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Review Paper

Challenges to the census: international trends and a need to consider public health benefits



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ABSTRACT

The Canadian government decision to cancel the mandatory long-form census in 2010 (subsequently restored in 2015), along with similar discussions in the United Kingdom (UK) and the United States of America (USA), have brought the purpose and use of census data into focus for epidemiologists and public health professionals. Policy decision-makers should be well-versed in the public health importance of accurate and reliable census data for emergency preparedness planning, controlling disease outbreaks, and for addressing health concerns among vulnerable populations including the elderly, low-income, racial/ethnic minorities, and special residential groups (e.g., nursing homes). Valid census information is critical to ensure that policy makers and public health practitioners have the evidence needed to: (1) establish incidence rates, mortality rates, and prevalence for the full characterization of emerging health issues; (2) address disparities in health care, prevention strategies and health outcomes among vulnerable populations; and (3) plan and effectively respond in times of disaster and emergency. At a time when budget and sample size cuts have been implemented in the UK, a voluntary census is being debated in the US. In Canada, elimination of the mandatory long-form census in 2011 resulted in unreliable population enumeration, as well as a substantial waste of money and resources for taxpayers, businesses and communities. The purpose of this article is to

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provide a brief overview of recent international trends and to review the foundational role of the census in public health management and planning using historical and current examples of environmental contamination, cancer clusters and emerging infections. Citing a general absence of public health applications of the census in cost-benefit analyses, we call on policy makers to consider its application to emergency preparedness, outbreak response, and chronic disease prevention efforts. At the same time, we call on public health professionals to improve published estimates of monetary benefit (via either cost-benefit or cost-effectiveness analysis) to a given public health intervention.

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Public health impact statement

Accurate census data are relied upon by epidemiologists and public health professionals to establish standardized incidence rates, mortality rates, and prevalence for the reliable identification and characterization of population groups for targeted public health intervention. The census is the chief source of information for denominators used for deriving and comparing rates of illness or conditions and contributing to the calculation of social deprivation scores and wider determinants of health within a locality. In general, cost-benefit analyses of the census do not consider public health benefits. Public health professionals should improve documentation of the actual and projected benefits of public health action. Policy makers considering cuts to the census should consider a full cost-accounting of hampered, disjointed, and ill-focused public health responses in relation to potential and current disease threats.

Background and purpose

Over the past few years, trends to cut or severely hamper census and public health information have occurred internationally. In Canada, response rates to the long-form census dropped substantially (as low as 25% in a number of communities with some communities providing zero responses) after it was made voluntary in 2011. Canadian census estimates among the poor and under-served are now considered to be unreliable by experts.¹

In the United Kingdom (UK), the Office for National Statistics (ONS) is a key UK government-funded provider of national statistics. Census data are used in the UK to inform local and national public health intelligence for the commissioning, design and delivery of community services, and for the investigation of and handling of disease clusters, outbreaks, and vaccination. Between 2008 and 2015, the ONS budget was cut by 25% in real terms.² The sample size of the UK General Lifestyle Reports (GLR) was cut by one-third. The GLR includes national UK data on smoking, drinking, and chronic health conditions.

Citing the right to privacy as the justification, a 2015 US House of Representatives legislative amendment proposed eliminating penalties for non-response to the US Census' American Community Survey (ACS), previously known as the

'long-form' of the census. In 2012, the US House of Representatives voted to prohibit the use of funds for conducting the ACS. The ACS uses a sample of approximately 1% (3 million households nationwide), and the data collected facilitates the distribution of federal assistance, including the Bureau of Economic Analysis' per capita income series and the Census Bureau's annual population estimates.

The purpose of this article is to: (1) provide an overview of recent proposed changes to the census in three different countries; (2) discuss the role of the census for effectively addressing public health threats and developing public health interventions; and (3) call on policy makers to consider costs to taxpayers of inadequate public health response to chronic disease prevention, emerging disease threats, and emergency preparedness in the absence of accurate census information.

What is a census?

A census is the official enumeration of a population defined according to administrative boundaries which includes enumeration by age, sex, race/ethnicity, and occupation, among other demographics. The term derives from the Latin word *censere* meaning 'to assess' as governments historically have used the census as a means of taxation. Debates about the census are not new. The census of Quirinius sparked a tax rebellion in Roman Syria and fueled the Zealot movement in the year 6 CE.³

As required in article 1, section 2 of the United States (US) Constitution, the census is central to political, economic, and public health planning. The US Supreme Court has referred to the census as the '*linchpin of the federal statistical system ... collecting data on the characteristics of individuals, households, and housing units throughout the country.*'⁴

There are three major approaches used internationally for the collection of census data:

1. Traditional (used by 115 countries, including, e.g., Canada, the UK, and Australia);
2. Population register (used by about 20 countries, particularly in Scandinavia); and
3. Rolling census/continuous measurement (used by the US and France).

Table 1 provides a summary of the approaches to the census and brief overview of the strengths and limitations.

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