These are interesting times to be a medical scientist in Canada. As has been well reported in the media, the federal government’s decision to discontinue the mandatory long-form census, in favour of a voluntary sample survey, has left many statisticians, epidemiologists and population health researchers aghast and in disbelief. Politically, the census controversy lies mostly in the decision’s enactment without consultation with any of the data users.

Ironically, it may be the very issue of consultation or public discussion that is the kernel of progressiveness that may arise from this troubling state of affairs. This controversy, considered by some to be exemplary of a secretive government, is more than simply the denial of key data to stakeholders; it is a case of a basic existentialist crisis with which all liberal democracies must eventually wrestle, characterized by a tension between the poles of individual citizens’ autonomy and the need to limit that autonomy for the “public good”. Exploration of that tension can be pursued within three domains: examining the data’s importance, the state’s reliability as a custodian of those data, and the extent of citizens’ presumed civil right to informed consent.

The importance of the data
Much has been made of the role that mandatory census data play in the daily operations of many of society’s key actors. The Canadian Nurses Association submitted a brief to Parliament, decrying the census’s abrogation as jeopardizing such diverse civil programming as pandemic planning, community information and health planning, workforce analysis and general data verification. Indeed, it is likely true that decades of research programs are in jeopardy and that the ability to use census data as a supremely reliable comparator for validating survey sampling data is also compromised. The latter point suggests a role for census data as a control against state duplicity, which is an interesting and important addition to the dialectic being constructed.

Scores of well-cited studies on the Canadian population have relied upon census data, such as one on ethnic representation in high-risk professions, one on Canadian mortality statistics, and one on the relationship between socio-economic status and wait times for elective surgery. Our present, information-rich environment – made so by the existence of population registries and mandatory collection regimes like the census – has made possible types of research of a quality previously unachievable.

This is all to say that the data are made freely available to a host of interests across the country, from administrators to community groups to professional researchers. They play a role in the smooth functioning of our society. Their importance is indisputable. But it is their degree of criticalness, for lack of a better word, that must be considered when assessing their role on the continuum of autonomy and civil liberties. In other words, while the data are undeniably important, how critical are they to the health and survival of our society?

The state as reliable custodian
Statistics Canada enjoys a reputation globally as an honourable and effective protector of its vast data stores. A letter to the Prime Minister by the executive of the Canadian Society for Epidemiology and Biostatistics urged the government to recognize that “Statistics Canada has always protected the privacy of survey and census respondents, and it is a respected leader nationally, and internationally, in this regard.”

ABSTRACT
The discontinuation of the Canadian long-form mandatory census presents a crisis for data users. Examined as a tension between the need to preserve individual civil liberties and the need to curtail those liberties for the public good, the census crisis presents an opportunity for a public discussion on the specifics of our national values, beliefs and expectations.

Key words: Public policy; censuses; informed consent; ethics, research

La traduction du résumé se trouve à la fin de l’article.


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While it is true that the present moment in history is characterized by responsiveness, honour and legality among the bureaucracies of the governments of Canada, there exists a larger history of organizational abuse of data within the liberal democratic context. Some point to the rapid processing of German census data in the 1930s as having abetted the Nazi Holocaust. Similarly, there is evidence that abuse of the US census was instrumental in allowing the Roosevelt government of 1942 to identify, locate and intern innocent Japanese-Americans, and that this process was commenced prior to the formal declaration of war. More recent is the case of the US Department of Homeland Security using census data to identify and locate Arab-Americans for the purposes of domestic surveillance.11

While there is no evidence that any Canadian government has ever misused public data in this manner, the lesson from these examples is that the existence of such rich information can be a temptation to some of the more dishonest characters who may rise to power; and that modern, Western liberal democracies are not immune to authoritarian impulses, especially in times of perceived crisis, such as when in a state of war or when under threat by domestic terrorism.

The right of informed consent

One perspective is that the national census is a form of research on human subjects. Certainly, professional researchers regularly employ census data in ongoing studies. But our society has determined that it is fundamentally unethical to conduct research on human subjects without first going to great lengths to secure the “informed consent” of those subjects. Indeed, the Tri-Council statement on ethics, which guides all policies for government-funded research in public institutions in Canada, states that, “Individuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons thus means respecting the exercise of individual consent. The principle of respect for persons translates into the process and requirements for free and informed consent by the research subject.”12

Our national census is unique in the annals of Canadian population research in that, not only is informed consent not sought, but participation is compelled through the threat of criminal prosecution.

An editorial in Nature points out that, should the mandatory census be replaced with a voluntary survey, “Vulnerable populations of the poor and downtrodden will be less likely to reply to a voluntary questionnaire, skewing the resulting data.”2 Yet, ironically, the Tri-Council statement on ethics overtly states that informed consent shall be sought for the explicit purpose of protecting the vulnerable and downtrodden.12

We are therefore mired in something of an ethical and philosophical quandary. To best serve the nation, proper data are required. The best data are collected via the mandatory census, which clearly has far-reaching uses and implications for public planning and policy and for civil society as a whole. But to collect these data, fundamental rights must be curtailed, even among society’s most vulnerable; and in the collection of these data, society is rendered more vulnerable to potential abuses of the state, which history has shown is quite possible, given the proper geopolitical stimulus, even among the fairest and most stable of liberal democracies.

CONCLUSION

The ongoing discourse is one of tension between the desire to achieve complete individual autonomy for every citizen, and the need to curtail some of that autonomy for the public good. As a society, we accept that autonomy can be suspended to allow the enforcement of taxation, for example, in order that the state not become bankrupted and thence collapse. We daily accept some enforced curtailment of our physical movements, in the form of traffic laws, to make transportation safer and more efficient. We accept that in extreme instances of disease outbreak, civil liberties can be suspended for some in the form of quarantine. We accept that in extreme cases of border insecurity, the state can enact military conscription, thus compelling individuals to both kill and die.

A previous generation even accepted internment of innocent citizens due to nothing more than their ethnicity, in the name of the perceived public good. And in truly exceptional instances of civil crisis, we have given the state legal power to enact martial law and temporarily suspend all individual liberties for everyone.

So in our modern, liberal society, individual autonomy is not absolute. Our social contract allows for limits to autonomy when a threat to the public good has been identified and deemed sufficiently critical to warrant a denuding of our most basic rights. Often, this is basic to public health, such as in enacting seatbelt laws or smoking bans.

The census issue is therefore ultimately one of engagement. The public discussion has never taken place for us as a nation to decide how to best define that line of “criticalness” that determines whether a particular public good warrants the curtailment of specific civil rights. Indeed, what are the criteria for even beginning to define that line? It is a question of fundamental national values, the sort of inner exploration in which every society needs to regularly engage in order to remain healthy and thriving. While troubling in many ways, the census crisis has at least given us the opportunity to begin this discussion.

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