

# Indigenous Mortality (Revealed): The Invisible Illuminated

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Inaccuracies in the identification of Indigenous status and the collection of and access to vital statistics data impede the strategic implementation of evidence-based public health initiatives to reduce avoidable deaths. The impact of colonization and subsequent government initiatives has been commonly observed among the Indigenous peoples of Australia, Canada, New Zealand, and the United States. The quality of Indigenous data that informs mortality statistics are similarly connected to these distal processes, which began with colonization. We discuss the methodological and technical challenges in measuring mortality for Indigenous populations within a historical and political context, and identify strategies for the accurate ascertainment and inclusion of Indigenous people in mortality statistics. (*Am J Public Health*. 2015;105:644–652. doi:10.2105/AJPH.2014.301994)

An accurate picture of mortality informs a society as to its social progress, because mortality is a key indicator of effective public health policies and programs. Mortality data, particularly the causes of infant and childhood mortality, also reflect a broader set of social, economic, and political issues.<sup>1</sup>

We address the key issues underpinning an accurate assessment of the excess burden of mortality carried by Indigenous populations, and cite the experiences of these populations in Australia, Canada, New Zealand, and the United States.<sup>2–7</sup> We provide an overview of the gaps, challenges, and strategies to improve the accuracy of Indigenous mortality assessment within a historical context and suggest how these challenges may be addressed.

Complete population ascertainment is essential to accurately define Indigenous life expectancy. Partial ascertainment of population groups results in erroneous information, most often because of the misclassification of Indigenous people as non-Indigenous. These effects are predominantly to the detriment of Indigenous populations.<sup>2,8</sup>

Five primary or core public health data sources are available—census, vital registration, surveillance, health care administrative or utilization data, and health survey data—and are affected by underlying challenges. In general, the challenge is about the correct, inclusive, and consistent identification of Indigenous

people in all 5 sets. However, the accurate ascertainment of population births and deaths (vital statistics) is fundamental to the accurate assessment of the trends in mortality, which is the main focus of our article. Although core public health data demonstrate the changing health status of the population and enable the effects of health policies, services, and interventions to be monitored and evaluated, vital statistics data provide the numerator and denominator necessary to calculate mortality rates. Deficiencies and inaccuracies in vital statistics and other data collections impede the strategic implementation of evidence-based public health interventions aimed at preventing avoidable mortality (e.g., lack of vaccination data and avoidable accident and injury).

Therefore, new strategies are required to improve data ascertainment, collection, and reporting within Indigenous populations, with more consideration given to ethical policy and methodological rigor.<sup>8–11</sup>

## HISTORICAL AND POLITICAL CONTEXT

To understand the current context of the excess burden of morbidity and mortality, it is necessary to understand the historical antecedents and the political context of the Indigenous peoples of Australia, Canada, New Zealand, and the United States, and the impact

that colonization has had upon their existence. Although considerable cultural distinctions exist within and across these groups, these populations share the experience (for the most part) of having lived on their lands for many thousands of years before the arrival of European settlers. The World Health Organization's investigation into health determinants now recognizes European colonization as a common and fundamental underlying determinant of Indigenous health.<sup>12</sup> Currently, Indigenous peoples share the experience of being minority populations in economically prosperous populations.<sup>13</sup>

As a result of the decimation of Indigenous civilizations and cultures, this purposeful colonial expansion has left a legacy of excess mortality, morbidity, and trauma that parallels the economic devastation and cultural loss of land alienation.<sup>14</sup> Gracey and King<sup>15</sup> describe the far-reaching effects that colonization had and continues to have on Indigenous populations. The invasion, disruption, and displacement of Indigenous people by Europeans who ventured across the Atlantic to the Americas in 1492 and across the Pacific to Australia in 1770 (settling in 1788) and New Zealand in the 1790s continues to adversely affect the physical, social, emotional, and mental health and well-being of Indigenous peoples.

