



The Impact of Cancelling the Mandatory Long-Form Census on Health, Health Equity and Public Health

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to the
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The Canadian Public Health Association is a national, independent, not-for-profit, voluntary association representing public health in Canada with links to the international public health community. CPHA's members believe in universal and equitable access to the basic conditions which are necessary to achieve health for all Canadians.

CPHA's mission is to constitute a special national resource in Canada that advocates for the improvement and maintenance of personal and community health according to the public health principles of disease prevention, health promotion and protection and healthy public policy.

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Executive Summary

In July 2010, Cabinet decided to replace the mandatory long-form census with a voluntary survey. The consequences of this decision will be felt for many years. It will affect the validity, reliability, representativeness and utility of the data produced by the proposed voluntary National Household Survey (NHS). This decision will also have a major impact on the capacity of Canada's public health community at all levels (federal, provincial/territorial and community) to design effective and appropriate responses to address the factors that affect the health and well-being of Canadians and to monitor and assess the impact of policies and programs on the nation's health.

Valid, reliable and representative data are essential to inform decision making in key sectors that have the greatest impact on the health and well-being of Canadians, including housing, education, labour force development, early learning and childcare, human services, and social and economic development. Over the long term, we can expect that this decision will contribute to an increase in the overall health burden within our society, especially for the more vulnerable and marginalized members of our society. The impact on the capacity of the health system to respond to essential needs will be adversely affected by poor decision-making, resulting from the absence of good data. This is cause for concern.

The Canadian Public Health Association (CPHA) urges the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities to take urgent action to resolve this situation. CPHA proposes three recommendations:

1. to make the NHS mandatory, through a legislative mechanism such as a Private Member's Bill, with or without penalties for non-compliance; or,
2. to postpone the census for a year, to allow time to examine and resolve the issues pertaining to a mandatory long-form census; and,
3. to reinstate the former census model (mandatory short- and long-form surveys) for the 2016 census, with public consultation about mechanisms to maximize compliance.

Time is of the essence if Canada is to maintain the continuity of 35 years of accurate and reliable data that are essential to formulate effective, appropriate health-affecting policies, programs and services.

The Canadian Public Health Association

CPHA is Canada's civil society leader in public health, representing the interests of the pan-Canadian public health community. The Association's membership is composed of public health professionals in all provinces and territories, many of whom work in the country's 115 public health units delivering essential public health services to Canadians. CPHA's members believe in universal and equitable access to the basic conditions which are necessary to achieve health for all Canadians. In this regard, it advocates for sound, evidence-informed public policies, strategies, programs and practices that protect and promote health and prevent illness.

What is Public Health?

Public Health is defined as "the science and art of promoting health, preventing disease, prolonging life and improving quality of life through the organized efforts of society." A "public health approach" is based on the principles of social justice, human rights and equity. It seeks to understand the underlying determinants of health, from a population perspective, and it is evidence-based. Canada has defined 6 essential functions of public health:

- Health protection (e.g., assurance of safe food and water, control of infectious diseases, protection from environmental threats)

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- Health surveillance (e.g., early recognition of outbreaks, disease trends, diagnosis of illness leading to early interventions, the influence of determinants of health)
- Disease and injury prevention (e.g., prevention or delay of onset of disease/illness/injury – for example, action on obesity, seatbelt legislation, tobacco control)
- Population health assessment (e.g., ability to understand the health of populations and the factors that affect health and create health risks)
- Health promotion (e.g., understanding and improving health through healthy public policy, community-based interventions and public participation)
- Emergency preparedness and response

The primary factors that shape the health of Canadians are not medical treatments or lifestyle choices. Rather, it is the social determinants of health (the political, socio-economic, and physical environments in which they live, work and play) that have the greatest impact on their health and well-being. Research is also finding that the quality of these health-shaping environments and conditions is strongly determined by decisions that governments take on a range of different public policy domains.¹

Governments at the municipal, provincial/territorial, and federal levels create policies, laws, and regulations that influence the income and income security of Canadians, the quality and availability of affordable housing, and as well the nature, availability and appropriateness of health and social services, and educational and recreational opportunities that Canadians can access. Much effort has been invested in monitoring the impact of policies and programs across Canada and at all levels on the health of Canadians and the degree of health equity enjoyed by all Canadians.

