

# “Just get on with it.” Linking data systems to report on infant mortality and the First Nations population in Manitoba (Canada)

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**Abstract.** The routine reporting of actionable statistics to improve system performance and prevent premature mortality has been promoted for decades. A key statistic produced nationally and globally is infant mortality. State governments define, collect and report vital events. In Canada, vital statistics is a provincial responsibility. The provinces, however, do not uniformly collect vital events for First Nations who are under Federal fiduciary responsibility or uniformly maintain a registration group field for disaggregation purposes. In 2008, Canada’s Public Health Agency conceded that a lack of a First Nations identifier has obscured any understanding of First Nations perinatal health. Given these drivers of variability and the complex multi-jurisdictional vital statistics environments in which they occur, this paper demonstrates, using data linkage methods, a way to improve the estimation of infant mortality for the First Nations population in Manitoba, Canada. The method improved estimation, and demonstrated a persistent gap in infant mortality.

Keywords: Indigenous, infant mortality estimation, vital statistics, data linkage, Canada

## 1. Introduction

The routine reporting of actionable statistics to improve system performance and prevent premature mortality has been promoted for decades. A key statistic produced nationally and globally is infant mortality. State governments define, collect and report vital events. The World Health Organization and the United Nations provide vital statistics guidance for comparative purposes. While uniformity is the goal, differential reporting is the norm, disadvantaging the most vulnerable populations (Elias [1]). Driving these differences

are political, societal, and medical advances (e.g. Armstrong [2]).

Although Canada promotes vital event standardization, a multi-jurisdictional environment creates variability. The Canadian federal government, bound by the British North America Act of 1867 (since renamed the Constitution Act of 1867), has jurisdiction over the census and statistics. The provinces have constitutional authority over all matters of a local and private nature (section 92(12)). While vital statistics are not explicitly mentioned in the constitution, the registration of births, deaths and marriages fall under this clause, thus resulting in each province and territory to enact vital statistics legislation. Through federal-provincial agreements for vital statistics and public health reporting, the provinces will share information for national reporting purposes. Some provinces, according to the Public Health Agency of Canada [3] have increased

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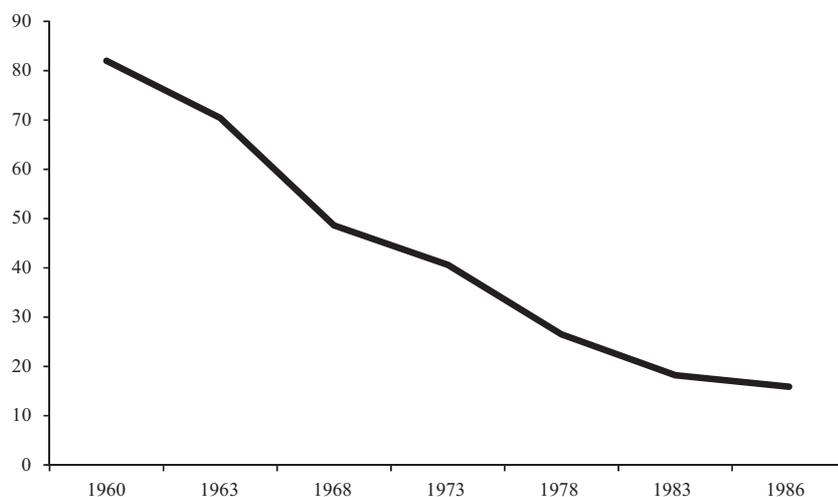


Fig. 1. On-Reserve Registered First Nations Infant mortality rates, as defined as children of one year of age and under per 1000 live births for the period 1960–1986. [Source: Indian and Northern Affairs, Basic Departmental Data, 1989 (QS-3482-000-EE-A1)].

their recognition of registration requirements. Some have made technological investments to increase the likelihood of survival for extremely low birth weight infants. Others have promoted the uptake of prenatal diagnosis and pregnancy termination for serious congenital anomalies, including the social reframing of the grieving process accompanying the death of such babies. It is within this multi-jurisdictional environment where infant mortality reporting challenges lay for the First Nations (Elias [1]), one of the first indigenous peoples of Canada (which also include Metis and Inuit peoples).