A universal right of good health should take into account the cultural values of Indigenous people,<sup>16</sup> as outlined in the United Nations Convention on the Rights of the Child<sup>17</sup> and the United Nations Declaration on the Rights of Indigenous People,<sup>18</sup> to ensure that they are able to exercise various human, legal, economic, social, and political rights. The right to be counted is implicit in such rights. However, invisibility in vital statistics data is common within these 4 countries because of the exclusion of Indigenous groups from population health data sets through underregistration of Indigenous births and deaths. In some cases, entire groups of Indigenous peoples have been

reported as being excluded from these data sets.<sup>19–22</sup> As an example, before 1976, no Australian jurisdiction included an Indigenous identifier in vital statistics or hospital-based collections.<sup>23</sup>

Indigenous populations in Australia, Canada, and the United States experienced family and community disruption and relocation from traditional lands through government-legislated acts, despite efforts by Indigenous peoples to obtain international recognition for their protection and cultural conservation. These efforts were met with limited recognition from governments despite an international obligation to take proactive steps to improve the health and well-being of disadvantaged and marginalized population groups, including children. These steps should take into account

the conceptualization of Indigenous health in terms of the right of Indigenous peoples to the highest attainable standard of health allows for a broader approach to Indigenous health that acknowledges the historic and ongoing impact of human rights violations on the health status of Indigenous peoples.<sup>24(p448)</sup>

In particular, many Indigenous children were forcibly and unjustly removed from their families by governments for many different reasons, but essentially as a result of the paternalistic belief by the non-Indigenous authorities that Indigenous parents were unable to look after their children properly. A child's removal from family was shown to have significant negative and far-reaching and intergenerational consequences. These children are now recognized as members of the Stolen Generations in Australia,<sup>25</sup> and residential school and child apprehension survivors in Canada and the United States. In response to the Indian Act (Canada), the Indian Relocation Act (United States), the segregation of Indigenous Australians,<sup>23</sup> and the placing of Māori children in the care of the state in New Zealand,<sup>26</sup> Indigenous identities were at times hidden to prevent the forced removal and relocation of children. As a consequence, generations of Indigenous people experienced disruption of their familial kinship systems, their languages, and an intergenerational transference of their cultural heritage. These losses, and the mistrust of the governments whose policies adversely affected Indigenous

people, resulted in a propensity of Indigenous people either not to participate in data collections or to self-identify as Indigenous. This resulted in complete or partial invisibility of some Indigenous populations in many vital statistics collections and subsequent incomplete ethnic or racial ascertainment.<sup>10,11</sup>

### ASCERTAINMENT OF INDIGENOUS PEOPLE IN VITAL STATISTICS

It is a human right to be counted in population statistics in an accurate and timely manner, and people must not be denied the right or opportunity to self-identify as Indigenous. Without complete and accurate ascertainment of Indigenous populations in vital statistics, the accuracy of mortality statistics is questionable at best. Definitions of Indigeneity, imposed upon Indigenous people, continue to create pressures on and tensions within Indigenous kin systems. Such definitions do not always respect the complexity of such systems or the heterogeneity of community cultural mores. Further challenges to accurate identification of Indigenous people in today's vital statistics, census and health care databases occur when identifications in birth and death registrations are made by non-Indigenous persons not knowledgeable of the Indigenous person's status, or (in census and health data collections) where an Indigenous person is not given the opportunity to self-identify.<sup>27–31</sup>

Blood quantum (or fractional amount of Indian blood of an individual, reflecting the number of generations of native ancestors) was an important arbiter for race in the 19th century, and some of the 20th century, in all 4 countries. However, an objective ascertainment of blood quantum was and continues to be problematic, and more so, in the absence of official birth documents for so many Indigenous people. Reliance by government officials on the provision of blood quantum information as evidence of ancestry resulted in many Indigenous people not being identified as Indigenous in data collections or population counts. In Canada, nonstatus Indians (or a person of Aboriginal ancestry who is not registered as an Indian under the Indian Act) and Métis peoples have been systematically excluded from being counted as members of their groups in health data collections, despite their

relatively large proportion within the total Indigenous population (more than 40%).<sup>3,10,19,32</sup> An accurate assessment of the size of the population of these Indigenous groups is difficult to estimate because of underenumeration and inconsistency in interpretation of their Indigenous status.<sup>19</sup> The incomplete ascertainment of Indigenous people or communities in basic public health surveillance data through the use of government-defined racial categories clearly violates the recommendation in the United Nations Declaration on the Rights of Indigenous Peoples for individual determination of identity and membership.<sup>18</sup>

