333</sup> These subtle nuances can have a significant effect on the outcomes of data collection, and thus should be considered when creating a data collection regime.

Utilizing observed race as a data collection category, which might assist in determining whether discrimination may play a role in health service delivery, presents further risks. Stepanikova found that racial misclassification associated with status loss in the American context (in a hierarchy where non-Hispanic White people were at the top, and Black people were at the bottom) was correlated with physical and mental symptoms of distress, whereas misclassification that did not map onto status loss had no health effects.<sup>334</sup> In other words, being classified as a race with ‘lower’ status could affect a person’s health. This study further highlights the potential risks that Varcoe et al. alluded to in their study about collecting ethnicity data in a clinical context (though that study allowed patients to self-identify). By collecting data about observed race without fully ascertaining an individual’s consent to be categorized in this way, researchers may be exposing participants to harm and distress through misidentification or stereotyping.

## **Conclusion**

The methodological challenges of collecting data based on race or ethnicity are profound. Lay person understandings of both terms obscure the complexity of self-identification vs. observation, nativity vs. community, and boundaries vs. innate membership. For policymakers to be able to measure health inequities, they need to utilize terminology that focuses on the role that power relationships might have on health

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<sup>333</sup> Kaplan, “The Quality of Data on ‘Race’ and ‘Ethnicity,’” 221.

<sup>334</sup> Stepanikova, “Applying a Status Perspective to Racial/Ethnic Misclassification.”

outcomes. To do this, they must be clear about what social processes they wish to understand and attempt to mitigate the harms that might emerge from perceptions of stereotyping. I do not mean to imply that ethnicity is a less impactful or relevant social stratifier than race is – that would be an inaccurate and offensive statement. Rather the notion that ethnicity is less divisive of a stratifier, and therefore a better tool to use in health research, is a problematic one if the goal of research is to address health inequities. When policymakers, researchers and community members are all aligned in the planning and execution of health research focusing on racial or ethnic communities, however, the technical difficulties outlined in Counterpoint 4 and this chapter become far easier to navigate. The next chapter will provide a pertinent example of what can be achieved regarding tracking and understanding health inequities when clarity of purpose meets a relationship of trust and respectful engagement.

## **Chapter 7: Indigenous peoples and data sovereignty**

### **Introduction**

First Nations, Inuit and Métis peoples have a long history of suffering from racial health inequities and racial discrimination within Canadian health systems. Some of these communities (hereby referred to as Indigenous peoples when mentioned together) have recently been able to implement innovative partnerships with provincial governments to create robust datasets that help policymakers, researchers and community members identify and address health inequities. These partnerships, when placed adjacent to the experiences of African-Canadian communities, offer a promising demonstration of community sovereignty over health data while maintaining robust communication between community leaders and provincial policymakers.

While the principles held by Indigenous peoples when securing health data partnerships may be instructive for racialized peoples, we cannot conflate the unique relationship between Indigenous peoples and the Crown as represented by governments in Canada with the relationships that racialized peoples have with federal or provincial governments. With this important caveat in mind, the existence of these partnerships (and the client registries that have these partnerships have spawned) offer some exciting opportunities for policymakers interested in finding community-centric approaches to health data collection. This chapter corresponds with Counterpoint 5 and demonstrates that the collection of disaggregated health data does not necessarily have to be divisive.

This chapter will provide a brief outline of the history of Indigenous communities in health systems across Canada, before discussing the advent of OCAP® data collection

principles and the data sovereignty movement. Finally, it will analyze some of the current partnerships that exist between provincial governments and Indigenous communities across Canada, noting the strengths and the weaknesses of the client linkage approach while also commenting on applicability from Indigenous communities to racialized peoples.

### **Indigenous communities and health**

There are three constitutionally recognized population groups comprising the original peoples of North America and their descendants: First Nations, Inuit, and Métis.<sup>335</sup> Within these groups, there is profound diversity – there are over 630 different First Nations communities in Canada that represent over 50 different Nations and 50 different languages.<sup>336</sup> While it is beyond the scope of this thesis to detail the extensive history of discrimination and cultural genocide that Indigenous peoples have faced in this nation,<sup>337</sup> it is important to touch on a small section of this history as it relates to the current patchwork of healthcare that Indigenous peoples in Canada receive.

In 1876, the federal government passed the *Indian Act*, which outlined the terms by which the federal government would engage with First Nations peoples (including the designation of people with status as wards of the Crown and the self-appointment of the federal government as the guardian of First Nations' land and resources).<sup>338</sup> Subsequent amendments to the *Indian Act* prevented First Nations peoples from traditional practices

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<sup>335</sup> Indigenous and Northern Affairs Canada, "Indigenous Peoples and Communities."

<sup>336</sup> Indigenous and Northern Affairs Canada, "First Nations."

<sup>337</sup> For more information, please consult the Royal Commission on Aboriginal Peoples, the Truth and Reconciliation Commission of Canada's report on residential schools, or read Mattison, Doxtater, and Lavis, "Care for Indigenous Peoples." for information on how this history applies to the current health governance structure for Indigenous peoples in Ontario.

<sup>338</sup> Mattison, Doxtater, and Lavis, 355.

including utilizing traditional medicine.<sup>339</sup> This act is fundamental in shaping the current structure of healthcare services for Indigenous peoples in Canada, as it “determines who has the right to live on-reserve, access Indian-specific federally funded programs and services, and qualify for certain individual-based health, social, and education benefits.”<sup>340</sup> Status, as defined by the Act was, however, used as a tool by the federal government to destroy First Nations communities as, until 1985, any status First Nations woman who married a non-status person lost her status and her benefits.<sup>341</sup> If this woman had any children, they would lose their status and benefits too.<sup>342</sup> While this section of the *Act* was amended in 1985 by Bill C-31, it merely pushes the loss of status to the second generation, which created problems of underfunding of social services and also of people born and raised on-reserve suddenly losing status.<sup>343</sup>

Indigenous peoples without status, including Métis and Inuit peoples excluded by the *Indian Act*, suffer social exclusion and cultural dislocation by being unable to engage with a communal identity – suffering from “statutory banishment” that removes political, social and economic rights.<sup>344</sup> These issues amplify the substantial health inequities that Indigenous peoples across Canada face, which include higher rates of chronic disease,

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<sup>339</sup> Mattison, Doxtater, and Lavis, 355.

<sup>340</sup> Lavoie, Forget, and Browne, “Caught at the Crossroad: First Nations, Health Care, and the Legacy of the Indian Act,” 86.

<sup>341</sup> Palmater, “Genocide, Indian Policy, and Legislated Elimination of Indians in Canada,” 28.

<sup>342</sup> Lavoie, Forget, and Browne, “Caught at the Crossroad: First Nations, Health Care, and the Legacy of the Indian Act,” 86.

<sup>343</sup> Lavoie, Forget, and Browne, 89.

<sup>344</sup> Palmater, “Genocide, Indian Policy, and Legislated Elimination of Indians in Canada,” 41, 42.



lower life expectancy, high rates of depression and post-traumatic stress disorder among many others.<sup>345</sup>

All Indigenous peoples, whether they have status or not, are eligible to access the same coverage and services that citizens of any province can access (which, of course, vary from province to province).<sup>346</sup> Despite the provinces' constitutional mandate to deliver healthcare, the *Constitution Act, 1867* gives the federal government jurisdiction over issues related to First Nations and their land,<sup>347</sup> while the *Indian Act* also gives the federal government jurisdictional authority over providing health services to First Nations and Inuit communities where a province or territory do not provide services.<sup>348</sup> Status, as defined by the *Indian Act*, determines access to the Non-Insured Health Benefits Program. The program covers a range of medically necessary goods and services including prescription medicines, dental and vision care, and crisis mental health counselling.<sup>349</sup> This jurisdiction overlaps with provincial governments' constitutionally demarcated responsibility for healthcare.<sup>350</sup> This overlapping governance structure can create significant issues for people who live near or on-reserve but who do not have status, as well as for people who live on-reserve in remote locations, as the implicit assumption is that they will revert to provincial care that could be challenging to access.<sup>351</sup>

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<sup>345</sup> Mattison, Doxtater, and Lavis, "Care for Indigenous Peoples," 360; Tait et al., "Our Next Generation," 56; Basdeo and Bharadwaj, "Beyond Physical: Social Dimensions of the Water Crisis on Canada's First Nations and Considerations for Governance," 7.

<sup>346</sup> Mattison, Doxtater, and Lavis, "Care for Indigenous Peoples," 350.

<sup>347</sup> Palmater, "Genocide, Indian Policy, and Legislated Elimination of Indians in Canada," 34.

<sup>348</sup> Mattison, Doxtater, and Lavis, "Care for Indigenous Peoples," 361.

<sup>349</sup> Mattison, Doxtater, and Lavis, 362.

<sup>350</sup> Lavoie, Forget, and Browne, "Caught at the Crossroad: First Nations, Health Care, and the Legacy of the Indian Act," 89.

<sup>351</sup> Lavoie, Forget, and Browne, 90.

Status also affects data collection policies that affect Indigenous peoples. The federal government maintains the Indian Register (IR), which is “the official record identifying persons registered as Status Indians under the *Indian Act*.”<sup>352</sup> This database contains information about band affiliation, residence status (on or off reserve), marital status and province of residence among others.<sup>353</sup> The IR is the data source that provincial governments can link to administrative data registries that, prompted by a person’s health card number, contain information about health service utilization.<sup>354</sup> Inuit and Métis peoples, as well as people who were excluded from status, are not included in this register.<sup>355</sup> These people, therefore, are typically identified by tools like the Census and other surveys administered by Statistics Canada, where they are asked to self-identify as being Indigenous.<sup>356</sup> The Indian Register operates as a repository of information, but also may be interpreted as a symbol of colonial dominion – an exclusive list held by the federal government outside of First Nations control. As seen below, this symbol can be repurposed to demonstrate sovereignty by First Nations in powerful ways.

### **Data sovereignty and OCAP® principles**

Part of the legacy of colonial control that Indigenous peoples have endured is being “researched to death” by scientists and governments who did not consult or involve their communities in any stage of the research design process while profiting from the results of the data collected.<sup>357</sup> This history of research on Indigenous peoples without

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<sup>352</sup> Indigenous and Northern Affairs Canada, “What Is Indian Status?”

<sup>353</sup> Walker et al., “Unlocking First Nations Health Information through Data Linkage,” 2.

<sup>354</sup> Walker et al., 2.

<sup>355</sup> Indigenous and Northern Affairs Canada, “What Is Indian Status?”

<sup>356</sup> Smylie and Anderson, “Understanding the Health of Indigenous Peoples in Canada,” 602.

<sup>357</sup> Schnarch, “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research,” 83; Elias, O’Neil, and Sanderson, “The Politics of Trust and Participation,” 69.

their consent stems back in part to ‘Indian hospitals,’ where researchers tested tuberculosis vaccines on First Nations infants segregated into dilapidated facilities that had a high likelihood of cross-infection with other patients suffering from pneumonia and gastrointestinal diseases.<sup>358</sup> With a long history of being excluded from the production and dissemination of research, First Nations are disempowered, for instance, when attempting to set policy agendas. As Schnarch notes, “[in] key venues where truth and facts are established about them, First Nations Peoples, themselves, have to shout to be heard, assuming they are present at all. In the research game, the playing field is anything but level.”<sup>359</sup> The need for control over data and research is shared by other Indigenous peoples across the Anglo-settler democracies (Canada, Australia, the United States and New Zealand), and combined with the creation of the UN Declaration of the Rights of Indigenous Peoples (UNDRIP), provided a platform for international conversations about Indigenous data sovereignty to emerge.<sup>360</sup>

The OCAP® data collection principles are a key method of how Indigenous peoples express data sovereignty in Canada. An acronym for Ownership, Control, Access and Possession, OCAP® originated as part of the discussions around the First Nations Regional Longitudinal Health Survey in 1998,<sup>361</sup> and “asserts that First Nations have control over data collection processes in their communities and that they own and control

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<sup>358</sup> Lux, “Care for the ‘Racially Careless,’” 423.

<sup>359</sup> Schnarch, “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research,” 83.

<sup>360</sup> Kukutai and Taylor, *Indigenous Data Sovereignty*, 38:1, 4, 5.