The Canadian federal government, constitutionally, has a legislative responsibility for “Indians and lands reserved for Indians”, now referred to as First Nations, including a fiduciary responsibility through the numbered treaties signed between the Indians of Canada and the Crown, particularly Treaty 6 that included a medicine chest clause to be held in the home of the Indian agent for the use of the people, which today First Nations interpret as health care. The provinces, as noted, have jurisdiction over vital statistics. Historically, the provinces included an ethno-cultural field on their birth and death registration forms to track immigration patterns. The provinces, however, reluctantly and unsystematically, assisted the federal government in registering the vital events of First Nations. After the federal and provincial governments enacted anti-discrimination laws and Bills of Rights, the ethno-cultural field disappeared from the vital events form (Elias [1]). Some provincial governments continued to track, albeit unsystematically according to Health

Canada [4], the vital events of First Nations. Health Canada, by agreement with the provinces, can access these records to calculate an infant mortality rate for this population (Elias [1]).

Historical trends suggest that Canada has made great strides in decreasing infant mortality rates amongst the First Nations. From 1925 to 1985, as illustrated by Young [5] the 1985 mortality rate for the First Nations population fell to less than one-fifth of the rate reported in 1955, only twice that of the national rate. At first glance, this decline suggests that improved health services, maternal health and social economic conditions increased maternal/child wellbeing. These estimates, however, are unreliable. Birth definitions changed over this period, and each province implemented this change at their discretion. The greatest bias generated, however, occurred when the provinces did not uniformly collect and report First Nations vital events to the Federal government, or consistently maintain a registration group field for disaggregation purposes (Elias [1]). Figure 1 shows data illustrating this dramatic decline for the On-Reserve population between 1960 and 1986. Figure 2 represents the last national official report of infant mortality rates for First Nations living On-reserve in Canada for the period 1979–2001. Data was derived from in-house statistics collected at Health Canada via federal-provincial agreements. Figure 2 illustrates a major reporting gap, between 1994–1998, when statistics were not available and a discrepancy in 1986, where the rate in Fig. 1 was 15.9 but changed in Fig. 2 to 17.5 per 1000 live births. In 2001, national reporting of infant mortal-

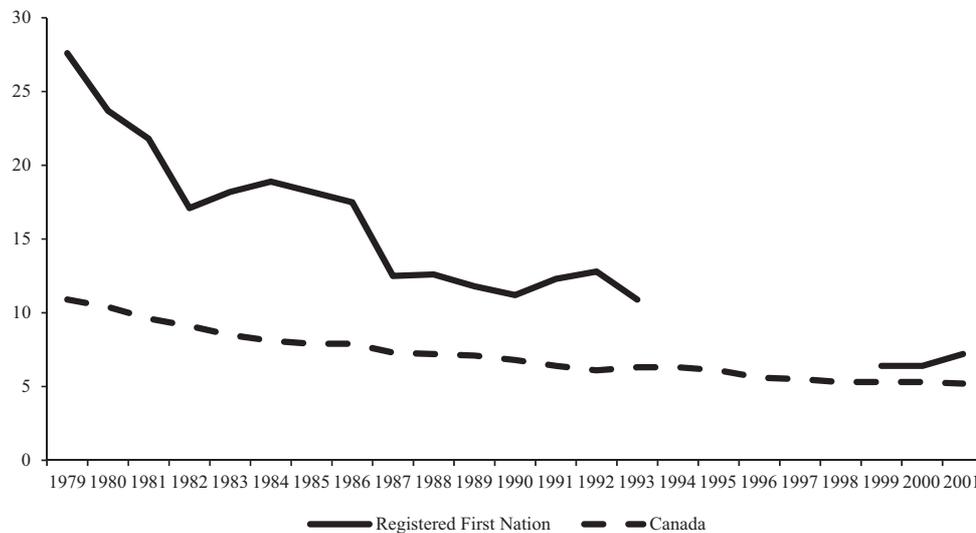


Fig. 2. Infant mortality rates (including all birth under 500 grams) per 1000 live births, comparing Canada and Registered First Nations Living On-Reserve, 1979–2001. [Source: Indian and Northern Affairs, Basic Departmental Data, 2004 (QS-3625-040-EE-A1)].

ity statistics for First Nations ended, and after 2005, Health Canada [4] and the Public Health Agency of Canada [3] conceded that a lack of a reliable First Nations identifier in vital statistical reporting systems has obscured any understanding of First Nations perinatal health.