It is important to acknowledge and respect cultural diversity within populations and among these nations with colonial histories. Diversity is expressed through different cultural mores, languages, traditions, and heritage. For example, in Canada, Indigenous peoples include the First Nations, the Métis, and the Inuit; the United States Indigenous peoples include different tribal groups collectively termed American Indian/Alaska Native (AI/AN); and in Australia, the Indigenous population includes Aboriginal peoples and Torres Strait Islander peoples. Respect for distinct groups requires the opportunity for appropriate self-identification to a specific Indigenous subpopulation group when Indigenous identity data are being collected. Furthermore, policymakers require more disaggregation of data by specific Indigenous subpopulation group, because health systems and benefits are different for different groups.<sup>10</sup>

Censuses and vital statistics collections are important sources of identity information and provide an opportunity for people to self-identify their Indigenous status, contributing to accurate population statistics. However, accurate ascertainment is complicated by modification and changes to questions of Indigenous identity in official data collections and official recognition of Indigenous groups within these collections. The degree to which these issues apply differs within the 4 countries. For example, in Australia, before 1966, Aboriginal people who lived beyond settled areas were not counted in official population statistics, and estimates of their numbers were provided only by authorities responsible for Aboriginal welfare. In 1967, by national referendum, section 127 of the Commonwealth

Constitution, which prohibited the inclusion of Aboriginal natives from population counts, was repealed. Thus, since 1971, counts and estimates of the Aboriginal and Torres Strait Islander populations have been included in the official population statistics.

In 1984, to improve ascertainment, the Australian Government initiated a national policy to enable the identification of Indigenous Australians in births and deaths data collections. Consistent definitions, based on self-identification, have been used since 1987. By the end of 1997, all major vital statistics and hospital-based collections in Australia included the Indigenous status of people who were born, died, or admitted to the hospital in every state and territory.<sup>23</sup>

However, in Canada, with the loss of the Indigenous identity question on the census in 2006, there is no longer an accurate population-based enumeration of Indigenous people, and therefore, it is not possible to ascertain an accurate current population-based denominator. This prevents an accurate comparison of population-based statistics with previous years. New Zealand has seen changes in the form of the ethnicity question in successive censuses. For the Māori population of New Zealand, these issues became evident after changes to the format and content of the census question on ethnicity pertaining to the Māori population,<sup>33</sup> as identified by Reid and Robson,<sup>34</sup> Mako,<sup>35</sup> and Kukutai.<sup>36</sup>

Indigenous people living on-reservation or on traditional lands are more readily enumerated than the rapidly growing population living off-reservation or in urban or inner regional communities. Research that considered misclassification within Washington State between 1989 and 1997 found evidence that AI/AN people living in metropolitan statistical areas in the United States at their time of death were slightly more likely to be misclassified, and a strong, statistically significant inverse association was found between blood quantum and misclassification.<sup>37</sup> Similar misidentification occurred less often in counties that contained or were adjacent to federally recognized tribal reservations or trust lands.<sup>26,38</sup>

## DATA ACCURACY AND COMPLETENESS

Although incomplete ascertainment is a common issue that adversely affects Indigenous

data quality in Australia, New Zealand, Canada, and the United States, several other common factors affect data accuracy and completeness. These include differences in how Indigenous status is identified, as well as inaccurate, incomplete, and inconsistent denominator and numerator data used to calculate mortality rates. The level and consistency over time of the propensity for self-identification and ethnic misclassification in vital statistics collections (discussed previously) are also associated with incomplete ascertainment of data.