<sup>361</sup> Schnarch, “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research,” 80.

how this information can be used.”<sup>362</sup> Schnarch explains that OCAP® principles utilize the usual ethical requirements for research as a baseline, but incorporate other components specific to Indigenous communities including incorporating local or traditional knowledge, maintaining community involvement and consultation throughout the project, and giving community members access to the data produced, not just the reports generated from that data.<sup>363</sup> Community trust is a major benefit of adopting a set of principles that assert First Nations’ jurisdiction and control over their information, and allows “research to happen where it might otherwise be impossible.”<sup>364</sup>

Research produced utilizing OCAP® principles includes the First Nations Regional Health Survey, the only national First Nations health survey in Canada, which provides detail about the social determinants of health and health status of members of First Nations from across the country.<sup>365</sup> The Regional Health Survey also produced a theoretical framework informed by First Nations conceptions of health and wellbeing, as seen in Figure 10:

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<sup>362</sup> First Nations Information Governance Centre, “The First Nations Principles of OCAP®.” OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC) – for more information, please visit [www.FNIGC.ca/OCAP](http://www.FNIGC.ca/OCAP).

<sup>363</sup> Schnarch, “Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research,” 85.

<sup>364</sup> Schnarch, 94.

<sup>365</sup> First Nations Information Governance Centre, “The First Nations Regional Health Survey.”

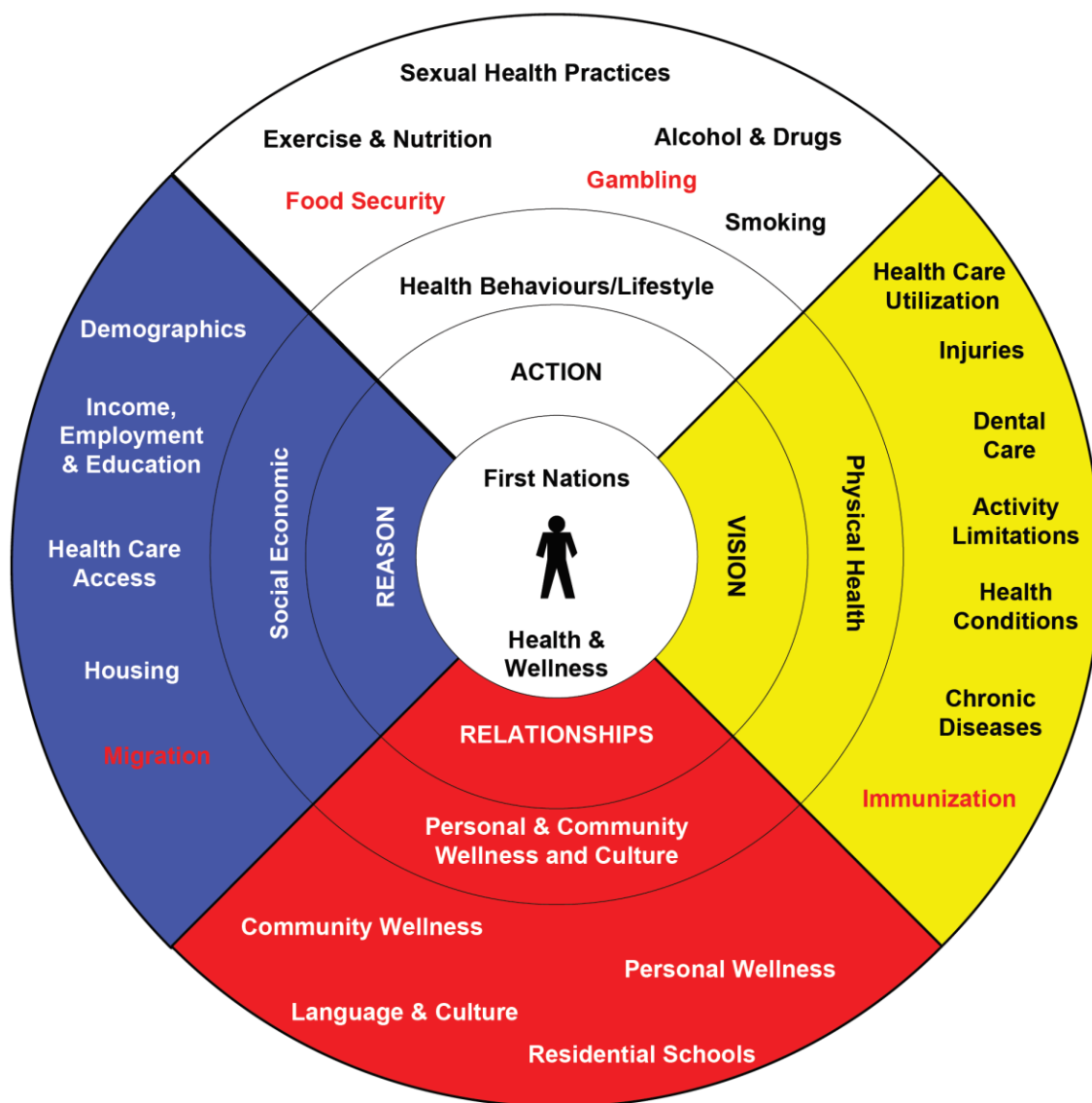


Figure 10: A visual representation of the cultural framework used in the First Nations Regional Health Survey<sup>366</sup>

This cultural framework provides a helpful summary of the framework that guided the First Nations Information and Governance Centre in creating and administering the First Nations Regional Health Survey. The cohesive perspective of “the total health of the total person in the total environment”<sup>367</sup> dovetails neatly with social determinants of health

<sup>366</sup> First Nations Information Governance Centre, 7.

<sup>367</sup> First Nations Information Governance Centre, 8.

approaches that public health policymakers may be familiar with, finding common ground to build on based on the outputs of research like the Health Survey.

OCAP® principles can also be used in data-sharing agreements like the Tui'kn Partnership, struck between five First Nations in Cape Breton and the Government of Nova Scotia. Supplemented with funding from Health Canada, the Strength in Numbers project aims to provide First Nations in Nova Scotia with more robust surveillance data that can allow policymakers, researchers and community members to monitor the health of the entire community better.<sup>368</sup> A core product of the project is the Unama'ki Client Registry, a data linkage agreement signed between the 5 First Nations Bands and the Government of Nova Scotia in 2010.<sup>369</sup> The Registry links data collected in health clinics operated by the Bands, as well as data from the Indian Registry to provincial health card information as produced by Medavie Blue Cross.<sup>370</sup> This registry allows the Tui'kn Partnership to create Health Information Bulletins: short that provide targeted information about chronic disease, health service utilization and maternal health within the five communities that are part of the Partnership for use and dissemination within those communities.<sup>371</sup> A similar initiative has been undertaken in Ontario with 133 First Nations communities.<sup>372</sup> In each partnership, the communities set the priorities for the research conducted, and the products of that research are made accessible to all.<sup>373</sup>

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<sup>368</sup> Tui'kn Partnership, "Strength In Numbers Project | Tui'kn Partnership."

<sup>369</sup> Tui'kn Partnership, "Data Sharing Agreement - Tuik'n Partnership."

<sup>370</sup> Tui'kn Partnership, 4.

<sup>371</sup> Tui'kn Partnership, "Chronic Disease in Unama'ki."

<sup>372</sup> Walker et al., "Unlocking First Nations Health Information through Data Linkage," 2.

<sup>373</sup> Walker et al., 7.

OCAP® operates, therefore, as a gold standard in research by and with First Nations. The principles address the core issues of participation and respect raised by the Indigenous data sovereignty movement while defining a practical set of research practices that can be used by researchers and by governments to begin addressing extant health inequities. Its community-focused and driven outputs are helpful to policymakers and community members alike and encourage participation and engagement in population health studies.

### **Limitations**

There are limitations to the efficacy of the data linkage approach for monitoring the health status of all Indigenous peoples, as opposed to those with status only. Indigenous peoples without status (including Inuit and Métis peoples) are not part of the Indian Register and thus appear in the federal survey tools identified in Chapter 4. The significant challenges with survey approaches explained in Chapter 4 are amplified by likely undersampling of Indigenous peoples in urban environments. Rotondi et al. found that urban Indigenous people in Toronto may have been undersampled by a factor of two to four by the Census, noting that only 16.8% of individuals who had lived in Toronto for five or more years had completed the census.<sup>374</sup> This undersampling means that health and social policies designed to cater to this marginalized and “hard-to-reach” population are less likely to be reflective of the services that they need and may utilize.<sup>375</sup> The population studied by Rotondi et al. included mainly First Nations individuals, but also some Métis and Inuit individuals as well.

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<sup>374</sup> Rotondi et al., “Our Health Counts Toronto,” 7.

<sup>375</sup> Rotondi et al., 7.

Collecting data about Métis people presents an entirely different set of challenges. As Anderson notes, counting oneself as Métis evokes two distinct definitions: a nationalist one and a racial one.<sup>376</sup> The Métis nation has an unambiguous definition, and is associated with “specific events, leaders, geographical territories, economy, land tenure, artistic styles, language, and kinship connections.”<sup>377</sup> The nation itself is governed by the Métis National Council, which has provincial affiliates in Ontario, British Columbia and the Prairie provinces.<sup>378</sup> The Métis Council of Ontario has a registry and a partnership with the Institute for Clinical Evaluative Sciences in Ontario to measure chronic disease rates among their membership.<sup>379</sup> Yet because of the complex history of non-status Indigenous people settling near or on Métis communities, loosely defined historical borders as well as the conflation of Métis identity with “mixedness”, the numbers of people self-identifying as Métis may be significantly skewed, hampering the capacity for the Métis nation and for policymakers to truly understand Métis health concerns.<sup>380</sup> While utilizing data linkage to connect a registry of Métis Nation members to provincial administrative data might assist in capturing the health information of that group, it might also leave non-members unable to be captured in official data sets, potentially further increasing their marginality.

Finally, this data linkage strategy is predicated on the discrete governance bodies that would be able to create data-sharing agreements on behalf of Nations. As noted above, due to the unique history of Indigenous peoples in Canada, these are strategies that

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<sup>376</sup> Andersen, “The Colonialism of Canada’s Métis Health Population Dynamics,” 73.

<sup>377</sup> Andersen, 73.

<sup>378</sup> Andersen, 73.

<sup>379</sup> Piper et al., “Walking the Path Together,” 7.

<sup>380</sup> Andersen, “The Colonialism of Canada’s Métis Health Population Dynamics,” 74, 75, 76.



are only suited for relations between those peoples and governments. Other racialized peoples like African-Canadians do not have the jurisdiction, authority or historically cohesive membership to be able to apply these methods in their entirety to their communities. Moreover, provincial governments (particularly those in Atlantic Canada) often operate in a policy context of limited financial and logistical resources.<sup>381</sup>

Policymakers may be unable to devote the necessary attention and rigour that is being applied to data linkage efforts in First Nations communities to efforts to disaggregate data for African-Canadians and other racialized peoples.

Yet if we return to the multiple streams approach in Chapter 3, some of the ways that policy windows can be opened are via the policy stream if technical feasibility is demonstrated, and via the problem stream if policymakers are given indicators to suggest that there is a problem. These data linkage projects, and projects like the First Nations Regional Health Survey, may operate as a demonstration of the feasibility of disaggregated data collection and may produce a set of indicators that demonstrate the significance of the problems that marginalized communities face in Canada.

The underlying premise of OCAP® – the idea that marginalized communities ought to have control of their data, and that data should be accessible and applicable to improving the lives of those communities – is undoubtedly one that is adaptable to other communities. Moreover, the principle of partnering with policymakers and researchers in a relationship of mutual respect and power is one that may improve the health outcomes of marginalized groups. Finally, the production of culturally relevant and useful outputs

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<sup>381</sup> Pate, “Why Health Care Is a Ticking Time Bomb in Atlantic Canada | CBC News.”

of population health research are necessary to foster community engagement in addressing inequities.

## **Conclusion**

Despite facing an extensive history of colonial injustices and predatory research practices, Indigenous peoples across Canada have found innovative ways of regaining control over their information while forming fruitful and respectful partnerships with governments and with researchers. Far from being technologically unfeasible, data linkage efforts offer a host of opportunities for governments and First Nations to combine their efforts in addressing health inequities for the benefit of all community members. While there are some limitations to this approach regarding transferability given the unique policy and historical context that Indigenous peoples in Canada are a part of, the fundamental principles of self-determination and respect when researching marginalized populations is one that may resonate with racialized peoples and with policymakers.