A movement across three countries, involving Canada, Australia and New Zealand, has challenged governments to improve methods for identifying indigenous infants in state databases (Smylie et al. [6–8], Freemantle [9]). In 2011, Health Canada [4] publicly acknowledged that data systems throughout Canada were not set up to account for First Nations deaths or birth, thus limiting public health practitioners in their ability to identify and respond to the conditions driving infant illness and death. A year later, the United Nations [10] challenged Canada to improve its reporting of indigenous children's health.

In the same period, Canada was chastised for having a disproportionately high infant mortality rate. In 2011, the Organization for Economic Co-operation and Development [11] reported that as of 2007 Canada had the 7<sup>th</sup> highest infant mortality rate (5.1 per 1000 live birth) among member countries, surpassing countries greatly disadvantaged by social-economic circumstances. In 2009, Statistics Canada [12] reported a small decline in the rate from 5.1 to 4.9 per 1000 live births. The Conference Board of Canada's [13] reviewed this progress, and in 2012 gave Canada a rank of "C" for a rate that was second to last among 17 peer countries. In its defense, Canada's Public Health

Agency [3] has maintained that such comparisons are inappropriate due to the varying ways countries define their numerators and denominators. Indeed, between and within country variability is often due to birth registration policy and adherence (e.g., Lancaster [14]), particularly at the borderline of viability (Joseph, et al. [15,16]). In the case of Canada, however, the higher rate may be, in part, due to a disproportionate number of deaths among its indigenous population as noted by the United Nations [10].

Given these drivers of variability and the complex multi-jurisdictional vital statistics environments in which they occur, what are some demonstrable ways to improve the estimation of infant mortality for indigenous populations in a post-colonial world? This paper explores this issue through the experiences of a data linkage program in the Province of Manitoba, Canada.

## 2. Manitoba and data linkage potential

In Manitoba, a research handbook on the operations of the Manitoba Health Services Commission, dated 1976, listed the group affiliation fields and codes for payer responsibilities (Roos and Roos [17]). Fields and codes for patient groups were assigned to forms for health services patient registration and hospital admission. Specific insured person codes covered provincial wards such as clients of mental hospitals, provincial institutions and the children's aid society, and fed-

eral wards like Treaty Indians, inmates of federal institutions, or members of federal civil forces (police and military). In municipal areas, registrants from Indian Bands were further distinguished geographically by adding an "A" in the three-digit municipality code. A code for Treaty Indian reserve was also added to the municipal size field on the hospital forms. This code distinguished federal Treaty Indians living on reserve from other provincial residential characteristics. Because Treaty Indian residency was not uniformly collected, the Manitoba government has relied on the municipal A-Code to estimate the registered First Nations population. In 1984, a federal act, Bill C-31, dramatically affected the reliability of the A-Code to estimate the First Nations on-reserve population in Manitoba. Historically, the federal Indian Act legally defined Indian status and the enfranchisement conditions for when Indians were no longer a federal fiduciary responsibility. Early on, Indian women lost their legal Indian status when they married non-Indian men, as did the children who were a product of this relationship. Bill C-31 initiated the dismantling of some of this gender discrimination and reinstated some generations of First Nations who had lost their status. Reinstatement, however, was not fully captured in the provincial data systems, thus resulting in the underestimation of the on-reserve First Nations population of Manitoba Bands (Elias [18]).

In 2001, a data linkage study sought to identify federally registered Manitoba First Nation band members in the provincial health registry in a one-time data linkage project (Jebamani et al. [19]). This study involved linking Health Canada's Manitoba Region First Nations and Inuit Health Program Status Verification file of living First Nations derived from the Indian Registry System of the Federal Department of Indian and Northern Affairs (INAC) and the Indian Registry mortality file provided by INAC (now Aboriginal Affairs and Northern Development Canada or AANDC as of 2011) to the provincial health registry. An enhanced code was limited to registered members of First Nation Bands with a land base in Manitoba. The study ascertained that Manitoba Band registered First Nations were underestimated by approximately 30 percent in the provincial administrative data systems. While the study improved estimation, there was still misclassification bias noted. First Nations living in Manitoba but registered to Bands from other provinces, or not registered to any Band, and the children of First Nations parents of any Band but not yet registered with the federal department of Indian Affairs were misclassi-

fied in the "all other Manitoban" category. Since then, the province has continued to use the A-code to estimate First Nations health status and health service utilization, even though this study demonstrated a viable means to improve estimation (Elias [1,18]).