Expected Impacts Resulting from the Shift to the Voluntary National Household Survey (NHS)

In July 2010 Cabinet decided to replace the mandatory long-form census with a voluntary survey. This decision was not based on the results of a comparative study of the relative effectiveness of mandatory versus voluntary surveys. Rather, it was made in response to complaints by a purportedly small minority of Canadians who reportedly found the mandatory process coercive and the detailed questions intrusive. It should be noted that no research data has been provided to substantiate these claims.

Statistics Canada and a wide range of Canada's business, not-for-profit and academic groups, as well as provincial, territorial and regional/municipal authorities have identified a number of expected impacts resulting from the shift to the voluntary NHS approach.

1. Loss of Data Accuracy

A voluntary survey means some people will answer, while others will not. Studies show that people from the lowest and highest incomes groups, as well as the socially and economically disadvantaged, have lower response rates for a voluntary than for a mandatory survey.^{2,3} Research also shows that some groups, mainly the most vulnerable, are less likely to respond than others. The poor, marginalized and immigrant communities tend to not participate in voluntary surveys because of barriers such as language, literacy and disability. First Nations, Métis and Inuit are already under-represented in census data. A voluntary NHS would exacerbate the problem.⁴

A high non-response bias will compromise the survey's findings. The resulting data will be of little value to those making evidence-informed plans and decisions at all levels of government, since many of the resulting policies and programs are targeted at the aforementioned groups.

2. Increased Costs

The NHS will be sent to approximately 4.5 million (1 in 3) Canadian households. This represents a 13% increase in distribution compared to the 2006 Census long-form. It is estimated that implementing the NHS, with the associated increased distribution to additional households and the advertising budget to encourage Canadians to complete the voluntary survey, could cost \$30 million more than the former census.⁵

The loss of 35 years of investments in continuous, standardized, accurate data is another significant cost to the country. Adherence to the same statistical collection methodology has allowed for accurate data comparison and invaluable trend analysis. The introduction of the voluntary NHS will represent a permanent break in the data, because the new data collected from the NHS will not be directly comparable to the more accurate data previously collected through the long-form census. By definition, a change in statistical collection methodology precludes direct statistical comparison of data gathered before and after the change. Asking more people to voluntarily complete the NHS questionnaire does not guarantee that the data generated will be useable or comparable to the data generated using the mandatory long-form census survey.⁶ This will limit the ability of statisticians and decision-makers to accurately track important long-term socio-economic trends.

3. Weakened Accountability and Sound Decision-making

Statistics Canada anticipates a 50% response rate from the voluntary NHS. A response rate of 94% was expected from a mandatory long-form census in 2011. Due to the lower expected response rate, the NHS presents a substantial risk of non-response bias.⁷ By switching to a voluntary census, it will be a challenge to assess the scale and location of the non-response bias. Statistics Canada's mitigation strategies to offset non-response bias are unknown and hence, there is a risk that data quality will be less than for a mandatory long-form census.

In order to maintain statistically accurate analysis, data will have to be generated at a higher geographic level than with the former census model. The information collected will be unusable at the local level, where census data has become instrumental over the past decade to target resources through place-based policies and programs. The lack of the ability to accurately track important long-term socio-economic and health trends and the availability of place-based data at a local level will negatively affect the capacity of decision-makers to take evidence-based decisions on policies and programs.⁸

The integrity of Statistics Canada's long-form census data is paramount in ensuring all levels of government maximize the effectiveness of their resource allocations to meet the needs of Canadians. The absence of a long-form census will have serious repercussions on the capacity of municipalities, provinces and territories, and the federal government itself, to accurately assess where poverty and other disparities exist, and more importantly whether policies and programs, and any changes made in these, are having an impact and the nature and degree of that impact.

4. Impact on Health Research

The very high response rate to the census in previous years provides unrivalled accuracy and allows many other key sources of data produced by Statistics Canada to be benchmarked and to

Over the past 15 years I have written, edited or co-edited seven books, 39 book chapters and 100 scholarly journal articles that have examined various aspects of Canadians' health and well-being. Without the reliable and valid data provided by the Canadian census and the related surveys whose reliability and validity depends upon accurate Census data, I would never have been able to produce these.

Dennis Raphael, PhD, Professor of Health Policy and Management, Faculty of Health/York University, and this year's recipient of the 2010 Dean's Award for Research

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be drawn from appropriately weighted samples.⁹ The Urban Public Health Network notes that much of the independent research conducted in the field of public health relies on census data to establish sample frames – to ensure accurate representativeness of the population.¹⁰

Although practitioners and researchers in public health frequently use data generated and collected through voluntary surveys, the representativeness of the response is usually checked against the census data. The absence of reliable data from the census is thus not just a deficiency within itself, but affects other data-gathering activities. Furthermore, the change in methodology will affect comparability over time. Data users will not be able to compare any values due to the discontinuity between earlier and later (2011 and beyond).