Far from being divisive as suggested in Counterpoint 5, these data linkage projects prove that when communities are given autonomy and choice over how to manage their data, they are willing to engage with policymakers in a relationship of mutual respect to address the challenges that they face. First Nations' pioneering approach to health data collection has established the feasibility and utility of disaggregated data collection. For policymakers interested in working with other marginalized communities, a host of opportunities to address racial health inequities await. The next chapter will detail some of those prospects while reflecting on what further research is needed based on this thesis.

## **Chapter 8: Conclusion**

### **Introduction**

A review of each of the barriers mentioned in this thesis demonstrates that the challenges of collecting disaggregated race-based health data are surmountable. By utilizing five Counterpoints as outlined in the introduction, I demonstrated how attempts to address racial health inequities via data collection are kept off the policy agenda. Canada's legacy of systemic racism, as obscured by discourses of multicultural unity, creates a policy context where racial health inequities are made invisible. A decentralized federal structure combined with underfunded public health systems contributes to a patchwork of data collection protocols that further obscure the extent of these inequities. A lack of understanding about the biological basis of race, combined with concern about alienating community members by identifying them by race or by using the wrong terminology further prevent policy progress towards racial health equity via data collection. The sum of these barriers is the status quo – where racial health inequities go mostly unaddressed, or efforts to address them are isolated to pilot projects in jurisdictions that have the resources to devote to policy proposals.

What has not been addressed, however, is the benefits for policymakers in addressing these challenges and choosing to collect this data. Far from being merely a symbolic act, disaggregated race-based data collection may operate as a foundation towards substantive action in addressing racial health inequities. For provincial policymakers, the benefits of this approach could extend further, including providing more efficient and effective health services for those who may be suffering the most and thus potentially utilizing the most resources. Moreover, the process of data collection

might establish more profound and trusting relationships between marginalized communities and provincial governments.

There are limitations, however, to the efficacy of seeing data collection as a final step in achieving racial health equity. Evidence alone does not necessarily presuppose policy progress – the policymaking process is more complicated than a simple process of inputs and outputs. Moreover, without continuous and active community engagement, data collection may be perceived as a technocratic exercise of little benefit to those it is designed to assist.

This concluding chapter will outline some of the opportunities for policymakers mentioned above, before acknowledging the limitations of this approach. Finally, I will outline an agenda for further research and reiterate what I hope readers take away from this project.

### **Opportunities**

As mentioned above, the opportunities for provincial policymakers in collecting disaggregated race-based health data are significant. Each of these opportunities, with time, may contribute to making significant progress towards racial health equity across the country.

#### *Providing a basis for policy change*

While the collection of disaggregated race-based health data is a policy achievement in and of itself for both policymakers and community advocates, the chief benefit of data collection is to provide evidence for targeted policy interventions. This data may be particularly useful in defining problems as seen in the multiple streams

approach outlined in Chapter 3. The data collected, especially if shared with the public, may also galvanize community advocates into pressuring policymakers into policy change. A recent example of the power of this advocacy saw evidence collected by the CBC showing that Black people in Halifax were 3.1 times more likely than white people to undergo street checks by police, which prompted the Nova Scotia Human Rights Commission to start an independent inquiry into the issue.<sup>382</sup> Halifax Regional Police also pledged to make a policy change because of the CBC's findings.<sup>383</sup>

*Increased efficiency in current program provision*

Another key opportunity for policymakers in collecting race-based health data is improving the efficacy and cost-effectiveness of current programs. Research conducted by the Institute for Clinical Evaluative Studies in Ontario demonstrated that 5% of Ontario residents contributed to 65% of governmental healthcare expenditures.<sup>384</sup> The study identified that the 5% of residents who contribute so heavily to healthcare costs have a diverse range of needs from chronic diseases, to neonatal care, to complex combinations of medical and functional impairments in older adults.<sup>385</sup> Given that racialized peoples tend to be more likely to suffer from chronic diseases (especially as a result of discrimination),<sup>386</sup> having disaggregated data may contribute to evaluating current programs to see whether they are effective at treating the roots of these diseases.

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<sup>382</sup> McGregor and MacIvor, “Black People 3 Times More Likely to Be Street Checked in Halifax, Police Say | CBC News”; Julian, ““Groundbreaking Endeavour.””

<sup>383</sup> Berman, “Changes to Halifax Police Street Checks Coming in the Fall | CBC News.”

<sup>384</sup> Institute for Clinical Evaluative Sciences, “Five per Cent of Ontario Residents Account for Majority of Health Care Costs.”

<sup>385</sup> Wodchis, Austin, and Henry, “A 3-Year Study of High-Cost Users of Health Care,” 187.

<sup>386</sup> Siddiqi et al., “Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada.”

*Strengthening inter-governmental ties*

Data linkage projects like the Tui'kn Partnership showcase the potential of provincial governments working together with First Nations to recognize and address health inequities that community members face. Disaggregated data collection also provides an opportunity for policymakers to improve inter-governmental ties, as establishing a common standard for data collection may facilitate effective comparison and collaboration on policy initiatives across jurisdictions. Despite the challenges of horizontal governance as outlined in Chapter 4, establishing a consistent surveillance protocol across the country may facilitate more effective action on policy initiatives that cannot be addressed by one province alone.

*Building trust with community members*

Lastly, and perhaps most importantly, developing a process for collecting race-based health data provides an opportunity for policymakers and researchers to build trust and engagement with community members. As seen in Chapter 7, this kind of trust is a manifestation of mutual respect and autonomy, with community members being included in discussions about the motivations behind and outputs of the research done about them. Initiatives like those found in the Tui'kn Partnership where researchers produce community-specific bulletins highlighting the prevalence and potential treatment of specific diseases may assist in making public health information more relevant to community members and may give them a sense of ownership over the outputs of research.

## Limitations

There are some limitations to prioritizing data collection as a means of putting racial health equity onto the policy agenda. Firstly, the existence of evidence does not presuppose policy change. The extensive literature that critically analyzes the evidence-based policymaking paradigm suggests that, in fact, an overreliance on evidence as the only basis behind a policy proposal may inhibit policy success.<sup>387</sup> Policymakers are inundated with reports and with data to parse through every day. Another set of indicators might add to the stacks of research and reports that often sit gathering dust on government shelves.

One important omission from this thesis is a discussion of the impact of personal privacy legislation on the efficacy of health research across Canada. As Harris et al. note, despite differing privacy laws in territories across Canada, the overall effect of an increased focus on protecting citizen data has been a suppression of participation in health research.<sup>388</sup> A discussion of how that legislative framework may serve as a barrier to disaggregated data collection is beyond the scope of this paper, but is still an important consideration that policymakers may wish to acknowledge.

Another potential limitation to this approach is that it, if applied without community input and engagement, could be perceived by community members as a technocratic exercise for a government that does little to meaningfully transform the lives

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<sup>387</sup> For an extensive look at some of the literature that critiques the evidence-based policymaking paradigm, please refer to: Carey and Crammond, “Action on the Social Determinants of Health”; Carey, Crammond, and Keast, “Creating Change in Government to Address the Social Determinants of Health”; Cairney and Oliver, “Evidence-Based Policymaking Is Not like Evidence-Based Medicine, so How Far Should You Go to Bridge the Divide between Evidence and Policy?”; Embrett and Randall, “Social Determinants of Health and Health Equity Policy Research.”

<sup>388</sup> Harris, Levy, and Teschke, “Personal Privacy and Public Health,” 293.

of those who are most in need. As Etowa et al. note, “In addition, much health research around marginalized populations is conducted *on* rather than *with* communities [emphasis original].”<sup>389</sup> Another data collection project may be perceived as the former if it is conducted in a top-down, directive manner. The resources necessary to deeply engage community members in such a project may be significant – the Tui’kn Partnership required nearly \$500,000 worth of funding from Health Canada over four years, with in-kind expertise being provided by the Government of Nova Scotia.<sup>390</sup> Thus, in an environment like Nova Scotia where the government is already being criticized for its health expenditures,<sup>391</sup> policymakers may be reticent to make such an investment with a risk of failure. Ultimately, political will may decide whether disaggregated data is implemented with community input, or implemented at all.

### **Agenda for further research**

Many topics were beyond the scope of this thesis that may be fertile ground for further research. I did not, for instance, include gender or class in my discussions of discrimination and marginality, despite the significant role they may play in determining health outcomes. An intersectional perspective on the issues presented in this thesis would enhance the depth of analysis contained within and is a worthy next step for interested researchers.

Another important next step for this research is to interview dedicated community advocates and policymakers to better understand their perspectives on the feasibility and

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<sup>389</sup> Etowa et al., “Determinants of Black Women’s Health in Rural and Remote Communities,” 351.

<sup>390</sup> Government of Nova Scotia, “Health Data Sharing Agreement Will Improve Health Care in First Nations Communities.”

<sup>391</sup> McPhee, “Budget’s Health Spending Falls Short, Critics Say | The Chronicle Herald.”



utility of disaggregated data in their communities and the policymaking process. Nova Scotia is a particularly relevant province to study due to its unique demography and history, as well as an active and vivid civil society engaged in addressing issues of structural racism and health inequities.

An obvious next step is to design some draft guidelines for the collection and distribution of race-based health data. By demonstrating the data collection process in action, policymakers and community advocates may be inclined to pay closer attention to these issues and, perhaps, decide to work together to implement these protocols.

## **Conclusion**

With this thesis, I attempted to demonstrate both the complexities and necessities of collecting disaggregated race-based health data. I used discursive and historical institutionalism to investigate how racial health equity has been kept off the policy agenda of provincial governments in Canada, and I detailed some of the opportunities that may be available to policymakers if they choose to collect disaggregated data. In doing so, I wanted to demonstrate two things: firstly, that issues of racial health equity ought to be studied from a political science perspective; and secondly, that policy progress on addressing racial health inequities is achievable.

Policymakers can, and should, address the concerns outlined in this thesis by acknowledging the extent and prevalence of systemic racism in Canada and developing rigorous approaches to addressing these injustices. Disaggregated data collection is not a solution, but it is a start.

## **Bibliography**

- Abdillahi, Idil, Beverly Bain, Dionne Brand, OmiSoore Dryden, Sandy Hudson, Robyn Maynard, Abdi Osman, Christina Sharpe, Christopher Smith, and Rinaldo Walcott. "Black Community Reps Pen Open Letter to John Tory and Doug Ford on Gun Violence." *NOW Magazine*, July 24, 2018. <https://nowtoronto.com/api/content/98d42524-8f39-11e8-920f-12408cbff2b0/>.
- Adams, Jean, Frances C. Hillier-Brown, Helen J. Moore, Amelia A. Lake, Vera Araujo-Soares, Martin White, and Carolyn Summerbell. "Searching and Synthesising 'Grey Literature' and 'Grey Information' in Public Health: Critical Reflections on Three Case Studies." *Systematic Reviews* 5 (September 29, 2016). <https://doi.org/10.1186/s13643-016-0337-y>.
- Agic, Branka, David McKeown, Kwame McKenzie, Andrew Pinto, and Samir Sinha. "We Ask Because We Care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report." Toronto, Ontario: Toronto Public Health, September 2013. <http://torontohealthequity.ca/wp-content/uploads/2014/10/FINAL-Full-Report-September-2013.pdf>.
- American Society of Hematology. "Sickle Cell Disease," January 8, 2018. </Patients/Anemia/Sickle-Cell.aspx>.
- Andersen, Chris. "The Colonialism of Canada's Métis Health Population Dynamics: Caught between Bad Data and No Data at All." *Journal of Population Research* 33, no. 1 (March 1, 2016): 67–82. <https://doi.org/10.1007/s12546-016-9161-4>.
- Angus Reid Institute. "What Makes Us Canadian? A Study of Values, Beliefs, Priorities and Identity." *Angus Reid Institute* (blog), October 3, 2016. <http://angusreid.org/canada-values/>.
- Aspinall, Peter J. "Operationalising the Collection of Ethnicity Data in Studies of the Sociology of Health and Illness." *Sociology of Health & Illness* 23, no. 6 (2001): 829–62. <https://doi.org/10.1111/1467-9566.00277>.
- . "What Kind of Mixed Race/Ethnicity Data Is Needed for the 2020/21 Global Population Census Round: The Cases of the UK, USA, and Canada." *Ethnic and Racial Studies* 0, no. 0 (July 26, 2017): 1–19. <https://doi.org/10.1080/01419870.2017.1346267>.