In 2011, Health Canada [20] released denominator guidelines for federal databases to improve health surveillance for the First Nations population. The databases identified to support analyses included the Indian Registry System housed at Aboriginal Affairs and Northern Development Canada (formerly Indian Affairs), the Health Canada Status Verification System (derived from the Indian Registry System), and Statistics Canada's Census. Significant database limitations were noted such as the late reporting of births and deaths, reserve and off-reserve residency, and regional and sub-regional counts (in-and-out migration). When linked to provincial administrative databases, these limitations could result in misclassifications. Any linkage process would therefore require the correcting for late reporting of births and deaths, including residency changes.

Another group at risk for misclassification are the First Nations children who are not eligible for registration under law because of the status code of their registered Indian parent. Such legal status definitions, however, are a form of colonial and post-colonial discrimination, undermining kinship ties, historic and current, which are the true foundation of First Nations identity and society according to the Assembly of First Nations [21]. Indeed, First Nations have historically defined citizenship more broadly using birth, marriage, adoption, residency, self-identification, gender-neutral kinship, or community ties as documented in Canada's Royal Commission of Aboriginal Peoples [22]. Producing a First Nations identifier via these various approaches to citizenship is more consistent with the United Nations Declaration of Indigenous Peoples, specifically articles 6, 9 and 33. As new citizenship systems evolve at the community level, a viable interim actionable data-linkage approach is still required.

Following the 2001 data linkage study, two other Manitoba linkage studies were undertaken. One used Statistics Canada linked stillbirth, live birth and infant mortality database (using self reported First Nations status) for the period 1991–2000, comparing First Nations and all other Manitoban infants (Luo et al. [23, 24], Martens et al. [25]). The other involved a data linkage research program funded by the Canadian Institute of Health Research and supported by the Assembly of Manitoba Chiefs Health Information and Re-

search Governance Committee to improve estimation for health interventions in the First Nations population. The first stage of this program involved building a more inclusive denominator using the national Indian Registry System file (as reported in Elias [18]). The linkage addressed the misclassification bias of First Nation infants and children, noted in the Health Canada [20] denominator guidelines. Mortality estimates were produced for a First Nations tribal report (Elias and Hall [26]), comparing First Nations and all other Manitobans. Stillbirths, infant and child mortality estimates were also produced, thus filling a major gap in the previous 2001 “First Nation report” (Martens, et al. [19]) that did not report on these indicators.

At the outset of this linkage program, while we expected some improvement in the overall First Nations infant mortality rate, we still anticipated a significant mortality gap between First Nation and all other Manitoban newborns. With the improved First Nations indicator, we projected an economic gradient for both groups, with rates lower in the highest income quintiles, regardless of area. We also predicted a north-south, rural-urban gradient, with rates still higher for First Nation newborns, particularly in the north. The following summarizes our approach and findings based on the more inclusive identifier.

### **3. Our approach and findings on First Nations stillbirths and infant mortality**

Data used for this study came from the Population Health Research Data Repository at the Manitoba Centre for Health Policy (MCHP). Using vital statistics records for the period 1997–2006, we calculated crude rates for overall infant mortality (per 1000 newborns aged 0–364 days), neonatal mortality (per 1000 newborns aged  $0 < 28$  days) and post-neonatal mortality (per 1000 newborns age 28 to 364 days) for First Nations (FN) and All Other Manitoban (AOM) newborns. The infant mortality rates included fragile infants with a birth weight less than 500 grams and those with a gestational age of less than 22 weeks. The denominator included all infants born alive in the ten-year period. Infants born alive and dying before their first birthday became the numerator, and so on. A stillborn or fetal death is identified as a fetal death with a gestation of 20 weeks or greater or a birth weight of at least 500 grams. The denominator for this rate is total births, which includes stillborn and live births. Within each

group, we estimated the proportion of crude deaths by cause for infant, neonatal and post-neonatal mortality. Crude rates per 1000 newborns were calculated using definition algorithms from the MCHP concept dictionary.