According to the United Nations, the most fruitful approach to ensuring that Indigenous people are included in statutory and administrative data is to identify, rather than define, Indigenous peoples. This is based on the fundamental criterion of self-identification, as underlined in a number of human rights documents.<sup>39</sup> Indigenous people (and bureaucracies) in the 4 countries choose different pathways to identification in birth and death data, which again reflect their individual mores and customs (and legislative frameworks). For example, according to a 1983 High Court of Australia definition, an Aboriginal Australian is identified as “a person of Aboriginal descent, albeit mixed, who identifies him/[her]self as such and who is recognized by the Aboriginal community as an Aboriginal.”<sup>40(p274)</sup> In Canada, Section 35(2) of the Constitution Act, 1982, defines Aboriginal peoples as “including the Indian, Inuit and Métis peoples of Canada.”<sup>41</sup>

However, it is important to note that these government-legislated definitions are not necessarily accepted by all Indigenous individuals and groups. Other identification methods include community identification and third-party identification, although the latter in many circumstances may result in significant misclassification if undertaken by people other than community or family members. Studies in the United States on American Indian self-identification in cancer screening report that, in this setting, self-identification was reported to be as reliable as other more complex measures.<sup>42</sup> However, self-identification of Indigenous status within administrative governmental or health care environment is not necessarily the safest choice for an Indigenous person. A continuing propensity to refrain from revealing identity reflects the pervasive influences of

historic policies and practices, and persistent attitudinal and systemic racism. In addition, the disproportionate levels of child removal and other social policies continue to dissuade people from self-identifying within administrative and statutory data collections. Systemic and attitudinal discrimination based on Indigenous status is unfortunately still common today, including in health care contexts.<sup>43</sup>

Although self-identification is the preferred approach, it is important that definitions and methods of self-identification be agreed upon with Indigenous peoples and that collection methods address the barriers to self-identification, through the principles of data ownership and control, privacy protection, use of Indigenous data collectors or liaison officers, and community engagement strategies.

In 2005, the Australian Bureau of Statistics reported a potential underestimation of 40% of Indigenous births in Victoria because of the lack of identification of fathers' ethnicity in the Perinatal Data Collection.<sup>44</sup> Similarly, there was a reported underestimation of Indigenous mothers of approximately 11.7%<sup>44</sup> between 2002 and 2006, in the Registry of Births, Deaths, and Marriages. Furthermore, there was an observed increase of 20.5% of people identifying as Aboriginal or Torres Strait Islander in the 2011 census<sup>45</sup> which, although greater than that could be explained by fertility, could be explained by improved methods in analysis of the census data and in the collection of the data, including a significant commitment of funding to assist the collection process. An Australian Bureau of Statistics publication provided a convincing case for the effect of an increased propensity to self-identify in the 2011 census.<sup>46</sup>

The undercounting of Indigenous deaths is a significant factor in determining the quality of Indigenous mortality rates. This is, in part, because of the inconsistency in collection protocols and the misclassification of ethnicity on birth and death certificates. The latter occurs particularly when collection of the racial/ethnic identity at birth or death is provided by a proxy or third party (for example, by funeral directors). Mistaken identification leads to misclassification and consequent underenumeration, as reported in New Zealand.<sup>47</sup> Underpinning such misclassifications is the potential for discrepancies between the deceased's preference

for Indigenous identification and the perception of an informant or recorder at the time of death. Linkage of census and death records has been used to address these misclassification issues in all 4 countries.

Death is a distressing time for families, and for Indigenous families, death more often occurs suddenly and away from home and community, and in the absence of beliefs, customs and practice, or in the care of health care providers unknown to the family. The potential for inaccurate information on race and ethnicity to be recorded at this time increases when the question of identity is not asked or third-party identification occurs (rather than identification by a family member). Although the provision for identification may be included in these data collections, it does not necessarily follow that an Indigenous person might choose to self-identify or that the question of the person's choice of identity is asked of the relatives at the time of death.