- Association of Ontario Health Centres. "Submission to the Standing Committee on General Government Regarding Bill 114, An Act to Provide for Anti-Racism Measures." Ontario, Canada: Association of Ontario Health Centres, May 15, 2017.  
[https://www.aohc.org/sites/default/files/documents/AOHC\\_submission\\_Bill-114.pdf](https://www.aohc.org/sites/default/files/documents/AOHC_submission_Bill-114.pdf).
- Attanasio, Laura, and Katy Backes Kozhimannil. "Patient-Reported Communication Quality and Perceived Discrimination in Maternity Care." *Medical Care* 53, no. 10 (October 2015): 863–71. <https://doi.org/10.1097/MLR.0000000000000411>.
- Bailey, Zinzi D, Nancy Krieger, Madina Agénor, Jasmine Graves, Natalia Linos, and Mary T Bassett. "Structural Racism and Health Inequities in the USA: Evidence and Interventions." *The Lancet* 389, no. 10077 (April 8, 2017): 1453–63. [https://doi.org/10.1016/S0140-6736\(17\)30569-X](https://doi.org/10.1016/S0140-6736(17)30569-X).
- Bamshad, Michael, Stephen Wooding, Benjamin A. Salisbury, and J. Claiborne Stephens. "Deconstructing the Relationship between Genetics and Race." *Nature Reviews Genetics* 5, no. 8 (August 2004): 598–609. <https://doi.org/10.1038/nrg1401>.
- Barber, Sharrelle, Ana V. Diez Roux, Leticia Cardoso, Simone Santos, Veronica Toste, Sherman James, Sandhi Barreto, Maria Schmidt, Luana Giatti, and Dora Chor. "At the Intersection of Place, Race, and Health in Brazil: Residential Segregation and Cardio-Metabolic Risk Factors in the Brazilian Longitudinal Study of Adult Health (ELSA-Brasil)." *Social Science & Medicine, The role of Racism in Health Inequalities: Integrating Approaches from Across Disciplines*, 199 (February 1, 2018): 67–76. <https://doi.org/10.1016/j.socscimed.2017.05.047>.
- Basdeo, Maya, and Lalita Bharadwaj. "Beyond Physical: Social Dimensions of the Water Crisis on Canada's First Nations and Considerations for Governance." *Indigenous Policy Journal* 23, no. 4 (April 8, 2013).  
<http://indigenouspolicy.org/index.php/ipj/article/view/142>.
- Bauer, Greta R. "Incorporating Intersectionality Theory into Population Health Research Methodology: Challenges and the Potential to Advance Health Equity." *Social Science & Medicine* 110, no. Supplement C (June 1, 2014): 10–17.  
<https://doi.org/10.1016/j.socscimed.2014.03.022>.
- Bayer, Ronald, and Sandro Galea. "Public Health in the Precision-Medicine Era." *New England Journal of Medicine* 373, no. 6 (August 6, 2015): 499–501.  
<https://doi.org/10.1056/NEJMp1506241>.

- Beckfield, Jason, and Nancy Krieger. “Epi + Demos + Cracy: Linking Political Systems and Priorities to the Magnitude of Health Inequities—Evidence, Gaps, and a Research Agenda.” *Epidemiologic Reviews* 31, no. 1 (November 1, 2009): 152–77. <https://doi.org/10.1093/epirev/mxp002>.
- Ben, Jehonathan, Donna Cormack, Ricci Harris, and Yin Paradies. “Racism and Health Service Utilisation: A Systematic Review and Meta-Analysis.” *PLOS ONE* 12, no. 12 (December 18, 2017): e0189900. <https://doi.org/10.1371/journal.pone.0189900>.
- Bergeron, Odile, Faisca Richer, Suzanne Bruneau, and Véronique Laberge. “L’alimentation Des Premières Nations et Des Inuits Au Québec: Document de Référence.” Québec, Canada: Institut national de santé publique du Québec, 2016. <http://www.deslibris.ca/ID/10049221>.
- Berman, Pam. “Changes to Halifax Police Street Checks Coming in the Fall | CBC News.” CBC, August 22, 2017. <https://www.cbc.ca/news/canada/nova-scotia/police-street-checks-changes-halifax-1.4257216>.
- Bibbins-Domingo, Kirsten, and Alicia Fernandez. “BiDil for Heart Failure in Black Patients: Implications of the U.S. Food and Drug Administration Approval.” *Annals of Internal Medicine* 146, no. 1 (January 2, 2007): 52. <https://doi.org/10.7326/0003-4819-146-1-200701020-00009>.
- Bitera, Raphaël, Micheline Fauvel, Michel Alary, Cécile Tremblay, Diane Sylvain, and Maureen Hastie. “Programme de surveillance de l’infection par le virus de l’immunodéficience humaine (VIH) au Québec : rapport annuel 2016.” Québec, Canada: Institut national de santé publique Québec, 2016. [https://www.inspq.qc.ca/sites/default/files/publications/2322\\_programme\\_surveillance\\_infection\\_vih.pdf](https://www.inspq.qc.ca/sites/default/files/publications/2322_programme_surveillance_infection_vih.pdf).
- Branker, Ron Robert. “Labour Market Discrimination: The Lived Experiences of English-Speaking Caribbean Immigrants in Toronto.” *Journal of International Migration and Integration* 18, no. 1 (February 1, 2017): 203–22. <https://doi.org/10.1007/s12134-016-0469-x>.
- Brattain, Michelle. “Race, Racism, and Antiracism: UNESCO and the Politics of Presenting Science to the Postwar Public.” Michelle Brattain Race, Racism, and Antiracism.” *The American Historical Review* 112, no. 5 (December 1, 2007): 1386–1413. <https://doi.org/10.1086/ahr.112.5.1386>.

Braun, Lundy, Anne Fausto-Sterling, Duana Fullwiley, Evelyn M Hammonds, Alondra Nelson, William Quivers, Susan M Reverby, and Alexandra E Shields. "Racial Categories in Medical Practice: How Useful Are They?" *PLoS Medicine* 4, no. 9 (September 2007). <https://doi.org/10.1371/journal.pmed.0040271>.

Brondolo, Elizabeth, Linda C. Gallo, and Hector F. Myers. "Race, Racism and Health: Disparities, Mechanisms, and Interventions." *Journal of Behavioral Medicine; New York* 32, no. 1 (February 2009): 1–8. <http://dx.doi.org/10.1007/s10865-008-9190-3>.

Brondolo, Elizabeth, Daniel J. Libby, Ellen-ge Denton, Shola Thompson, Danielle L. Beatty, Joseph Schwartz, Monica Sweeney, et al. "Racism and Ambulatory Blood Pressure in a Community Sample." *Psychosomatic Medicine* 70, no. 1 (January 1, 2008): 49–56. <https://doi.org/10.1097/PSY.0b013e31815ff3bd>.

Brosseau, Laurence, and Michael Dewing. "Canadian Multiculturalism." Background Paper. Ottawa, Ontario: Library of Parliament, January 3, 2018. <https://lop.parl.ca/Content/LOP/ResearchPublications/2009-20-e.pdf>.

Brown, Erin. "The Silent Majority and the Issue of Canadian Values." *Corporate Research Associates Inc (CRA)* (blog), June 30, 2017. <https://cra.ca/the-silent-majority-and-the-issue-of-canadian-values/>.

Bruhn, Jodi. "Identifying Useful Approaches to the Governance of Indigenous Data." *International Indigenous Policy Journal* 5, no. 2 (April 2014). <https://doi.org/10.18584/iipj.2014.5.2.5>.

Cairney, Paul, and Kathryn Oliver. "Evidence-Based Policymaking Is Not like Evidence-Based Medicine, so How Far Should You Go to Bridge the Divide between Evidence and Policy?" *Health Research Policy and Systems* 15, no. 1 (December 2017). <https://doi.org/10.1186/s12961-017-0192-x>.

Calabrese, Sarah K., Valerie A. Earnshaw, Kristen Underhill, Nathan B. Hansen, and John F. Dovidio. "The Impact of Patient Race on Clinical Decisions Related to Prescribing HIV Pre-Exposure Prophylaxis (PrEP): Assumptions About Sexual Risk Compensation and Implications for Access." *AIDS and Behavior* 18, no. 2 (February 1, 2014): 226–40. <https://doi.org/10.1007/s10461-013-0675-x>.

Came, Heather, and Derek Griffith. "Tackling Racism as a 'Wicked' Public Health Problem: Enabling Allies in Anti-Racism Praxis." *Social Science & Medicine*, March 16, 2017. <https://doi.org/10.1016/j.socscimed.2017.03.028>.

- Canadian Institute for Health Information. "Health Expenditures in the Provinces and Territories: Provincial and Territorial Chartbook, 2017." Ottawa, ON: CIHI, 2017.
- Canadian Public Health Association. "The Impact of Cancelling the Mandatory Long-Form Census on Health, Health Equity and Public Health." Ottawa, ON: Canadian Public Health Association, November 18, 2010. [https://www.cpha.ca/sites/default/files/assets/briefs/longformcensus\\_e.pdf](https://www.cpha.ca/sites/default/files/assets/briefs/longformcensus_e.pdf).
- Carey, Gemma, and Brad Crammond. "Action on the Social Determinants of Health: Views from inside the Policy Process." *Social Science & Medicine* 128 (March 2015): 134–41. <https://doi.org/10.1016/j.socscimed.2015.01.024>.
- Carey, Gemma, Brad Crammond, and Robyn Keast. "Creating Change in Government to Address the Social Determinants of Health: How Can Efforts Be Improved?" *BMC Public Health* 14 (October 20, 2014): 1087. <https://doi.org/10.1186/1471-2458-14-1087>.
- CBC News. "Vancouver's Racist Real Estate Titles Reveal City's Dark History | CBC News." CBC, August 27, 2014. <https://www.cbc.ca/news/canada/british-columbia/vancouver-real-estate-titles-reveal-city-s-racist-history-1.2747924>.
- Centers for Disease Control and Prevention. "Data and Statistics | Sickle Cell Disease." Centers for Disease Control and Prevention, August 31, 2016. <https://www.cdc.gov/ncbddd/sicklecell/data.html>.
- Centre for Arctic Medicine, Thule Institute, University of Oulu, Sandra A. Juutilainen, Ruby Miller, Six Nations Council, Lydia Heikkilä, North Finland Social Centre for Excellence, Sámediggi, SámiSoster (NGO), Arja Rautio, and Centre for Arctic Medicine, Thule Institute, University of Oulu. "Structural Racism and Indigenous Health: What Indigenous Perspectives of Residential School and Boarding School Tell Us? A Case Study of Canada and Finland." *International Indigenous Policy Journal* 5, no. 3 (June 2014). <https://doi.org/10.18584/iipj.2014.5.3.3>.
- Chin, Marshall H., and Catherine A. Humikowski. "When Is Risk Stratification by Race or Ethnicity Justified in Medical Care?" *Academic Medicine* 77, no. 3 (March 2002): 202. [https://journals.lww.com/academicmedicine/Fulltext/2002/03000/When\\_Is\\_Risk\\_Stratification\\_by\\_Race\\_or\\_Ethnicity.5.aspx](https://journals.lww.com/academicmedicine/Fulltext/2002/03000/When_Is_Risk_Stratification_by_Race_or_Ethnicity.5.aspx).
- Collier, Roger. "A Race-Based Detour to Personalized Medicine." *CMAJ* 184, no. 7 (April 17, 2012): E351–53. <https://doi.org/10.1503/cmaj.109-4133>.