A rural-urban measure was created to understand rate differences between urban, rural south, rural north and the rural mid section of the province. For the First Nations population, potential rural differences were assessed between the on and off reserve population. To investigate these differences, we had to develop a new on and off reserve status indicator. The original indicator, which came with the IRS file, did not account for in-and-out migration. To confirm reserve residency, we created a new On-reserve status indicator, using the algorithms developed in the previous linkage study (e.g., Jebamani et al. [19]), by combining a geographic code for residence from the MCHP provincial population health registry and a band (community affiliation) identifier from the Indian Registry System data. If the geographic code and band code identifier reflected similar geographic space, as in on or near reserve, the individual was identified as residing On-reserve. The individual was identified as living Off-reserve if the geographic code and band code differed. Pair-wise comparisons were made, the most straightforward way to measure progress toward eliminating disparities between groups. The relative disparity measure (R1/R2 base population) was calculated to provide some indication of the progress (or lack thereof) one group has made, regardless of the actual level of health.

An income quintile measure was also used to identify if there is a social economic gradient in infant mortality. This measure divided the population into five income groups, from 1 representing the lowest income quintile to 5 the highest income quintile, with 20% of the population in each group. Income quintiles were calculated separately for rural areas (R1 to R5) and then for the urban social economic hubs (U1 to U5). This measure is an area-based measure and does not represent individual income and is dependent on census participation. Each person within an area level is attributed the average household income for that area. Linear trend tests were conducted to determine statistically the existence of a trend by income quintile ( $P < 0.01$ ).

Statistical differences were tested at a probability of less than 0.01 due to multiple comparisons to avoid inflated type 2 errors and were reported between groups within an area and by comparing a group's area rate to its provincial average. For leading causes, the method

used to calculate a confidence interval between two proportions was the Newcombe-Wilson method without continuity correction. Data was suppressed for cell sizes of five or less. SAS software was used for database development and administrative database analyses. Ethics and research approval was received from the University of Manitoba health research ethics board, the Manitoba Health Information Privacy Committee, the Assembly of Manitoba Chiefs Health and Information Research Committee, and the Manitoba Centre for Health Policy.

Our analysis yielded the following findings. For the period 1997–2007, the FN crude stillbirth rate was statistically higher when compared to AOM births in all regions, with the exception of the north. In the rural mid area of the province, the FN stillbirth rate was nearly twice (10.6/1000 total births) that of the AOMs (5.81/1000 total births).

The provincial FN crude annual infant mortality rate (10.7/1000) was nearly twice that of the AOM newborns (5.73/1000) ( $P < 0.01$ ). FN infant mortality rates were significantly higher than the AOM rates in all rural and urban areas. The rate was highest in the urban area (12.7), followed by the rural north (10.5), rural south (9.6) and mid-province (8.6). These differences were not significantly different from the FN provincial average. For the AOM newborns, the infant mortality rate was similar across all regions (only ranging from 5.42/1000 rural mid-province to 6.36/1000 rural north), with no significant difference from the provincial AOM average ( $P > 0.62$ ). When we compared the on-and-off reserve newborn populations, the rates were statistically similar, with the exception of the rural north where the on-reserve rate (ONR 11.6/1000) was nearly double that of the off-reserve rate (OFF-R 6.8/1000) ( $P < 0.01$ ).

For neonatal mortality, we found a significant provincial difference, with a higher rate for FN newborns (FN 5.85/1000 versus AOM 4.25/1000). Area rates were similar with the urban exception. The neonatal mortality rate for FN newborns was significantly higher (FN 6.87/1000 versus AOM 4.13/1000 newborns). There were no statistical differences between the On-and-Off Reserve FN neonatal rates. For the post-neonatal period, the provincial FN mortality rate was three times greater than the rate for AOM newborns ( $P < 0.01$ ), and a similar pattern of difference was evident in all sub-regions, rural and urban. While rates On-and-Off Reserve differed, the rates were not statistically different at  $P < 0.01$ .