Particular attention is therefore required to avoid errors that affect the mortality rate. The outcome of misclassification of death of the relatively small Indigenous populations is a minor overestimation of the reported death rate of non-Indigenous people, but it is a substantial underestimation in the reported Indigenous death rate.<sup>48</sup> Inequities are veiled by the resultant underestimation of disparities between the Indigenous and non-Indigenous populations. An example of the methodological issues that affect accurate ascertainment was the significant undercount of infant mortality reported in 2005 for First Nations persons in Canada living on reservations.<sup>10</sup>

Contributing to the difficulties in accurate Indigenous mortality surveillance reported among children (aged 0–12 years) in the 4 countries, and the potential for cross-jurisdictional comparisons, are deficits in cross-jurisdiction standards within government agencies, inconsistency in identification, lack of coordination across and within jurisdictional boundaries, and the wide geographic spread of these countries.<sup>7,13</sup> In addition, there are no consistent ways of tracking movement across provincial or territorial boundaries, so deaths are usually missed if they occur in a location different from the province, territory, or state of birth. Commitment by governments to provide nationwide support for the development of

administrative and governance protocols to enable the linking of deaths occurring away from usual residence or residence of birth would greatly improve the accuracy and completeness in reporting of Indigenous infant mortality and birth outcomes.

Complete and accurate ascertainment on a national level is also commonly compromised by varying levels of ascertainment across and within jurisdictions.<sup>49,50</sup> These inconsistencies are, in part, the result of differing protocols of identification, the perception of the cultural safety of the local environment (in a place where the individual feels respected, their dignity preserved, and their information protected and used positively for their benefit), sensitivity to asking and responding to the question of identity (proxy ascertainment), and changes over time of a person's willingness to identify as Indigenous (ethnic mobility). The effect of these inconsistent population misclassifications across different data sources is a variety of different base population estimates (denominators) and significant inconsistencies in various measurements of population health. These factors must be considered when comparing the data derived from populations from disparate sources.<sup>51</sup>

## DATA OWNERSHIP

A document produced by the National Aboriginal Health Organization of Canada describes ownership as

the relationship of a First Nations community to its cultural knowledge/data/information . . . a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.<sup>52(p8)</sup>

Codes of practice or principles that enable data ownership include an imperative to provide appropriate feedback to the Indigenous individuals and communities that provide the information. Such principles set out a culturally respectful foundation for the collection, storage, and use of Indigenous health and health-related information. The same principles emphasize an ethical expectation of sound data management and commitment to extensive consultation and negotiation with Indigenous

communities and individuals throughout the data cycle (from the development of the study or collection protocols to the interpretation and disbursement of the data and findings).<sup>53</sup> The development of trustful and transparent relationships between those who collect (and use) data and the populations who are described in these data are critical to the complete ascertainment and to the accurate interpretation of the data.

In response to the past misuses of Indigenous data and the exclusion of Indigenous peoples from meaningful involvement in, and access to, their data and data systems, multiple Indigenous groups have implemented policies of Indigenous governance and management of Indigenous health data. Such initiatives have been observed in Canada<sup>9,10</sup> and in the United States, where tribes have asserted their sovereignty. Initiatives to better respect data ownership have been started in Australia and New Zealand, the former through the Australian Government endorsement of a set of national data principles, by the Australian Health Ministers Advisory Council and developed by the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data.<sup>53</sup> In New Zealand, the Tōmaiora Māori Health Research Centre has developed comprehensive protocols and procedures to guide Māori ownership of data, particularly in research settings.<sup>54</sup> In the United States, many tribes require agreements with institutions on the use and reporting of tribe-specific or AI/AN data.