- Comité d'éthique de santé publique. "Avis sur Qanuilirpitaa? 2017 – How are we now? Enquête sur la santé des Inuits du Nunavik." Québec, Canada: Institut national de santé publique Québec, July 4, 2017.
- Commission des droits de la personne et des droits de la jeunesse. "The Commission Des Droits de La Personne et Des Droits de La Jeunesse to Continue Its Reflection on Systemic Discrimination and Racism," October 20, 2017. <http://www.cdpcj.qc.ca/en/medias/Pages/Communique.aspx?showItem=785>.
- Corneau, Simon, and Vicky Stergiopoulos. "More than Being against It: Anti-Racism and Anti-Oppression in Mental Health Services." *Transcultural Psychiatry* 49, no. 2 (April 1, 2012): 261–82. <https://doi.org/10.1177/1363461512441594>.
- Crammond, Brad, and Gemma Carey. "What Is Policy and Where Do We Look for It When We Want to Research It?" *J Epidemiol Community Health* 71, no. 4 (April 1, 2017): 404–8. <https://doi.org/10.1136/jech-2016-207945>.
- De Maio, Fernando G., and Eagan Kemp. "The Deterioration of Health Status among Immigrants to Canada." *Global Public Health* 5, no. 5 (September 1, 2010): 462–78. <https://doi.org/10.1080/17441690902942480>.
- Department of Canadian Heritage. "A Canada for All: Canada's Action Plan Against Racism - An Overview." Ottawa: Canadian Heritage, 2005. <http://www.deslibris.ca/ID/203070>.
- Department of Health and Wellness. "Business Plan 2018-19." Nova Scotia, Canada: Government of Nova Scotia, March 2018. <https://novascotia.ca/government/accountability/2018-2019/2018-2019-business-plan-Department-of-Health-and-Wellness.pdf>.
- . "Nova Scotia Public Health - Health Equity Protocol." Nova Scotia, Canada: Government of Nova Scotia, 2014. <http://novascotia.ca/dhw/publichealth/documents/05-Health-Equity-Protocol.pdf>.
- Du Mont, Janice, and Tonia Forte. "Perceived Discrimination and Self-Rated Health in Canada: An Exploratory Study." *BMC Public Health* 16 (August 8, 2016): 742. <https://doi.org/10.1186/s12889-016-3344-y>.
- Dutt, Monika. "How Public Health Is Funded in Canada and Why That Needs to Change," February 25, 2013. <http://healthydebate.ca/opinions/how-public-health-is-funded-in-canada-and-why-that-needs-to-change>.

- EKOS Politics, and iPolitics.ca. "Attitudes to Immigration and Visible Minorities - A Historical Perspective." EKOS Politics, February 26, 2013. [http://www.ekospolitics.com/wp-content/uploads/full\\_report\\_immigration\\_february\\_26\\_2013.pdf](http://www.ekospolitics.com/wp-content/uploads/full_report_immigration_february_26_2013.pdf).
- Elias, Brenda, John O'Neil, and Doreen Sanderson. "The Politics of Trust and Participation: A Case Study in Developing First Nations and University Capacity to Build Health Information Systems in a First Nations Context." *Journal of Aboriginal Health; Victoria* 1, no. 1 (January 2004): 68–78. <https://search.proquest.com/docview/1131158662/abstract/C6A121E331F9498FPQ/1>.
- Embrett, Mark G., and G. E. Randall. "Social Determinants of Health and Health Equity Policy Research: Exploring the Use, Misuse, and Nonuse of Policy Analysis Theory." *Social Science & Medicine* 108, no. Supplement C (May 1, 2014): 147–55. <https://doi.org/10.1016/j.socscimed.2014.03.004>.
- Enticott, Joanne, Kimberly Buck, and Frances Shawyer. "Finding 'Hard to Find' Literature on Hard to Find Groups: A Novel Technique to Search Grey Literature on Refugees and Asylum Seekers." *International Journal of Methods in Psychiatric Research*, 2017, 1–7. <https://doi.org/10.1002/mpr.1580>.
- Escarce, José J., Rita Carreón, German Veselovskiy, and Elisa H. Lawson. "Collection Of Race And Ethnicity Data By Health Plans Has Grown Substantially, But Opportunities Remain To Expand Efforts." *Health Affairs* 30, no. 10 (October 2011): 1984–91. <https://search.proquest.com/docview/900995728/abstract/CCA451E853A94EC9PQ/1>.
- Etowa, Josephine, Juliana Wiens, Wanda Thomas Bernard, and Barbara Clow. "Determinants of Black Women's Health in Rural and Remote Communities." *Canadian Journal of Nursing Research Archive* 39, no. 3 (September 15, 2007). <http://cjunr.archive.mcgill.ca/article/view/2069>.
- Fierlbeck, Katherine. *Health Care in Canada: A Citizen's Guide to Policy and Politics*. 1 edition. Toronto ; Buffalo, NY: University of Toronto Press, Scholarly Publishing Division, 2011.
- First Nations Information Governance Centre. "The First Nations Principles of OCAP®," 2017. <http://fnigc.ca/ocap.html>.



- . “The First Nations Regional Health Survey: Phase 3: Volume 1.” The First Nations Regional Health Survey. Ottawa, ON: First Nations Information Governance Centre, 2018.  
<https://apps.uqo.ca/LoginSigparb/LoginPourRessources.aspx?url=http://www.desl.ibris.ca/ID/10096190>.
- Frank, John, and Erica Di Ruggiero. “Public Health in Canada: What Are the Real Issues?” *Canadian Journal of Public Health / Revue Canadienne de Santé Publique* 94, no. 3 (2003): 190–92. <http://www.jstor.org/stable/41993640>.
- Galabuzi, Grace-Edward. “Social Exclusion as a Determinant of Health.” In *Oppression: A Social Determinant of Health*, edited by Elizabeth Anne McGibbon, 97–112. Halifax: Fernwood Publishing, 2012.
- Gaucher, Megan. “Monogamous Canadian Citizenship, Constructing Foreignness and the Limits of Harm Discourse.” *Canadian Journal of Political Science/Revue Canadienne de Science Politique* 49, no. 3 (September 2016): 519–38.  
<https://doi.org/10.1017/S0008423916000810>.
- Gee, Gilbert C., and Chandra L. Ford. “Structural Racism and Health Inequities: Old Issues, New Directions.” *Du Bois Review: Social Science Research on Race* 8, no. 1 (ed 2011): 115–32. <https://doi.org/10.1017/S1742058X11000130>.
- Gergin, Maria. “Silencing Dissent: The Conservative Record.” Canadian Centre for Policy Alternatives, April 6, 2011.  
<https://www.policyalternatives.ca/publications/commentary/silencing-dissent-conservative-record>.
- Gionet, Linda, and Shirin Roshanafshar. “Select Health Indicators of First Nations People Living off Reserve, Métis and Inuit.” Statistics Canada, November 27, 2015.  
<https://www.statcan.gc.ca/pub/82-624-x/2013001/article/11763-eng.htm>.
- Government of Alberta, ed. *Immigrant Health in Alberta*. Edmonton, AB: Alberta Health and Wellness, Surveillance and Assessment Branch, Community and Population Health Division, 2011.
- Government of Canada. “2016 Census of Population Questions, Long Form (National Household Survey),” December 8, 2015. <http://www12.statcan.gc.ca/nhs-enm/2016/ref/questionnaires/questions-eng.cfm>.
- . “Budget 2018: Chapter 4 - Advancement,” February 27, 2018.  
<https://www.budget.gc.ca/2018/docs/plan/chap-04-en.html>.

- . “Canadian Community Health Survey - Annual Component (CCHS) - 2013 Questionnaire: Everyday Discrimination Scale / Component: Rapid Response - EDS,” January 30, 2014. [http://www23.statcan.gc.ca/imdb-bmdi/instrument/3226\\_Q6\\_V1-eng.htm](http://www23.statcan.gc.ca/imdb-bmdi/instrument/3226_Q6_V1-eng.htm).
- Government of Canada, Statistics Canada. “Adult Correctional Statistics in Canada, 2015/2016,” March 1, 2017. <https://www.statcan.gc.ca/pub/85-002-x/2017001/article/14700-eng.htm>.
- . “Canadian Community Health Survey - Annual Component (CCHS),” December 21, 2015. <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvVariableList&Id=259374>.
- . “Census of Population,” April 1, 2014. <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3901>.
- . “Statistics Canada: 2011 National Household Survey Profile,” May 8, 2013. <https://www12.statcan.gc.ca/nhs-enm/2011/dp-pd/prof/help-aide/aboutdata-a-proposdonnees.cfm?Lang=E>.
- . “The 2011 National Household Survey—the Complete Statistical Story,” June 4, 2015. <https://www.statcan.gc.ca/eng/blog-blogue/cs-sc/2011NHSstory>.
- Government of Newfoundland and Labrador. “Newfoundland and Labrador Indigenous Administrative Data Identifier Standard.” Government of Newfoundland and Labrador, December 2017. [https://www.nlchi.nl.ca/images/NL\\_Indigenous\\_Administrative\\_Data\\_Identifier\\_Standard\\_FINAL\\_\\_2017-12-12.pdf](https://www.nlchi.nl.ca/images/NL_Indigenous_Administrative_Data_Identifier_Standard_FINAL__2017-12-12.pdf).
- Government of Nova Scotia. “Health Data Sharing Agreement Will Improve Health Care in First Nations Communities.” [Novascotia.ca](http://novascotia.ca), March 24, 2016. <https://beta.novascotia.ca/news-and-events/health-data-sharing-agreement/>.
- . “Reflection and Action Task Group Report to Legislature.” Nova Scotia Home for Colored Children Restorative Inquiry. Nova Scotia, Canada: Government of Nova Scotia. Accessed July 24, 2018. <https://ansa.novascotia.ca/sites/default/files/Reflection-and-Action-Task-Group-Report.pdf>.
- Government of Ontario. “A Better Way Forward: Ontario’s 3-Year Anti-Racism Strategic Plan.” Toronto, Ontario: Government of Ontario, March 1, 2017. <https://www.ontario.ca/page/better-way-forward-ontarios-3-year-anti-racism-strategic-plan>.

- . Anti-Racism Act, 2017, 267/18 O. Reg. § (2018).  
<https://www.ontario.ca/laws/view>.
- . “Data Standards for the Identification and Monitoring of Systemic Racism.” Government of Ontario, December 2, 2018.  
<http://www.ontariocanada.com/registry/showAttachment.do?postingId=26766&attachmentId=37084>.
- . “News from the Secretary | Ontario.Ca,” June 29, 2018.  
<https://www.ontario.ca/page/news-secretary>.
- . Personal Health Information Protection Act, 2004, S.O. 2004, CHAPTER 3 § (2004). <https://www.ontario.ca/laws/view>.
- Government of Ontario, and Anti-Racism Directorate. “Data Standards for the Identification and Monitoring of Systemic Racism.” Toronto, Ontario: Government of Ontario, April 20, 2018.
- Grosse, Scott D., Isaac Odame, Hani K. Atrash, Djesika D. Amendah, Frédéric B. Piel, and Thomas N. Williams. “Sickle Cell Disease in Africa.” *American Journal of Preventive Medicine* 41, no. 6 (December 2011): S398–405.  
<https://doi.org/10.1016/j.amepre.2011.09.013>.
- Guo, Shibao. “The Colour of Skill: Contesting a Racialised Regime of Skill from the Experience of Recent Immigrants in Canada.” *Studies in Continuing Education* 37, no. 3 (September 2, 2015): 236–50.  
<https://doi.org/10.1080/0158037X.2015.1067766>.
- Guyon, Ak’ingabe, and Robert Perreault. “Public Health Systems under Attack in Canada: Evidence on Public Health System Performance Challenges Arbitrary Reform.” *Canadian Journal of Public Health; Ottawa* 107, no. 3 (2016): 326–29.  
<http://dx.doi.org/10.17269/CJPH.107.5273>.
- Hall, Peter A., and Rosemary C. R. Taylor. “Political Science and the Three New Institutionalisms.” *Political Studies* 44, no. 5 (December 1, 1996): 936–57.  
<https://doi.org/10.1111/j.1467-9248.1996.tb00343.x>.
- Hampton, Sharon B., James Cavalier, and Rae Langford. “The Influence of Race and Gender on Pain Management: A Systematic Literature Review.” *Pain Management Nursing* 16, no. 6 (December 1, 2015): 968–77.  
<https://doi.org/10.1016/j.pmn.2015.06.009>.