For FN newborns, the leading cause of infant mortality was congenital anomalies followed by “causes”

in the perinatal period, which includes short gestation (pre-maturity), low birth weights, and maternal complications during pregnancy. The third cause of death was sudden infant death syndrome (SIDS), followed by respiratory failure and then external causes of injuries. For AOM newborns, the leading cause of death was congenital anomalies, followed by causes in the perinatal, complications in labor, SIDS, and respiratory system. Significant differences were found. FN newborns, when compared to AOM newborns, were 4.5 times more likely to die of SIDS, 3.5 for ill-defined conditions, 3.2 for external causes of injury, 2.6 for respiratory, and 2 for short gestation/low birth weight ( $P < 0.01$ ). For FN and AOM neonates, the first and second leading causes of mortality, with little difference between, were congenital anomalies and “causes” originating in the perinatal period, particularly for short gestation/low birth weight. When compared to all other Manitoban neonates, FNs were 2 times more likely to die of short gestation/low birth weight and approximately 1.5 times more likely for congenital anomalies ( $P < 0.01$ ). In the post-neonatal period, the leading causes of FN mortality were SIDS, ill-defined conditions, congenital anomalies, and external causes of injury. The leading causes for AOM newborns were congenital anomalies, SIDS, external causes of injury, and ill-defined or other causes. FN newborns, however, were 8.6 times more likely to die of a respiratory condition, 4.7 for ill-defined causes, 4.6 for SIDS, 3.5 for external causes of injuries and 3.4 for other causes ( $P < 0.01$ ).

Socio-economic area differences were found for infant mortality. Within rural income quintile areas, there were significant differences in the lower three income levels of R1, R2 and R3 where the FN infant mortality rate was higher. There was no significant rural trend for either FNs or AOMs. In the urban population, significant mortality differences were found between FN and AOM newborns in the lowest urban income quintile and in the higher U4 income quintile. There was a significant linear trend for AOM newborns ( $P < 0.01$ ), with infant mortality rates decreasing as urban area income increased. Social economic differences were not investigated for stillbirths, neonatal or post-neonatal rates due to small cell sizes.

#### 4. Discussion and conclusion

While this linkage study built a more inclusive denominator for First Nations, the new numerators

and denominators did not result in radically different provincial rates from the linkage study using the Statistics Canada linked stillbirth, live birth and infant mortality database for the period 1991–2000 (e.g., Luo et al. [29]). Our research showed that out of all births First Nation women have significantly more stillbirths than all other Manitoban women, with the exception of the north. As well, the First Nation infant mortality rate was still approximately double that of all other Manitoban newborns. Neonatal and post-neonatal on-and-off reserve rates were not statistically different, also supporting a similar on-and-off reserve finding in the Statistics Canada linkage study reported by Heaman et al. [30]. In the north, however, the overall on-reserve infant mortality rate was statistically greater than the off-reserve rate. This finding suggests that the off-reserve environment, represented by northern economic, health and social service hubs, may provide some advantage to First Nation newborns. Taken as a whole, the persistent infant mortality gap found between the First Nation and all other Manitoban newborn population is quite troubling, particularly in light of a recent study of the Manitoba Métis population that found no difference between Métis infants and all other Manitoban infants for the same time period and aggregate areas (Martens et al. [28]). The higher First Nation rate appears unique to this population and its persistence suggests that the underlying causes run deep, are historic, and are socially and biologically complex.

While there were no neonatal mortality differences in most regions, the rate was higher for First Nations in the urban area, where ironically services and programs should be more accessible. As well, First Nations newborns, regardless of region, experienced higher post-neonatal mortality rates than other Manitoban infants. These infants were more likely to die of such preventable conditions as SIDS, respiratory failure, and external causes (e.g. injuries). Also contributing to these higher infant mortality rates were congenital anomalies and ill-defined causes. While injury prevention, positive parenting, and safe home environments are key approaches to resolve external causes, SIDS is also intertwined epigenetically with respiratory and cardiovascular system health (e.g., Lagercrantz [31]). Proposed mechanisms and genetic variants, like polymorphisms for cardiac channelopathy genes, and genes related to serotonin, autonomic nervous system development, inflammation and energy production might predispose an infant to SIDS (Hunt and Rauck [32]). In these cases, without a trigger, there is hope that death may not occur. A Manitoba study by

