Data or Politics? Why the Answer Still Remains Political

Rinaldo Walcott, Women and Gender Studies Institute, University of Toronto | November 12, 2020

Abstract

This essay suggests that a significant gap exists between calls for race-based data collection and the claim it will lead to better policy making. Instead the paper argues that there is a gap between data collection and the political decision making needed to implement sound policy. The paper uses Toronto as a case study to demonstrate how recent COVID race-based data collection did not lead to immediate good policy decisions and implementation that would benefited those currently being the most impacted by COVID infections.

In the Canadian context, the race to collect race-based data is on. Beginning in Ontario and now spreading across the country, the collection of raced-based data has been offered as an important element for evidenced-based policy-making with the assumption that policy will be better made. Indeed, raced-based data are now offered up as necessary for moving forward on any policy that might impact the lives of racialized Canadians in health, education, employment, poverty and so on. It is not easy to pinpoint when the demand for change shifted from clearly articulated calls for policy reforms of all kinds to a singular demand for the collection of race-based data before any policy reform might be possible. Race-based data therefore have become a middle ground, so to speak, before reform can happen. There are indeed some truths about calls for race-based data, but there are many half-truths too. Evidence is important and few would dismiss evidence as unnecessary, however race-based data can quite frankly slow down reform. In that context, "doing the research," when a problem is already identified and its solutions known, means that the collection of race-based data does not actually add much to policy-making. In fact, in some cases, it can do more harm than good. Race-based data collection, as currently articulated, is a response to a set of political concerns masquerading as if it is the answer.

The history of data collection — with Black people in particular — is a difficult and torturous one. Most often, the collection of data benefits the researchers collecting the data more than the people being researched. Indeed, if we were to account for all the SSHRC funded projects on racialized Canadians we know quite a lot about them. Add the national census and various school board and health data routinely collected and we know even more. Yet, race-based data calls entirely ignore these already existing bodies of data to make a different kind of claim – a claim that must begin from scratch and one of absence. So, where did the idea that we have no data arrive from then? Why is this the case? The positivism of the call for race-based data is one of the principle half-truths of its call. The claim that collecting such data will inevitably lead to better policy-making is a significant half-truth. In the Canadian context, it is clear that race-based data benefits the researchers and not communities. Indeed, those benefits are so clear that research protocols were developed for Indigenous communities because of prior research extraction that did not benefit those communities.ⁱ In the arena of calls for race-based data, it is currently a wide-open field on collecting data on non-white people in Canada. This wide-open field means that anyone can apply for funds, conduct research using whatever methods their ethical review boards find acceptable, seek out willing populations using all kinds of methods of "consent" and benefit from the research without communities themselves also benefiting. And if this characterization appears to be too stark a claim, HIV/AIDS research and Black people in Canada can be used as an example to bear it out (further discussion to follow)...

But something more complicated and potentially troubling is at stake now that data across all areas of our lives is one of the most significant currencies of our time. Ethically, researchers committed to collecting race-based data need to think about how their work is not only extractive, but also how it will and can be monetized beyond their individual projects, again, without any benefit to the communities studied. The ethics of race-based data are particularly acute given how extraction in terms of racialized labour has already positioned specifically poor racialized people as reserved populations for exploitation and or wasted populations in the most extreme cases.

In Canada, excluding the national census, and various school boards and health units collecting basic data on demographics that included race, nationality and ethnicity, the infrastructure for collecting race-based data is deeply flawed. Indeed, when the Ontario government agreed to collect race-based data, one could not help but ask who would collect the data — the very people who had previously said it was impossible to collect ? Who would design the data collection instruments? Who would analyze the data? The announcement garnered more questions than answers for me. And furthermore, given the specificity of race as a key component of the data collection, what kind of training would the data collectors have in terms of antiracism in all its many manifestations that would allow them not to reproduce racist ideas? These kinds of questions remain unanswered in the race for race-based data collection. What we are certain of is the institutions being asked to collect this data do not possess the kinds of knowledge necessary to do so. . And furthermore, no monies have been made available to either hire or train people who have the requisite knowledge. In the absence of serious and significant infrastructure for collecting race-based data, the arena for race-based data remains one that is open to all kinds of potential abuse, misuse and exploitation.