In Canada, Indigenous leadership in, and ownership of, health data based on the principles of Ownership, Control, Access and Possession has informed the development of several Indigenous-owned and controlled data systems or data-sharing agreements and protocols with non-Indigenous provincial or territorial health data custodians. Examples include the First Nations Regional Longitudinal Health Survey (RHS),<sup>55</sup> the Naasautit: Inuit Health Statistics Web resource; Health Indicators of Inuit Nunangat within the Canadian Context (Inuit Tapiriit Kanatami, the national Inuit organization in Canada); the Metis Health Status report<sup>56</sup>; and the “Our Health Counts” Urban Aboriginal Database project.<sup>43</sup>

As Indigenous groups assume responsibility for their own health care data, adequate

resourcing and development of sound governance protocols, which include self-determination and carefully negotiated data partnerships between the people whose information is being collected and the data custodians, will be essential. The RHS is an excellent example of the establishment of regional partnerships in the ownership and administration of the RHS health data.<sup>57</sup>

Given the relatively small population numbers, development and observing of protocols that preserve anonymity within the reporting of Indigenous mortality data are crucial to prevent breaches of confidentiality. The recognition of protocols for reporting of small population numbers should also include acknowledgment of associated limitations in the translation of these data. However, aggregating data at a level sufficient to preserve anonymity may illustrate or conceal statistically meaningful regional differences. Strategies and planning for data pooling and linkages between data sets, within the First Nations principles of Ownership, Control, Access and Possession, should be explored. These principles advocate that departments and agencies in receipt of Indigenous community services information have a responsibility to assist with the development of strategies to ensure that data are appropriately reported back to the individuals and communities that provide the information.

The question of how ownership and management of data by communities can ameliorate the risk of being identified in the data is an important one. Potentially, this risk could be reduced through the development, by communities, of protocols and systems for the appropriate and transparent management, storage, and interpretation and release of data.

## ADDRESSING INACCURACIES IN VITAL STATISTICS DATA

Significant efforts have been undertaken in the 4 countries to address inaccuracies in reporting Indigenous mortality. A method to address undercounts in the United States has been to oversample tribal communities through the use of existing surveillance mechanisms. In New Zealand, to provide numerator and denominator consistency, the Ministry of Health recommended a standard of ethnic self-identification in both births and deaths to

be instituted. These data have been purposefully linked.<sup>58</sup> In New Zealand, the collection of these data are based on the prescribed census ethnicity question in the census, which has demonstrated improved numerator quality and significant reduction in numerator denominator bias between 2001 and 2004.<sup>59</sup> Thus, in this case, and generally, a numerator denominator bias would occur in the calculation of mortality rates in which there are differences between the populations in the denominator and the numerator. Blakely et al. found that classifying ethnicity in the same manner for births and deaths:

There is now little bias in ethnic group counts between census and mortality data for a “total” definition of ethnic group. Calculations of mortality rates by ethnicity using unlinked census and mortality data and a total definition of ethnicity should be unbiased. These results strongly support using the census definition of ethnicity on all health datasets.<sup>60(p58)</sup>

Improving the quality and accurate ascertainment of Aboriginal and Torres Strait Islander people in vital statistics collections has also been a priority in the past decade in Australia. Agreements and strategic plans have been developed by national bodies, such as the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data, and government agencies such as the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. These national bodies have provided important structures for addressing the quality and availability of Indigenous mortality statistics.<sup>61</sup> Initiatives have included a coordinated approach to information on Aboriginal and Torres Strait Islander peoples in the health, community services, and housing sectors, regular reporting on the health and welfare of Aboriginal and Torres Strait Islander peoples, and improved data quality and availability in survey, census, and administrative data.

## ESTIMATING LIFE EXPECTANCY

Life expectancy is a broad measure of a population's long-term health and well-being. To date, 2 main methodologies for compiling Indigenous life tables and life expectancies have been used in Australia. These methods are broadly grouped into indirect demographic

methods and direct demographic methods.<sup>62</sup> Bhat,<sup>63</sup> and, before him, Preston and Hill,<sup>64</sup> formulated an indirect method to calculate life expectancy for Indigenous populations.