Wilson [33], for example, showed that prior to a SIDS event First Nation infants were more likely to have a poor respiratory history due to poor living conditions (bacterial and fungal). To decrease rates, prevention efforts are still required to achieve smoking cessation, alcohol abstinence, a healthy diet, nutritional supplementation, breastfeeding, back-to-sleep, healthy housing conditions, and socially supportive, less stressful and safe home environments to decrease stress-related risk behaviors (alcohol, smoking, violence, poor nutritional choices) at pre-conception, conception, and post pregnancy (as illustrated in [34–40]). As for congenital anomalies and ill-defined conditions, the province has re-established a congenital anomaly surveillance system that includes documenting associated modifiable behaviors, many of which are associated with SIDS and related biological system issues. While this surveillance system will help inform public health interventions, we still do not fully understand the link between the environment and human biology, and how this interaction promotes congenital anomalies, SIDS, system failure, or ill-defined conditions as noted by Lagercrantz [31] and Hunt and Hauck [32]. Understanding the life course of mothers and fathers before conception, at conception, during pregnancy, and post pregnancy in relation to the social, economic, behavioral and nutritional environment would not only increase our understanding of the trajectory of children who survive infancy but can also help explain why some infants do not.

While we projected with some hope that there would be a social economic gradient, with rates lower in the highest income quintiles regardless of group, rural or urban, the gradient was not there for the First Nations population. We found significantly higher mortality rates for First Nations infants born of mothers residing in rural areas characterized by lower to middle socioeconomic status, and this finding was consistent with a previous study by Luo et al. [29]. Mortality rates, however, were not socioeconomically different for rural “all other Manitoban newborns”, thus prompting the question of whether infant mortality is more of a maternal-child rural health service and prevention issue. As expected, a significant trend, however, was found for urban “all other Manitoban” infants. While we expected the same for urban First Nations, we found a higher mortality rate among First Nation newborns of mothers residing in higher income urban environments. These findings, while counter-intuitive, may be a product of an area-based measure, which does not represent the income of the infant’s parent or

household or may not be reliable due to low indigenous participation in some census areas.. While improved neonatal health is highly influenced by healthcare systems, research suggests that lower family income tends to correlate with increased post-neonatal risk, despite access to universal government paid health care services (e.g., Joseph et al. [41]). Unfortunately, we cannot confirm this relationship because we were limited to an area-based measure. Another point to consider is that factors driving poor health may not be income-based as noted by Anand et al. [42] who found that First Nations living in higher income circumstances were at much higher risk for cardiovascular disease than a non-Indigenous comparator population. From an indigenous social determinant approach [43], poor outcomes may not be entirely income-based but in part due to multi-generational inequalities and a loss of culture, a disconnection from the land and community, and high levels of racism and social exclusion.

Other study limitations are as follows. The infant mortality measure included all fragile infants, thus raising the question whether the rates would differ between the groups if fragile infants were excluded. A recent Manitoba study by Brownell et al. [44] did not find a difference between the infant mortality rate with fragile infants included and a rate excluding fragile infants. Whether this holds true when disaggregating the data by First Nations and all other Manitoba newborns is a question for further research and would be the subject of another paper. As for grouping identifiers, the First Nations identifier is still a point of contention. The linkage algorithm used at the Manitoba Centre for Health Policy resulted in the exclusion of children who could not be geographically located, particularly the children under the public trustee. Postal codes only represent the current location of the registered head of the family rather than the location of the child. During a pregnancy where family circumstances suggest a potential risk, a birth alert could result in the infant at birth being placed under the public trustee, severing the link between the child and the family. It is unclear how many infants were in that circumstance at the time of birth. Further research is required to investigate this decoupling and the estimation bias it may create for both populations. Nevertheless, by expanding the inclusion criteria in our study, we may have addressed previous misclassification bias identified as under reporting by Health Canada [4] or related to different linkage files identified in other studies. For instance, a previous study by Martens et al. [25] using the Statistics Canada linked file showed that place mat-