Indeed, in the realm of HIV/AIDS research in Canada, we have witnessed many research projects carried out on Black, Caribbean and African people given the prevalence of the virus in our communities.ⁱⁱ Yet, this research has not impacted the health outcomes of those infested. That is to say, the research has had no affect on seroconversion (the time period during which the HIV antibody develops and results in an HIV positive status) numbers in our communities and all of the other problems that can accompany an HIV positive diagnosis. It is therefore my assessment of the context that more specifically, what this research has accorded is for researchers to excel in their fields, garner more research funding, expand their arenas of research, be nominated for and win awards and so on.

Importantly, what we have witnessed is that research and the link to better policy is not self-evident and that researchers and the populations researched can constitute a range of unequal relations in which the benefits of the research flow to the most advantaged in the relationship. And finally, when the social determinants of health were eventually articulated this had little to no impact on Black communities. In fact, while white gay men can see the endgame of HIV, HIV remains an epidemic for Black populations not just in Canada but across the world. Additionally, this example is rarely referenced because HIV remains linked to the "perverse" sex of queers. I would also suggest that calls for race-based data are premised on the assumption that a racialized (Black) middle-class desires to prove why they should be further and better included since their calls for justice using available evidence have been largely ignored. Indeed, my argument is that race-based data calls are deeply classed – the poor will be studied, and any potential benefit will accrue to the racialized middle class.

The case of the HIV epidemic and Black people is one of the most significant in terms of demonstrating how race-based data does not automatically lead to any impact on policy-making. It is a half-truth to link data and in particular race-based data collection with good policy-making. The most that can be garnered

from race-based data collection is a wish for good policy-making and setting the terrain for a political fight. The race then for race-based data collection is both a slowing down of implementing better policy, but also an acknowledgement that those who hold power reserve the right to decide whether to trust racialized people's articulation of their own experiences and what requisite reforms are necessary. Given what we have learned from the social determinants of health, there should be no surprise then that COVID-19 affects mostly poor racialized communities the hardest.

Late into the pandemic, Ontario has yet to create sites where families not able to fully isolate because of their home spaces could be billeted at hotels at no cost to them. Indeed, this lack of policy exists in spite of the evidence demonstrating who is experiencing the most severe impact of COVID-19. One can only ask the researchers why they perpetuate the myth that race-based data collection will lead to better policy-making when the body of evidence continues to demonstrate otherwise?

COVID-19 in Toronto: A Brief Case Study

First, it is important to note that at the time of writing, we remain in a pandemic. It is jarring to hear people continually use the phrase "during the pandemic" as if it is already over. The reopening of the economy has led many to behave as if the pandemic was only happening when national isolation was mandated and conversely, many seem to see the lifting of strict national isolation as the end of the pandemic. Nothing can be further from the truth. The logic that the pandemic might be over as "reopening" progresses is one that again alerts us to the gap between data-driven calls for equity and justice and the absence of policy-making that produces equity and justice. Poor racialized people have been working throughout the pandemic in long-term care homes, hospitals, food services, on farms and in the food-processing industries. We can examine the city of Toronto as a case study in this gap and the consequences of the gap.

In June 2020, Toronto Public Health published its interactive COVID-19 map.^{III} The map allowed Torontonians to see where concentrations of COVID-19 infections were by postal code. What the map demonstrated was that COVID-19 infections were concentred in poor racialized communities. The map confirmed what frontline health-care works were already making plainly clear in the news media, even as they too joined the bandwagon call for race-based data. A number of things are worth observing here. I think there is a nuance between the health-care workers' call for data collection and professional researchers' call. The health-care workers are hoping to redirect funds and practice in the midst of the emergency. ^{IV} For example a health care worker is quoted as saying, "she wants to see political will and money put into improvements such as higher pay to retain personal support workers, sick leave and in some cases safer commuting options for those without private vehicles."^{VV} There is clearly a gap between various elements involved in the research process that any careful analyst can discern.

The professional researchers are seeking to cement their own relevance in their workplaces. This is an important nuance to hold on to. Also, health-care workers already knew who would count as "essential workers" and how these low-paid workers would occupy at least two data points in any COVID-19 data collection – poor and racialized. Health-care workers at the lowest rungs are among the most vulnerable and live in the postal coded areas of concentrated infection. What was being asked for was already known. The second moment in making sense of COVID-19 and race-based data collection is the plan to reopen schools. A searchable database was released in which elementary schools with potential for infections was released.^{vi} The schools marked for potential problems were in the same areas that the interactive map had already singled out as zones of and for infection.