- Harrell, Camara Jules P., Tanisha I. Burford, Brandi N. Cage, Travette McNair Nelson, Sheronda Shearon, Adrian Thompson, and Steven Green. "Multiple Pathways Linking Racism To Health Outcomes." *Du Bois Review: Social Science Research on Race* 8, no. 01 (March 2011): 143–57.  
<https://doi.org/10.1017/S1742058X11000178>.
- Harris, M. Anne, Adrian R. Levy, and Kay E. Teschke. "Personal Privacy and Public Health: Potential Impacts of Privacy Legislation on Health Research in Canada." *Canadian Journal of Public Health; Ottawa* 99, no. 4 (August 2008): 293–96.  
<http://search.proquest.com/docview/231996737/abstract/1FD28B271C1D4612PQ/1>.
- Hassan, Ghayda, Abdelwahed Mekki-Berrada, Cécile Rousseau, Gabrielle Lyonnois-Lafond, Uzma Jamil, and Janet Cleveland. "Impact of the Charter of Quebec Values on Psychological Well-Being of Francophone University Students." *Transcultural Psychiatry*, July 14, 2016, 1363461516656972.  
<https://doi.org/10.1177/1363461516656972>.
- Henry, Frances, Carol Tator, Winston Mattis, and Tim Rees. "The Ideology of Racism." In *The Politics of Race in Canada: Readings in Historical Perspectives, Contemporary Realities, and Future Possibilities*, edited by Maria Wallis and Augie Fleras. Ontario: Oxford University Press, 2009.
- Hicken, Margaret T., Nicole Kravitz-Wirtz, Myles Durkee, and James S. Jackson. "Racial Inequalities in Health: Framing Future Research." *Social Science & Medicine*, January 2, 2018. <https://doi.org/10.1016/j.socscimed.2017.12.027>.
- Hinterberger, Amy. "The Genomics of Difference and the Politics of Race in Canada." In *What's the Use of Race?: Modern Governance and the Biology of Difference*, edited by Ian Whitmarsh and David S. Jones, 1st edition., 147–67. Cambridge, Mass: The MIT Press, 2010.
- Historica Canada. "Black History Canada - End of Segregation in Canada." Accessed June 27, 2018. <http://www.blackhistorycanada.ca/events.php?themeid=7&id=9>.
- Hoffman, Kelly M., Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver. "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites." *Proceedings of the National Academy of Sciences* 113, no. 16 (April 19, 2016): 4296–4301.  
<https://doi.org/10.1073/pnas.1516047113>.

- Hollingshead, Nicole A., Samantha M. Meints, Megan M. Miller, Michael E. Robinson, and Adam T. Hirsh. "A Comparison of Race-Related Pain Stereotypes Held by White and Black Individuals." *Journal of Applied Social Psychology* 46, no. 12: 718–23. Accessed July 21, 2018. <https://doi.org/10.1111/jasp.12415>.
- HoSang, Daniel Martinez. "On Racial Speculation and Racial Science: A Response to Shiao et Al." *Sociological Theory* 32, no. 3 (September 1, 2014): 228–43. <https://doi.org/10.1177/0735275114551771>.
- Hunt, Linda M., and Mary S. Megyesi. "The Ambiguous Meanings of the Racial/Ethnic Categories Routinely Used in Human Genetics Research." *Social Science & Medicine* 66, no. 2 (January 1, 2008): 349–61. <https://doi.org/10.1016/j.socscimed.2007.08.034>.
- Hyman, Ilene, Agnes Meinhard, and John Shields. "The Role of Multiculturalism Policy in Addressing Social Inclusion Processes in Canada." Canadian Multicultural Education Foundation, 2011.
- Ibbitson, John. "Liberal Investigation into Systemic Racism Should Keep a Low Profile." *The Globe and Mail*, March 20, 2018. <https://www.theglobeandmail.com/politics/article-liberal-investigation-into-systemic-racism-should-keep-a-low-profile/>.
- Indigenous and Northern Affairs Canada. "First Nations." Fact sheet; resource list, November 14, 2008. <https://www.aadnc-aandc.gc.ca/eng/1100100013791/1100100013795>.
- . "Indigenous Peoples and Communities." Administrative page; fact sheet; resource list, January 12, 2009. <https://www.rcaanc-cirnac.gc.ca/eng/1100100013785/1529102490303>.
- . "What Is Indian Status?" Reference material, November 3, 2008. <http://www.aadnc-aandc.gc.ca/eng/1100100032463/1100100032464>.
- Institut de la statistique Québec. "Enquête québécoise sur la santé de la population, 2014 – 2015 Questionnaire." Institut de la statistique Québec, 2015. <http://www.stat.gouv.qc.ca/enquetes/sante/eqsp2014-2015-questionnaire.pdf>.
- Institute for Clinical Evaluative Sciences. "Five per Cent of Ontario Residents Account for Majority of Health Care Costs," January 11, 2016. <https://www.ices.on.ca/Newsroom/News-Releases/2016/Five-per-cent-of-Ontario-residents-account-for-majority-of-health-care-costs>.

- Ipsos Public Affairs, and Global News. "Canada's 150th Anniversary." Ipsos Public Affairs, June 2017. <https://www.ipsos.com/sites/default/files/2017-06/Canada%20150-report-2017-07-01.pdf>.
- Jacoby, Sara F., Beidi Dong, Jessica H. Beard, Douglas J. Wiebe, and Christopher N. Morrison. "The Enduring Impact of Historical and Structural Racism on Urban Violence in Philadelphia." *Social Science & Medicine*, The role of Racism in Health Inequalities: Integrating Approaches from Across Disciplines, 199 (February 1, 2018): 87–95. <https://doi.org/10.1016/j.socscimed.2017.05.038>.
- Jedwab, Jack. "Opinion | How Angus Reid, CBC Got It Wrong about Multiculturalism." *Toronto Star*. December 10, 2016. <https://www.thestar.com/opinion/commentary/2016/10/12/how-angus-reid-cbc-got-it-wrong-about-multiculturalism.html>.
- Jones, Michael D., Holly L. Peterson, Jonathan J. Pierce, Nicole Herweg, Amiel Bernal, Holly Lamberta Raney, and Nikolaos Zahariadis. "A River Runs Through It: A Multiple Streams Meta-Review." *Policy Studies Journal* 44, no. 1: 13–36. Accessed July 4, 2018. <https://doi.org/10.1111/psj.12115>.
- Julian, Jack. "'Groundbreaking Endeavour': Expert Brought in to Study How Halifax Police Use Street Checks | CBC News." CBC, September 18, 2017. <https://www.cbc.ca/news/canada/nova-scotia/halifax-street-checks-study-1.4295008>.
- Kaplan, Judith B. "The Quality of Data on 'Race' and 'Ethnicity': Implications for Health Researchers, Policy Makers, and Practitioners." *Race and Social Problems* 6, no. 3 (September 1, 2014): 214–36. <https://doi.org/10.1007/s12552-014-9121-6>.
- Khan, Mushira, Karen Kobayashi, Sharon M. Lee, and Zoua Vang. "(In) Visible Minorities in Canadian Health Data and Research." *Population Change and Lifecourse Strategic Knowledge Cluster Discussion Paper Series/Un Réseau Stratégique de Connaissances Changements de Population et Parcours de Vie Document de Travail* 3, no. 1 (2015): 5. [http://ir.lib.uwo.ca/pclc/vol3/iss1/5/?utm\\_source=ir.lib.uwo.ca%2Fpclc%2Fvol3%2Fiss1%2F5&utm\\_medium=PDF&utm\\_campaign=PDFCoverPages](http://ir.lib.uwo.ca/pclc/vol3/iss1/5/?utm_source=ir.lib.uwo.ca%2Fpclc%2Fvol3%2Fiss1%2F5&utm_medium=PDF&utm_campaign=PDFCoverPages).
- Khoury, Muin J., and Sandro Galea. "Will Precision Medicine Improve Population Health?" *JAMA* 316, no. 13 (October 4, 2016): 1357–58. <https://doi.org/10.1001/jama.2016.12260>.

- Kouyoumdjian, Fiona, Andrée Schuler, Flora I. Matheson, and Stephen W. Hwang. "Health Status of Prisoners in Canada." *Canadian Family Physician* 62, no. 3 (March 2016): 215–22. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4984599/>.
- Krieger, Nancy. "Does Racism Harm Health? Did Child Abuse Exist Before 1962? On Explicit Questions, Critical Science, and Current Controversies: An Ecosocial Perspective." *American Journal of Public Health; Washington* 98 (September 2008): S20–25. <http://search.proquest.com/docview/215093184/abstract/D9919E281D424CA3PQ/1>.
- . "Methods for the Scientific Study of Discrimination and Health: An Ecosocial Approach." *American Journal of Public Health* 102, no. 5 (May 2012): 936–44. <https://doi.org/10.2105/AJPH.2011.300544>.
- Krieger, Nancy, Pamela D. Waterman, Anna Kosheleva, Jarvis T. Chen, Kevin W. Smith, Dana R. Carney, Gary G. Bennett, David R. Williams, Gisele Thornhill, and Elmer R. Freeman. "Racial Discrimination & Cardiovascular Disease Risk: My Body My Story Study of 1005 US-Born Black and White Community Health Center Participants (US)," 2013. <https://dash.harvard.edu/handle/1/11878984>.
- Ku, Jane, Rupaleem Bhuyan, Izumi Sakamoto, Daphne Jeyapal, and Lin Fang. "'Canadian Experience' Discourse and Anti-Racialism in a 'Post-Racial' Society." *Ethnic and Racial Studies* 0, no. 0 (February 20, 2018): 1–20. <https://doi.org/10.1080/01419870.2018.1432872>.
- KUKUTAI, TAHU, and JOHN TAYLOR, eds. *Indigenous Data Sovereignty: Toward an Agenda*. Vol. 38. ANU Press, 2016. <http://www.jstor.org/stable/j.ctt1q1crgf>.
- Kymlicka, Will. "The Three Lives of Multiculturalism." In *Revisiting Multiculturalism in Canada: Theories, Policies and Debates*, edited by Shibao Guo and Lloyd L. Wong, 17–35. Transnational Migration and Education, volume 1. Rotterdam Boston Taipei: Sense Publishers, 2015.
- Landry, Latrice G., Nadya Ali, David R. Williams, Heidi L. Rehm, and Vence L. Bonham. "Lack Of Diversity In Genomic Databases Is A Barrier To Translating Precision Medicine Research Into Practice." *Health Affairs* 37, no. 5 (May 2018): 780–85. <https://doi.org/10.1377/hlthaff.2017.1595>.

- Lavoie, Josée G, Evelyn L. Forget, and Annette J. Browne. "Caught at the Crossroad: First Nations, Health Care, and the Legacy of the Indian Act." *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 8, no. 1 (2010): 19. [https://www.researchgate.net/profile/Annette\\_Browne2/publication/265197453\\_Caught\\_at\\_the\\_Crossroad\\_First\\_Nations\\_Health\\_Care\\_and\\_the\\_Legacy\\_of\\_the\\_Indian\\_Act\\_1/links/5439925a0cf2d6698be166b4.pdf](https://www.researchgate.net/profile/Annette_Browne2/publication/265197453_Caught_at_the_Crossroad_First_Nations_Health_Care_and_the_Legacy_of_the_Indian_Act_1/links/5439925a0cf2d6698be166b4.pdf).
- Lee, Catherine. "'Race' and 'Ethnicity' in Biomedical Research: How Do Scientists Construct and Explain Differences in Health?" *Social Science & Medicine* 68, no. 6 (March 1, 2009): 1183–90. <https://doi.org/10.1016/j.socscimed.2008.12.036>.
- Lee, Sandra Soo-Jin, Joanna Mountain, and Barbara A. Koenig. "The Meanings of Race in the New Genomics: Implications for Health Disparities Research." *Yale Journal of Health Policy, Law, and Ethics* 1 (2001): 33–76.
- Leung, Ho Hon. "Canadian Multiculturalism in the 21st Century." In *Revisiting Multiculturalism in Canada: Theories, Policies and Debates*, edited by Shibao Guo and Lloyd L. Wong, 107–19. Transnational Migration and Education, volume 1. Rotterdam Boston Taipei: Sense Publishers, 2015.
- Liberal Party of Canada. "A New Plan for a Strong Middle Class." Liberal Party of Canada, 2015. <https://www.liberal.ca/wp-content/uploads/2015/10/New-plan-for-a-strong-middle-class.pdf>.
- LOO, TINA. "Africville and the Dynamics of State Power in Postwar Canada." *Acadiensis* 39, no. 2 (2010): 23–47. <http://www.jstor.org/stable/41803299>.
- Lux, Maureen K. "Care for the 'Racially Careless': Indian Hospitals in the Canadian West, 1920–1950s." *Canadian Historical Review* 91, no. 3 (September 2010): 407–34. <https://doi.org/10.3138/chr.91.3.407>.
- Maina, Ivy W., Tanisha D. Belton, Sara Ginzberg, Ajit Singh, and Tiffani J. Johnson. "A Decade of Studying Implicit Racial/Ethnic Bias in Healthcare Providers Using the Implicit Association Test." *Social Science & Medicine*, The role of Racism in Health Inequalities: Integrating Approaches from Across Disciplines, 199 (February 1, 2018): 219–29. <https://doi.org/10.1016/j.socscimed.2017.05.009>.
- Manitoba Health, Healthy Living, and Seniors. "Annual Statistical Update: HIV and AIDS 2014." EpiREPORT. Manitoba, Canada: Manitoba Health, Healthy Living and Seniors, December 2015. <https://www.gov.mb.ca/health/publichealth/surveillance/hiv aids/docs/dec2014.pdf>