The basic inputs (required by gender and 5-year age groups) in their calculations are age distribution of the population in question at the first and second censuses, and the age distribution of registered deaths during the intercensal period. The Bhat method also incorporated additional data on the age distribution of net migration, or if these data were not available, an independent estimate of the natural growth rate.<sup>63</sup>

There are 2 main concerns with the use of indirect methods. First, for both the Bhat and the Preston and Hill methods, the resulting estimates of coverage of Indigenous deaths in Australia for 2001 to 2006 were 20% to 25% lower than the coverage rates for 1996 to 2001. The Australian Bureau of Statistics suggested that this implied that coverage of Indigenous deaths in death registration data worsened considerably over the 5 years. Such a result would seem implausible compared with the observed data. Second, analyses have found that life expectancy estimates are very sensitive to the quality of the population estimates at the respective end points.<sup>65</sup> Errors in the age distribution and level of population estimate (estimated at the beginning and end of the 5-year period) can result in inaccurate expectancy estimates. The key problem has been the assumption of consistency (in completeness of reporting across age bands). Violation of this assumption, as Barnes<sup>51</sup> showed, has major effects on the life expectancy estimates and is considered to be a factor in errors in the estimates of trends in death rates. However, although there is general agreement about the desirability of direct methods (based on estimated deaths and populations), the application of these methods in Australia has been controversial, largely because of concerns over whether the methods used have completely and consistently identified numerator and denominator populations.<sup>66</sup>

## STRATEGIES FOR MOVING FORWARD

The most important step to improve the accurate ascertainment of Indigenous vital

statistics, and the quality and utility of Indigenous health data, is to acknowledge that a problem does exist. The development of mechanisms to establish and maintain partnerships with and between Indigenous organizations, data custodians, and statistical and other government data agencies is vital to improving the ascertainment, and therefore, the accuracy, coverage, and appropriate use of data. The development of such mechanisms is not merely recommended, but is an essential way forward.<sup>20,48</sup>

The importance of further developing and implementing consistent national plans to address the paucity in ascertainment within data collections cannot be underestimated. The development of national plans within Australia clearly outlined the importance of data ownership, including the imperative to provide appropriate feedback to the Indigenous individuals and communities that provide the information.<sup>67</sup> Such initiatives ensure that mortality data and other health measures are available to Indigenous health service planners and practitioners.

National commitments to address the existing inequalities in Indigenous mortality include the commitment made in Australia in 2009 to halve the gap in mortality rates for Indigenous children younger than 5 years of age within a decade and to close the gap in life expectancy within a generation<sup>68</sup>; these commitments include the United States' *Healthy People 2020* objective<sup>69</sup> and the New Zealand's *He Korowai Oranga: Māori Health Strategy*.<sup>70</sup> However, accurate monitoring of the progress of health targets is compromised when there is inconsistency in the accuracy and completeness of Indigenous identification data across jurisdictions. Furthermore, the question of changes in accuracy that happen over time or at different rates in different sources may have a flow-on effect on the derived rates and give an inaccurate estimate of change. These factors must be considered in interpreting longitudinal data and in comparisons across jurisdictions. Strategies to address these factors could include focused initiatives to improve data collection at its source, through education programs that emphasize the importance of collecting accurate data, protecting the confidentiality of information, and ensuring transparency in the application of the data. Such

education programs should be directed toward those who collect the data and those about whom the data are being collected.<sup>71</sup>

Using infant mortality as an example, the gold standard for infant mortality rate calculations could rely on standardized ethnicity-specific identification on both the birth and infant death certificates. In contrast to the approach where the numerator and denominator are drawn from different birth cohorts, a linked infant birth–infant death cohort approach allows for correction of missed Indigenous identity on the death certificate by using the birth certificate to capture accurate ethnic identity. Given the possibility that identification in birth and death data (undertaken by a third party) might differ depending on the person making the identification, further linkages (for example, to hospital data) would strengthen the accuracy of the numerator. The use of linked numerator–denominator data sets is preferable to the use of cross-sectional data in calculations of Indigenous mortality.