Accurate and Valid Information is Critical for Public Health

The conventional census model provided a critical foundation for the generation of data from other health surveys. One example is the intersection between the long-form census model and the Canadian Community Health Survey (CCHS), a very important public health decision-making tool. This essential data base for the country's Public Health Units and Medical Officers of Health is used for the planning and assessment of policies and programs in their regions. The CCHS bases its sampling methodology on the census data. The questions raised about the quality and reliability of the NHS data cannot be ignored, as they will compromise the CCHS's sampling framework, and hence the validity of the data it produces. The consequence would be poor decision-making due to bad data.

The absence of reliable information on key aspects of our society will severely hinder our capacity to identify subgroups of the population with special needs and to target specific public health interventions.

Dr. Gilles Paradis, Scientific Editor/
Canadian Journal of Public Health

For 35 years, the census has provided high quality data about the residents in our community. It is the sole source of information for many indicators used for planning and delivery of Public Health services, not only in our area but province-wide. In fact, local Boards of Health are mandated [by provincial law] to use the census information found in the long form....

Dr. Hazel Lynn, Medical Officer of
Health/Grey Bruce Health Unit

The information gathered and made available through the long-form census is essential to understanding the health of our communities and to designing and targeting programs and policies to improve the health and well-being of Canadians, particularly for the most vulnerable and at-risk populations. The shift to the NHS is of particular concern to the public health community in Canada. Accurate statistics are important to determine the needs of communities and to identify and address the conditions having the greatest influence on health outcomes of population such as income, security, housing, education, day care, transportation, employment, recreation services, immigration settlement and support services, and other community services.¹¹ But, as mentioned previously, the population groups whose health and living conditions are most at risk will be under-represented in the NHS data.

A place-based approach to service coordination and investment requires accurate neighbourhood-level data profiles to plan strategic approaches to community development accurately and to inform service provision and neighbourhood investment priorities going forward.¹² Long-form census data enables the public health community to assess the efficacy of public health programs, measuring

whether health outcomes in particular areas are better, worse, or the same in the wake of an investment or intervention.

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Planning for health human resources will be adversely affected by the move to a voluntary NHS. Without the availability of adequate census information, health care system planners will not be able to formulate sound policy for the training, deployment and monitoring of the effectiveness and appropriateness of health personnel at the national, provincial or local levels.¹³

Accurate and Valid Information is Critical to Reduce Health Disparities

Canada's Chief Public Health Officer has made a forceful argument to Canadians for a comprehensive and accurate understanding of the conditions that affect the health of disadvantaged individuals and families as a means of addressing their needs and health issues.¹⁴ Census data help to identify these groups and to set priorities to reduce health inequities in Canada. Without reliable census data, we will not have as accurate an idea of where the pockets of poverty and other disparities are, and whether the policy changes being made are having an impact, and how. Yet these are the Canadians who will be most adversely affected if our census data no longer fully reflects their situation and their needs.

Only a few of many examples highlighting the use and importance of the long-form census data to the public health community in Canada are cited in this document. For example, a study conducted in Saskatoon found infant mortality rates in low-income areas to be over four times (448%) higher than in the rest of the city.¹⁵ In Hamilton researchers, using census data cross-tabulated with hospital admission records and Ontario death records, found a 21-year difference in average age of death between the residents in two neighbourhoods.¹⁶ Many public health units and researchers across the country have conducted similar studies to inform governments and community members about the prevailing situations and to provide the basis for discussions on how to address these important socio-economic and health issues. Census data were a critical element in all of these studies.

The information produced through the Canadian Census, including the Long Form Census questionnaire, is critical to support the efforts of front-line public health practitioners and those of decision-makers in public health departments to target health resources in an appropriate, effective and cost-efficient manner.

Debra Lynkowsky, Chief Executive Officer/Canadian Public Health Association

Census data enable public health workers to target particular migrant populations for initiatives that would be of specific benefit to them by reducing the risk to their health of certain disease conditions. For instance, Toronto Public Health offers tuberculosis prevention classes in neighbourhoods with high concentrations of people who have migrated from areas where TB is endemic. The data used to identify this situation and upon which the response was generated came from the census data. This would not have been possible without the data generated through the long-form census.