- Manitoba Health, Seniors and Active Living. "Annual Statistics 2015-2016." Manitoba, Canada: Manitoba Health, Seniors and Active Living, 2016.
- Marks, Jonathan. "The Realities of Races." Social Science Research Council, June 7, 2006. <http://raceandgenomics.ssrc.org/Marks/>.
- Mattison, Cristina A., Kody Doxtater, and John N. Lavis. "Care for Indigenous Peoples." In *Ontario's Health System: Key Insights for Engaged Citizens, Professionals and Policymakers*, edited by John N. Lavis and McMaster Health Forum, 349–73, 2016.
- Maynard, Robyn. *Policing Black Lives: State Violence in Canada from Slavery to the Present*. Halifax: Fernwood Publishing, 2017.
- McBride, Kate. "Data Resources and Challenges for First Nations Communities." Alberta: Alberta First Nations Information Governance Centre, 2017. [http://afnigc.ca/main/includes/media/pdf/digital%20reports/Data\\_Resources\\_Report.pdf](http://afnigc.ca/main/includes/media/pdf/digital%20reports/Data_Resources_Report.pdf).
- McElhinny, Bonnie. "Reparations and Racism, Discourse and Diversity: Neoliberal Multiculturalism and the Canadian Age of Apologies." *Language & Communication, Discourses of Diversity*, 51 (November 1, 2016): 50–68. <https://doi.org/10.1016/j.langcom.2016.07.003>.
- McGibbon, Elizabeth Anne, and Josephine B. Etowa. "Race and Racism as Determinants of Health." In *Oppression: A Social Determinant of Health*, edited by Elizabeth Anne McGibbon, 73–88. Halifax: Fernwood Publishing, 2012.
- McGregor, Phlis, and Angela MacIvor. "Black People 3 Times More Likely to Be Street Checked in Halifax, Police Say | CBC News." CBC, January 9, 2017. <https://www.cbc.ca/news/canada/nova-scotia/halifax-black-street-checks-police-race-profiling-1.3925251>.
- McPhee, John. "Budget's Health Spending Falls Short, Critics Say | The Chronicle Herald." *The Chronicle Herald*. March 20, 2018. <http://thechronicleherald.ca/novascotia/1554812-budget%E2%80%99s-health-spending-falls-short-critics-say>.
- Merriam-Webster. "Definition of ETHNIC." Accessed July 24, 2018. <https://www.merriam-webster.com/dictionary/ethnic>.

- Mihoko Doyle, Jamie, and Grace Kao. "Are Racial Identities of Multiracials Stable? Changing Self-Identification Among Single and Multiple Race Individuals." *Social Psychology Quarterly* 70, no. 4 (December 2007): 405–23. <https://doi.org/10.1177/019027250707000409>.
- Morgan, Anthony. "Populism and Racism in Two Ontario Elections." Canadian Centre for Policy Alternatives, April 26, 2018. <https://www.policyalternatives.ca/publications/monitor/populism-and-racism-two-ontario-elections>.
- Moscou, Susan, Matthew R. Anderson, Judith B. Kaplan, and Lisa Valencia. "Validity of Racial/Ethnic Classifications in Medical Records Data: An Exploratory Study." *American Journal of Public Health* 93, no. 7 (July 1, 2003): 1084–86. <https://doi.org/10.2105/AJPH.93.7.1084>.
- Moscou, Susan, and Serena Baker. "The Role of Race in Clinical Decision Making." *The Nurse Practitioner* 43, no. 3 (March 2018): 41–46. <https://doi.org/10.1097/01.NPR.0000530212.09407.bd>.
- Mussa, Idil. "Activists Question Federation of Black Canadians' Leadership, Ties to Liberals | CBC News." CBC, February 27, 2018. <https://www.cbc.ca/news/politics/black-canadians-scrutiny-1.4549853>.
- Nadal, Kevin L., Katie E. Griffin, Yinglee Wong, Kristin C. Davidoff, and Lindsey S. Davis. "The Injurious Relationship Between Racial Microaggressions and Physical Health: Implications for Social Work." *Journal of Ethnic & Cultural Diversity in Social Work* 26, no. 1–2 (January 2, 2017): 6–17. <https://doi.org/10.1080/15313204.2016.1263813>.
- Nanji, Sabrina. "Black Canadians Mobilize Nationally for the First Time in Decades." *The Toronto Star*, January 3, 2018. <https://www.thestar.com/news/gta/2018/01/03/black-canadians-mobilize-nationally-for-the-first-time-in-decades.html>.
- Nanos Research. "Exploring Canadian Values - Values Survey Summary." October 2016. <http://www.nanos.co/wp-content/uploads/2017/07/Oct-24-Exploring-Canadian-values.pdf>.
- National Collaborating Centre for Determinants of Health. "Let's Talk: Racism and Health Equity." Let's Talk. Antigonish, N.S.: National Collaborating Centre for Determinants of Health, 2017. <http://nccdh.ca/resources/entry/lets-talk-racism-and-health-equity>.

- Nelson, Alan. "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care." *Journal of the National Medical Association* 94, no. 8 (August 2002): 666–68. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2594273/>.
- Nestel, Sheryl. "Colour Coded Health Care: The Impact of Race and Racism on Canadians' Health." Toronto, Ontario: Wellesley Institute, 2012.
- Ngabo, Gilbert. "Toronto Advocates Applaud Race-Based Data Collection Initiative | Metro Toronto." *Metro Toronto*. March 8, 2017. <http://www.pressreader.com/canada/starmetro-toronto/20170309/281565175558859>.
- Nova Scotia Health Authority. "Healthier Together: 2016-19 Strategic Plan." Nova Scotia Health Authority, 2016. <http://www.nshealth.ca/sites/nshealth.ca/files/nsha-strategic-plan-poster-final.pdf>.
- . "Talk about Health: The Story." Nova Scotia, Canada: Nova Scotia Health Authority, 2016. [http://www.nshealth.ca/sites/nshealth.ca/files/tah\\_final\\_report\\_final\\_aug\\_242c2016.pdf](http://www.nshealth.ca/sites/nshealth.ca/files/tah_final_report_final_aug_242c2016.pdf).
- Novac, Sylvia, Joe Darden, David Hulchanski, and Anne-Marie Seguin. "Housing Discrimination in Canada: What Do We Know About It?," December 2002, 7.
- Ontario Council of University Libraries. "Cancellation of the Mandatory Long-Form Census - Background and Impact | Ontario Council of University Libraries." Accessed July 22, 2018. <https://ocul.on.ca/node/3400>.
- Ontario Human Rights Commission. "Racism and Racial Discrimination: Systemic Discrimination (Fact Sheet)." Ontario Human Rights Commission. Accessed July 17, 2018. <http://www.ohrc.on.ca/en/racism-and-racial-discrimination-systemic-discrimination-fact-sheet>.
- Owusu-Bempah, Akwasi, and Scot Wortley. "Race, Crime, and Criminal Justice in Canada." *The Oxford Handbook of Ethnicity, Crime, and Immigration*, January 1, 2014. <https://doi.org/10.1093/oxfordhb/9780199859016.013.020>.
- Palmater, Pamela. "Genocide, Indian Policy, and Legislated Elimination of Indians in Canada." *Aboriginal Policy Studies* 3, no. 3 (June 26, 2014). <https://doi.org/10.5663/aps.v3i3.22225>.
- Pan-Canadian Public Health Network. "About the Pan-Canadian Public Health Network," July 17, 2012. <http://phn-rsp.ca/network-eng.php>.

- Pate, David. "Why Health Care Is a Ticking Time Bomb in Atlantic Canada | CBC News." CBC, October 30, 2016. <https://www.cbc.ca/news/canada/nova-scotia/atlantic-canada-health-care-time-bomb-1.3827288>.
- Piel, Frédéric B., Anand P. Patil, Rosalind E. Howes, Oscar A. Nyangiri, Peter W. Gething, Thomas N. Williams, David J. Weatherall, and Simon I. Hay. "Global Distribution of the Sickle Cell Gene and Geographical Confirmation of the Malaria Hypothesis." *Nature Communications* 1 (November 2, 2010): 104. <https://doi.org/10.1038/ncomms1104>.
- Piper, Evelyn, David Henry, Erica Yates, Graham Mecredy, Sujitha Ratnasingham, Brian Slegers, and Jennifer D Walker. "Walking the Path Together: Indigenous Health Data at ICES." *Healthcare Quarterly (Toronto, Ont.)* 20 (January 4, 2018). <https://doi.org/10.12927/hcq.2018.25431>.
- Potvin, Louise. "Canadian Public Health under Siege." *Canadian Journal of Public Health = Revue Canadienne De Sante Publique* 105, no. 6 (December 16, 2014): e401-403.
- Provincial Health Services Authority. "Priority Health Equity Indicators for British Columbia: Selected Indicators Report." British Columbia: British Columbia Centre for Disease Control, January 2016. [http://www.bccdc.ca/pop-public-health/Documents/Priority%20health%20equity%20indicators%20for%20BC\\_selected%20indicators%20report\\_2016.pdf](http://www.bccdc.ca/pop-public-health/Documents/Priority%20health%20equity%20indicators%20for%20BC_selected%20indicators%20report_2016.pdf).
- Pruss, Viola. "2/3 of Atlantic Canadians Support 'values' Screening of Immigrants, Poll Suggests | CBC News." CBC, March 15, 2017. <https://www.cbc.ca/news/canada/new-brunswick/survey-screening-immigrants-values-cra-canada-1.4026297>.
- Public Health Agency of Canada. "Health Inequalities Data Tool," September 3, 2017. <https://infobase.phac-aspc.gc.ca/health-inequalities/>.
- . "What Makes Canadians Healthy or Unhealthy?" Policies. aem, November 25, 2001. <https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health/what-makes-canadians-healthy-unhealthy.html>.
- Public Health Agency of Canada, and Pan-Canadian Public Health Network. *Blueprint for a Federated System for Public Health Surveillance in Canada: Vision and Action Plan.*, 2016. <http://www.deslibris.ca/ID/10089533>.
- Reardon, Jenny. *Race to the Finish: Identity and Governance in an Age of Genomics.* Princeton: Princeton University Press, 2005.

- Reich, David. "Opinion | How Genetics Is Changing Our Understanding of 'Race.'" *The New York Times*, March 23, 2018, sec. Opinion.  
<https://www.nytimes.com/2018/03/23/opinion/sunday/genetics-race.html>.
- Reverby, Susan M. "'Special Treatment': BiDil, Tuskegee, and the Logic of Race." *The Journal of Law, Medicine & Ethics* 36, no. 3 (September 1, 2008): 478–84.  
<https://doi.org/10.1111/j.1748-720X.2008.294.x>.
- Roberts, Dorothy E. "Race, Gender and the Political Conflation of Biological and Social Issues." *Du Bois Review: Social Science Research on Race* 9, no. 1 (ed 2012): 235–44. <https://doi.org/10.1017/S1742058X12000100>.
- Roberts, Dorothy E. "What's Wrong with Race-Based Medicine?: Genes, Drugs, and Health Disparities." *Minnesota Journal of Law, Science and Technology* 12, no. 1 (2011): 1–21.  
[https://www.law.upenn.edu/cf/faculty/roberts1/workingpapers/12MNJLSciAndTech1\(2011\).pdf](https://www.law.upenn.edu/cf/faculty/roberts1/workingpapers/12MNJLSciAndTech1(2011).pdf).
- Roth, Wendy D. "Methodological Pitfalls of Measuring Race: International Comparisons and Repurposing of Statistical Categories." *Ethnic and Racial Studies* 40, no. 13 (October 21, 2017): 2347–53. <https://doi.org/10.1080/01419870.2017.1344276>.
- . "The Multiple Dimensions of Race." *Ethnic and Racial Studies* 39, no. 8 (June 20, 2016): 1310–38. <https://doi.org/10.1080/01419870.2016.1140793>.
- Rotondi, Michael A., Patricia O'Campo, Kristen O'Brien, Michelle Firestone, Sara H. Wolfe, Cherylee Bourgeois, and Janet K. Smylie. "Our Health Counts Toronto: Using Respondent-Driven Sampling to Unmask Census Undercounts of an Urban Indigenous Population in Toronto, Canada." *BMJ Open* 7, no. 12 (2017): 1–8.
- Royal, Charmaine D M, and Georgia M Dunston. "Changing the Paradigm from 'race' to Human Genome Variation." *Nature Genetics* 36, no. 11s (November 2004): S5–7.  
<https://doi.org/10.1038/ng1454>.
- Rt. Hon. Justin Trudeau, Prime Minister of Canada. "Statement by the Prime Minister of Canada on Multiculturalism Day." Prime Minister of Canada, June 27, 2016.  
<https://pm.gc.ca/eng/news/2016/06/27/statement-prime-minister-canada-multiculturalism-day>.
- Ryan, Phil. "Does Canadian Multiculturalism Survive through State Repression?" *Nationalism and Ethnic Politics* 22, no. 3 (July 2, 2016): 342–50.  
<https://doi.org/10.1080/13537113.2016.1203708>.