The Mayor of Toronto could be heard on CBC Radio on September 1, 2020, acknowledging that no specific policies had been implemented for affected areas. Again, the link between data and policy-making, even in a crisis, is a fiction especially when racialized poor people are the beneficiaries of such policy. Significantly, one of the most important outcomes of the COVID-19 era is the focus on housing and unhoused people. City of Toronto statistics suggest that that about 30 per cent of unhoused people are Black and Indigenous.^{vii} The data act as evidence, but that evidence has in no way led to policy-making meant to stem the tide of the growing unhoused. Indeed, the science of COVID-19 alerts us to the importance of housing to slow the rate of infections and community spread. There is a gap between data collection, evidence, policy and action, and that gap requires attention. It is the gap that represents a political question.

What does it mean then to say that the way to create a better society is to collect race-based data? It is apparent that response works to delay good policy-making and action in the face of demands for transformative change that has been articulated by social movements. My argument is not in opposition to the collection of race-based data, but that the evidence or data needed to make good and better policy already exists. I repeat, race-based data collection does not correlate with good policy-making, as shown by the history of African American life. In Canada, the belief that the collection of race-based data will result in better policy-making urgently needs to be uncoupled from policy conversations. All data can do is inform policy-making, if anything at all. Policy-making, after all, is ultimately about political decisions.

What Is to Be Done?

Recommendations:

1. Trust communities and their experiences. Know that communities can and do diagnose their problems/issues and have evidence for their conclusions. Additionally, actively refuse the idea that communities require professional researchers to validate their evidence.

2. Political demands based on communities' experiences of the world must be accorded the same measure as professionally researched driven analyses.

3. Seek out community research protocols that take the research relationship between communities and professional researchers seriously. For example, the Indigenous health research protocols that attempt to limit and or mitigate against research extraction, exploitation and harm that can be caused to Indigenous peoples by professional researchers is a case in point. Scholar-activists in Black communities are building a similar protocol: LLana James (doctoral candidate, Medicine UofT)^{viii} and Ciann Wilson (Associate Professor, Waterloo) community research protocol and the REDE4BlackLives protocols.^{ix}

4. Empower community researchers and work with them to make sure that they have the adequate resources to run their own identified research projects in the interests of their communities.

5. Recognize that local community organizations are fully informed about their localities and when given the resources, they can and do enact practices that improve lives based on the evidence they already have and know.

6. Be honest about the differences between what professional researchers need data for (it rarely is about helping communities) and what communities actually need for their well-being.

These recommendations are not an attempt to place professional researchers outside communities, but to stem the parasitic tide of research extraction from marginalized and vulnerable communities while the issues affecting those communities continue unabated. In terms of race-based data collection, professional researchers need to make clear to communities that research aims to influence policy, but that good policy is not always the outcome of research. The political nature and context of research therefore needs to be highlighted. Lastly, professional researchers need to alert racialized communities through public education campaigns that data can be heavily monetized and also used across many different platforms. It can be used and abused to potentially harm communities for years to come, and we should be more than cautious.

https://cihr-irsc.gc.ca/e/29134.html

https://www.whiwh.com/hiv-aids

https://globalnews.ca/news/6993844/coronavirus-toronto-neighbourhoods-covid-19-map/

^{iv} <u>https://cupe.ca/covid-19s-impact-indigenous-black-and-racialized-communities;</u>

https://www.allianceon.org/news/Statement-Black-Health-Leaders-COVID-19s-impact-Black-Communities-Ontario * <u>https://www.cbc.ca/news/health/female-immigrants-covid-19-protection-1.5717465</u>

^{vi} <u>https://www.tdsb.on.ca/Portals/0/docs/Schools%20in%20the%20Highest-</u> <u>Risk%20Neighbourhoods%20for%20COVID-19%20Identified%20by%20To</u>.pdf

^{vii} <u>https://www.toronto.ca/wp-content/uploads/2018/11/99be-2018-SNA-Results-Report.pdf</u> <u>https://www.cbc.ca/news/canada/british-columbia/vancouver-homeless-count-disproportionate-black-indigenous-1.5675414</u>

^{viii} https://theconversation.com/race-based-covid-19-data-may-be-used-to-discriminate-against-racializedcommunities-138372

^{ix} <u>https://rede4blacklives.com</u>

ⁱ https://www.albertahealthservices.ca/assets/healthinfo/MentalHealthWellness/hi-mhw-aborigina-researchprotocols.pdf

https://www.afn.ca/uploads/files/rp-research_ethics_final.pdf

ⁱⁱ <u>https://www.blackhivday.ca/about.html</u>

Also see the long list of research partnership Women's Health in Women's Hands has conducted for further evidence of how I make my assessment.