Detailed community demographic information drawn from the census is also used to target public health programs groups with particular needs, such as immigrants and specific ethno-cultural groups, and to provide services and resources to those who speak neither official language. Census data enable public health workers to deliver services and information in appropriate languages — whether Cantonese or Tagalog in a Vancouver neighbourhood or French in a northern Ontario community.

In Canada, large health administrative databanks used for surveillance of life expectancy, birth outcomes, hospitalizations and cancer do not have information to identify Canada's Aboriginal populations (nor any other ethnic or immigrant communities). It is through the long-form census that we are able to develop and report on infant mortality, life expectancy, and causes of death for areas where First Nations, Métis and Inuit live. Without

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this resource it would be very difficult to understand if we are making progress to reduce the significant gap in health between Aboriginal peoples and other Canadians.

Accurate and Valid Information is Critical to Anticipate Needs for Emergency Preparedness and Response

Long-form census data also enable public health workers to anticipate places and populations that might be at especially high risk during a pandemic, such as high-population-density areas. For example, a neighbourhood with a high concentration of two-bedroom apartments populated by families composed of eight or ten people is a very important place to situate a vaccination clinic in the event of an H1N1-type outbreak. Toronto Public Health reports that during the 2009/2010 H1N1 vaccination campaign, census data was used and critically important to target effective interventions.

In Montreal, the detailed census data was used to target health promotion messages to places and populations that were not being vaccinated for H1N1. As a result, the gap between vaccination rates in the higher and lower socioeconomic population groups were reduced in a few weeks.

Recommendations

While the content of the NHS in terms of the questions asked does not differ substantially from the 2006 mandatory census long-form questionnaire, the switch from a mandatory to a voluntary survey will adversely affect data quality and utility.¹⁷

The biases introduced by converting the long-form census to a voluntary survey will have serious repercussions on the capacity of governments and communities across this country to accurately assess where poverty and other disparities exist, and more importantly whether policies and programs are having an impact or not, and the nature of that impact. Over the long term, we can anticipate that this decision will contribute to an increase in the overall health burden within our society, especially for the more vulnerable and marginalized members of our society. The impact on the capacity of the health system to respond to essential needs will be affected adversely by poor decision-making.

Many groups representing the voluntary, health, business, education and other sectors have spoken out on this topic. The Canadian Public Health Association (CPHA) urges the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities to take urgent action to resolve this situation. CPHA proposes three recommendations:

1. to make the NHS mandatory, through a legislative mechanism such as a Private Member's Bill, with or without penalties for non-compliance; or,
2. to postpone the census for a year, to allow time to examine and resolve the issues pertaining to a mandatory long-form census; and,
3. to reinstate the former census model (mandatory short- and long-form surveys) for the 2016 census, with public consultation about mechanisms to maximize compliance.

A portion of the funds allocated to encourage Canadians to respond to the NHS voluntary survey should be redirected to increase awareness of the Canadian population about the use of census data and the measures in place to protect personal information.

On the question of whether data sharing and aggregation of information extracted from Canadians by a myriad of actors in provinces and territories and in private corporations across Canada can replace the detailed information we get from the census, our answer is the same as that of the now-resigned Canada's Chief Statistician to whether a voluntary survey can replace the mandatory survey: it cannot.

Dr. David L. Mowat Medical Officer of Health/Peel Region and President of the Urban Public Health Network

Concluding Remarks

Time is of the essence. Effective community-based policies and programs will be compromised as a result of implementing the voluntary National Household Survey. Replacing the mandatory form by a voluntary survey will also negatively impact municipal research, planning, and policy development in key sectors that have the most impact on health of Canadians such as education, labour force development, housing, early learning and childcare, human services, and social and economic development.

Effective community-based policies and programs will be compromised. Consequently, the impact of these changes will be disproportionately borne by those who are already most vulnerable - ultimately increasing socio-economic and health disparities in the country. Poor data will result in poor decision-making. The capacity of the health system to respond rapidly, effectively and appropriately to essential needs will be adversely affected. This is cause for concern.

As said by Monique Bégin, former Minister of Nation Health and Welfare and Member of the WHO Commission on Social Determinants of Health: *"Health inequities are not a problem just of the poor. It is our challenge and it is about public policies and political choices and our commitments to addressing these issues."*

The members of the CPHA urge the Committee to help bring about a just and fair solution that safeguards the health of all Canadians, does not impede the capacity of public health professionals to take good decisions based on good quality and reliable data, and is based upon the principles of equity, mutuality and an adherence to the Canadian tradition of evidence-based policy making to meet the needs of all Canadians.

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