Linking population data from different data collections provides an important opportunity to gather information describing Indigenous identification from multiple sources, and in the process, enables a validation process.<sup>72</sup> Since the mid-1990s, successful population record linkage has been undertaken in parts of Australia<sup>73–75</sup> and New Zealand.<sup>59</sup> In the United States, the Centers for Disease Control and Prevention have used record linkage studies to evaluate the extent of racial misclassification of AI/ANs in the cancer registries in the Portland, Oregon, area Indian Health Service.<sup>76</sup> In New Zealand, record linkage is achieved using an anonymized national health index identifier.<sup>58</sup> However, in Australia, Canada, and the United States, different legislative requirements and frameworks are associated with the linking of statutory and administrative data across differing jurisdictions. Although there is general agreement that data linkage will provide significant improvements in accuracy of Indigenous identification in data sets, there are also issues to be considered in applying this method. For example, without accurate primary data in vital registration or surveillance data, linkage alone would be insufficient, because the degree of misclassifications could not be quantified. For example, linking data sets to a registry of Indigenous persons (for example, the Canadian

Indian Registry or Indian Health Service) does not necessarily yield the most accurate results. In such circumstances, there is the potential for data inaccuracies in applying this method, because of the misclassification of AI/ANs not listed in the Indian Health Service files and the use of out-of-date or incomplete linked data.

In addition to the growth of population data linkage, there has been increasing development and implementation of common measurement standards and expectations of best practice in Indigenous identification within and across countries with respect to Indigenous involvement and technical measurement. The continuation of the periodic evaluation of the progress of the implementation of these standards is recommended; examples of the use of report cards have been developed in the United States by the *Healthy People 2020* objective,<sup>69</sup> in New Zealand's *Whakatātaka Tuarua: Māori Health Action Plan*,<sup>77</sup> and in Australia through a dedicated, federally appointed body convened to specifically address the issue of the paucity of these data.<sup>53</sup>

Given the similarities and challenges in Indigenous data ascertainment being experienced by the 4 countries, the International Group for Indigenous Health Measurement was established to enable the sharing of information regarding the challenges of achieving accurate and complete health data describing Indigenous populations within and among the 4 countries. The group, which meets biennially, includes a network of people from government and nongovernment organizations and research and community arenas within Australia, Canada, New Zealand, and the United States. The group is united in its commitment to advise and recommend more consistent and comparable ways to measure and estimate infant and child mortality and life expectancy, the need to improve data at the source for these measures, and the need to progress mentoring and international exchange for Indigenous people from all 4 countries studying or working in indigenous health measurement.<sup>78</sup>

## SUMMARY

Indigenous people from the colonized countries of Australia, Canada, New Zealand, and the United States experience similar

impediments to the collection of accurate and complete vital statistics data. The methodological and technical challenges to attaining the accurate and complete mortality data we described must be addressed as a matter of priority.

The way forward requires formal and genuine partnerships between government statistical agencies and Indigenous peoples, and national plans to recognize and deal with the current deficiencies in Indigenous statistics. These plans will involve education, development, and adherence to standards, and continual monitoring of their implementation. The issues involved are complex, and the continuing exchange of information and expertise across national boundaries through the International Group for Indigenous Health Measurement has assisted, and will continue to assist, progress in each country.

Such actions can assist in mitigating the effects of colonial processes that have undermined Indigenous self-determination and the recognition of Indigenous knowledge systems. However, to achieve change in systems of collection, ascertainment, management, and translation of these data, the leadership and the active participation of Indigenous people are fundamental.

To act with scientific and human integrity in the closing of the current gap in outcomes, accurate and complete public health, community, and mortality data are essential. Importantly, we need to ask who is doing the counting and why. It is only by working together with Indigenous communities that an accurate assessment of mortality rates can be determined. With information, evidence-based policies aimed at reducing the gap in Indigenous mortality can be developed and implemented, initiatives can be evaluated, and we can demonstrate that we are a just and moral society. ■

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J. Freemantle led the collaboration, initiated the first draft, and undertook the reviews of the article in response to reviewers' comments. I. Ring assisted with the writing and document review and assisted in the responses to reviewers. T. G. Arambula Solomon, F. C. Gachupin, and J. Smylie assisted with the writing and document review. T. L. Cutler compiled the author contributions and organized the document for publication. J. A. Waldon assisted with the writing and document review.

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