- Rydgren, Jens. "Meso-Level Reasons for Racism and Xenophobia: Some Converging and Diverging Effects of Radical Right Populism in France and Sweden." *European Journal of Social Theory* 6, no. 1 (February 2003): 45–68.  
<https://doi.org/10.1177/1368431003006001560>.
- Saney, Issac. "The Black Nova Scotian Odyssey: A Chronology." *Shunpiking Magazine*, February 1998.  
<http://journals.sagepub.com.ezproxy.library.dal.ca/doi/pdf/10.1177/030639689804000107>.
- Saskatoon Health Region. "Better Health for All: Advancing Health Equity in Health Care." Health Status Reporting Series. Saskatoon, SK: Saskatoon Health Region, June 2014.  
[https://www.saskatoonhealthregion.ca/locations\\_services/Services/Health-Observatory/Documents/Reports-Publications/2014\\_shr\\_phase3\\_advancing\\_healthequity\\_healthcare\\_series.pdf](https://www.saskatoonhealthregion.ca/locations_services/Services/Health-Observatory/Documents/Reports-Publications/2014_shr_phase3_advancing_healthequity_healthcare_series.pdf).
- . "Social Determinants of HIV and AIDS - Ethnicity." Health Status Reporting Series. Saskatoon, SK: Saskatoon Health Region, December 2017.  
[http://www.communityview.ca/pdfs/2017\\_shr\\_series5\\_hiv\\_aids\\_ethnicity\\_gender.pdf](http://www.communityview.ca/pdfs/2017_shr_series5_hiv_aids_ethnicity_gender.pdf).
- Schmidt, Vivien A. "Discursive Institutionalism: The Explanatory Power of Ideas and Discourse." *Annual Review of Political Science* 11, no. 1 (2008): 303–26.  
<https://doi.org/10.1146/annurev.polisci.11.060606.135342>.
- Schnarch, Brian. "Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research," 2004, 17.
- Serjeant, Graham R. "The Natural History of Sickle Cell Disease." *Cold Spring Harbor Perspectives in Medicine* 3, no. 10 (October 2013).  
<https://doi.org/10.1101/cshperspect.a011783>.
- Shiao, Jiannbin Lee, Thomas Bode, Amber Beyer, and Daniel Selvig. "The Genomic Challenge to the Social Construction of Race." *Sociological Theory* 30, no. 2 (June 2012): 67–88. <https://doi.org/10.1177/0735275112448053>.
- Siddiqi, Arjumand, Faraz Vahid Shahidi, Chantel Ramraj, and David R. Williams. "Associations between Race, Discrimination and Risk for Chronic Disease in a Population-Based Sample from Canada." *Social Science & Medicine* 194, no. Supplement C (December 1, 2017): 135–41.  
<https://doi.org/10.1016/j.socscimed.2017.10.009>.

- Singhal, Astha, Yu-Yu Tien, and Renee Y. Hsia. "Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse." *PLOS ONE* 11, no. 8 (August 8, 2016): e0159224. <https://doi.org/10.1371/journal.pone.0159224>.
- Smylie, Janet, and Marcia Anderson. "Understanding the Health of Indigenous Peoples in Canada: Key Methodological and Conceptual Challenges." *CMAJ* 175, no. 6 (September 12, 2006): 602–602. <https://doi.org/10.1503/cmaj.060940>.
- Statistics Canada. "Visible Minority Immigrant Definition," December 1, 2008. <http://www.statcan.gc.ca/pub/81-004-x/def/4068739-eng.htm>.
- Stepanikova, Irena. "Applying a Status Perspective to Racial/Ethnic Misclassification: Implications for Health." In *Advances in Group Processes*, 27:159–83. *Advances in Group Processes* 27. Emerald Group Publishing Limited, 2010. [https://doi.org/10.1108/S0882-6145\(2010\)0000027009](https://doi.org/10.1108/S0882-6145(2010)0000027009).
- Tait, Caroline L., Peter Butt, Robert Henry, and Roger Bland. "'Our Next Generation': Moving Towards a Surveillance and Prevention Framework for Youth Suicide in Saskatchewan First Nations and Métis Populations." *Canadian Journal of Community Mental Health* 36, no. 1 (April 17, 2017): 55–65. <https://doi.org/10.7870/cjcmh-2017-004>.
- The Canadian Press. "Conservative Party Pulls Attack Ad Showing Black Man Walking over Trudeau Tweet | CBC News." CBC, July 18, 2018. <https://www.cbc.ca/news/politics/conservative-asylum-seeker-ad-pulled-1.4751350>.
- The Wellesley Institute. "Socio-Demographic Data and Equity in Health Services in Ontario: Building on Strong Foundations." Toronto, Ontario: The Wellesley Institute, September 2017. <http://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf>.
- . "Wellesley Institute Submission in Response to the Proposed Regulation under the Anti-Racism Act on Data Standards for the Identification and Monitoring of Systemic Racism." Ontario, Canada: The Wellesley Institute, March 14, 2018. <http://www.wellesleyinstitute.com/wp-content/uploads/2018/03/Anti-Racism-Directorate-Data-Standards-Submission.pdf>.

- The Working Group of Experts on People of African Descent. “Report of the Working Group of Experts on People of African Descent on Its Mission to Canada.” Racism, Racial Discrimination, Xenophobia and Related Forms of Intolerance, Follow-up to and Implementation of the Durban Declaration and Programme of Action. United Nations General Assembly, Human Rights Council, August 16, 2017.
- Thompson, Debra. “Is Race Political?” *Canadian Journal of Political Science/Revue Canadienne de Science Politique* 41, no. 3 (September 2008): 525–47. <https://doi.org/10.1017/S0008423908080827>.
- Tui’kn Partnership. “Chronic Disease in Unama’ki.” Health Information Bulletin. Membertou, Nova Scotia: Tui’kn Partnership, 2013. <http://www.tuikn.ca/wp-content/uploads/2015/06/CDM-bulletin-FINAL.pdf>.
- . “Data Sharing Agreement - Tuik’n Partnership,” 2010. <http://www.tuikn.ca/wp-content/uploads/2015/03/signed-DSA-2010.pdf>.
- Tui’kn Partnership. “Strength In Numbers Project | Tui’kn Partnership.” Accessed November 12, 2017. <http://www.tuikn.ca/health-information/strength-in-numbers-project/>.
- Valdez, Zulema, and Tanya Golash-Boza. “Towards an Intersectionality of Race and Ethnicity.” *Ethnic and Racial Studies* 40, no. 13 (October 21, 2017): 2256–61. <https://doi.org/10.1080/01419870.2017.1344277>.
- Varcoe, Colleen, Annette J. Browne, Sabrina Wong, and Victoria L. Smye. “Harms and Benefits: Collecting Ethnicity Data in a Clinical Context.” *Social Science & Medicine*, Part Special Issue: Early life effects on socioeconomic performance and mortality in later life: A full life course approach using contemporary and historical sources, 68, no. 9 (May 1, 2009): 1659–66. <https://doi.org/10.1016/j.socscimed.2009.02.034>.
- Veenstra, Gerry, and Andrew C. Patterson. “Black–White Health Inequalities in Canada.” *Journal of Immigrant and Minority Health* 18, no. 1 (February 1, 2016): 51–57. <https://doi.org/10.1007/s10903-014-0140-6>.
- Waldron, Ingrid R. G. “Experiences of Environmental Health Inequities in African Nova Scotian Communities.” Nova Scotia, Canada: The ENRICH Project, Dalhousie University, September 10, 2016. <http://www.enrichproject.org/wp-content/uploads/2016/10/Final-Environmental-Racism-Report.pdf>.
- Walker, James St. G. “Race and the Law.” In *The Politics of Race in Canada*, edited by Augie Fleras and Maria Wallis, 5–23. Ontario: Oxford University Press, 2009.



- Walker, Jennifer, Evelyn Pyper, Carmen R. Jones, Saba Khan, Nelson Chong, Dan Legge, Michael J. Schull, and David Henry. "Unlocking First Nations Health Information through Data Linkage." *International Journal of Population Data Science* 3, no. 1 (May 22, 2018). <https://doi.org/10.23889/ijpds.v3i1.450>.
- Walker, Rebekah J., Joni Strom Williams, and Leonard E. Egede. "Impact of Race/Ethnicity and Social Determinants of Health on Diabetes Outcomes." *The American Journal of the Medical Sciences* 351, no. 4 (April 2016): 366. <https://doi.org/10.1016/j.amjms.2016.01.008>.
- Walt, Gill, Jeremy Shiffman, Helen Schneider, Susan F. Murray, Ruairi Brugha, and Lucy Gilson. "'Doing' Health Policy Analysis: Methodological and Conceptual Reflections and Challenges." *Health Policy and Planning* 23, no. 5 (September 1, 2008): 308–17. <https://doi.org/10.1093/heapol/czn024>.
- Wane, Njoki Nathani. "African Women and Canadian History: Demanding Our Place In The Curriculum." In *Inequality in Canada: A Reader on the Intersections of Gender, Race, and Class*, edited by Valerie Zawilski and Cynthia Levine-Rasky, 156–67. Don Mills, Ont. ; New York: Oxford University Press, 2005.
- White, Patrick. "Doug Ford Plans to Restore Controversial Measures after Toronto Shootings." *The Globe and Mail*. June 26, 2018. <https://www.theglobeandmail.com/canada/toronto/article-amid-recent-gun-violence-incoming-ontario-tories-propose-restoring/>.
- Williams, David R., and Selina A. Mohammed. "Racism and Health I: Pathways and Scientific Evidence." *American Behavioral Scientist* 57, no. 8 (August 1, 2013): 1152–73. <https://doi.org/10.1177/0002764213487340>.
- Wimmer, Andreas. "Herder's Heritage and the Boundary-Making Approach: Studying Ethnicity in Immigrant Societies\*." *Sociological Theory* 27, no. 3 (September 2009): 244–70. <https://doi.org/10.1111/j.1467-9558.2009.01347.x>.
- Winant, Howard. "Race, Ethnicity and Social Science." *Ethnic and Racial Studies* 38, no. 13 (October 21, 2015): 2176–85. <https://doi.org/10.1080/01419870.2015.1058514>.
- Winks, Robin W. "Negro School Segregation in Ontario and Nova Scotia." In *The Politics of Race in Canada*, edited by Maria Wallis and Augie Fleras, 24–30. Ontario: Oxford University Press, 2009.
- Winter, Elke. "Rethinking Multiculturalism After Its 'Retreat': Lessons From Canada." *American Behavioral Scientist* 59, no. 6 (May 1, 2015): 637–57. <https://doi.org/10.1177/0002764214566495>.

Wodchis, Walter P., Peter C. Austin, and David A. Henry. "A 3-Year Study of High-Cost Users of Health Care." *CMAJ* 188, no. 3 (February 16, 2016): 182–88.  
<https://doi.org/10.1503/cmaj.150064>.

Wynia, Matthew K., Susan L. Ivey, and Romana Hasnain-Wynia. "Collection of Data on Patients' Race and Ethnic Group by Physician Practices." *New England Journal of Medicine* 362, no. 9 (March 4, 2010): 846–50.  
<https://doi.org/10.1056/NEJMs0910799>.