tered for rural non-First Nations, with rates lower in the south and highly elevated in the north. Our study, however, did not find any statistical difference in neonatal, post-neonatal, or overall infant mortality for all other Manitobans. This finding suggests that the national IRS file, the derived First Nation Key File, and the vital statistics resources and repository registration file at MCHP may have resolved some of the First Nation misclassification and rural/urban residency limitations of the Statistics Canada linked file. Nevertheless, we need to be mindful that the national IRS file is still a post-colonial data system using a colonial classification schema. First Nations have their own views of citizenship criteria, as noted. At the same time, provincial governments may entertain an ethno-cultural identifier in clinical pathway systems. We can speculate that if self-report becomes the norm and if First Nations decide not to self-report their identity, there may be a question of misclassification, and depending on the degree of non-engagement, the rate may be impacted. As well, if parents decide to self report their First Nations heritage and that of their newborn, greater disclosure may also affect the rate. Another matter is whether providers will consistently collect the identifier. Manitoba tribal organizations, such as South East Resource Development Council, have stepped up, challenged the colonial system, and now has the authority to validate the births of new tribal members. These various issues may also emerge for other ethno-cultural groups in Manitoba and Canada. That being said, we will need to address how self-reported identity will be handled at the data processing stage. Any shift to self-identification will prompt a movement towards standardized ethno-cultural definitions, nationally and provincially, much like what has been promoted by the Australian Institute of Health and Wellness [45]. Of course, any form of harmonization will require a dramatic shift in federal-provincial-and-First Nation relations to forge a multi-group collaborative relationship for a national or provincial First Nations vital statistics reporting system. If we consider the time it took to develop a national vital statistics system in Canada and the extension of that system to First Nations people, we may be looking at decades of multi-jurisdictional debating, lamenting and positioning over what constitutes a valid ethno-cultural identifier in health and social administrative databases (Elias [1]). In the meantime, innovative data linkage studies are still required to inform health reform initiatives to address persistent gaps in health status. Whether guidelines are required for data linkage studies, within and across groups, is

still open to debate in Canada. We may even want to consider the efforts of the Australian Institute of Health and Wellness [46] in setting national and state data linkage guidelines.

Needless to say, the time of stating that we lack data in Canada to act is over. This study has showed, once again, that we have access to a First Nations identifier. We just need to get on with it. In Manitoba, there is a persistent infant mortality gap between First Nations and all other Manitoban newborns. This tenacious disparity raises many questions, particularly about the state of maternal child health services and interventions in a universal health care system. For instance, what is the overall state of maternal child health services, including prevention services, on and off reserve, rural versus urban, including by social-economic areas? As well, what are the availability, quality and responsiveness of care, including routine and emergency care for First Nations mothers and the newborn population?

Currently, provincial programs as reported by Heaman et al. [47] are expanding for the early initiation of prenatal care, supportive parenting for low birth weight and preterm infants throughout the first years of life, and neonatal screening programs. How these initiatives will support the First Nations population, regardless of where they live, or whether programs will address post-neonatal disparity throughout the province is not clear at this time. In addition to existing tribal and on-reserve prenatal programs, Health Canada has funded innovative family maternal child health pilot projects in some Manitoba First Nations communities (e.g., Eni and Phillips-Beck [48]). How such pilot services are supporting and integrating with provincial programs and existing tribal and on-reserve programs, how provincial regional health authority programs are linking with existing tribal and on-reserve prenatal programs, and how provincial and tribal programs support the rural-urban off-reserve First Nations population in relation to all other Manitobans still require in-depth investigation. While low-cost, community-based interventions and strategies, as reported by Tinker et al. [49], have been shown to significantly reduce infant mortality, further research is required to report on the state of these initiatives in tribal areas, on-and-off-reserve, across rural-urban social-economic environments, and on the very inclusiveness of these initiatives.

A life course approach to maternal child health, as promoted by Brown et al. [50], could also steer policy away from single interventions towards program clus-

ters. Cluster programs, however, should not be limited to the mother and the child according to Martens [36], but should also extend to fathers and the whole family, including maternal grandmothers and aunties. In addition, while we ponder whether new communication technologies, enhanced referral systems, community-run versus government provider controlled transportation systems, or new health data systems can improve outcomes, the question still remains whether there is a will to make these innovative approaches universally accessible and inclusive of First Nations, on and off reserve.

To ensure new policies make a positive difference at the regional level (e.g., Postl et al. [51]), we should also be mindful of how colonial policies and jurisdictional debates have promoted intergenerational poverty, food and nutrition insecurity, social disruption, behavioral risk, and denial or delay of health services, all of which are structural forms of violence that drive mortality risk, inter-generationally. In the final analysis, this study has shown that infant mortality is an important metric. In Manitoba, the infant mortality gap is persistent, and if there is a will, there is a way to harness data to inform interventions to improve First Nations outcomes. We just need to get on with it and close the gap.

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