

# PAUCITY OF MÉTIS-SPECIFIC HEALTH AND WELL-BEING DATA AND INFORMATION: UNDERLYING FACTORS

*Prepared for the NCCAH by the Métis Centre of the National Aboriginal Health Organization*

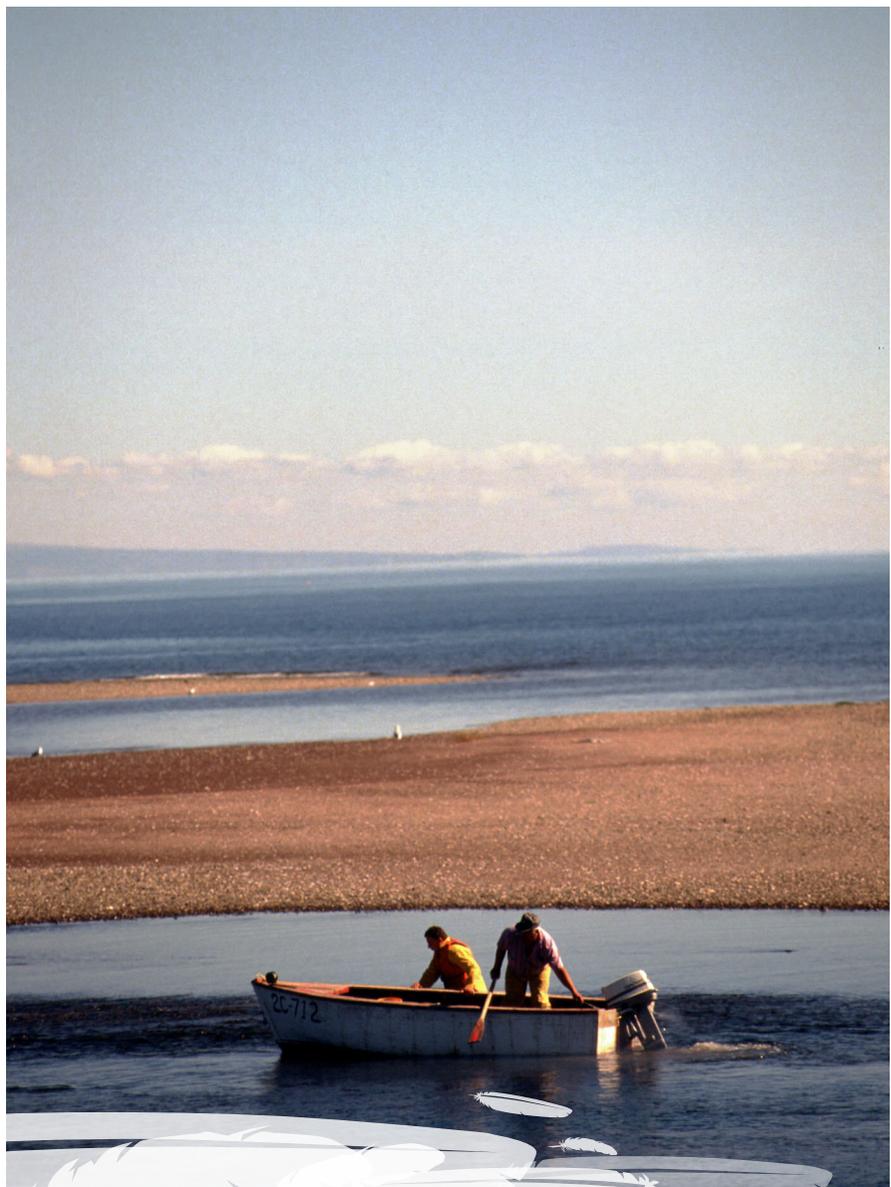
Adequate, accurate and accessible data and information on health and well-being is essential to understanding the health status of a population and the disparities that exist. An accurate assessment of the health status and the disparities of a given population will allow development of effective programs. For Métis in Canada, a true picture of population health and well-being has been missing, the predominant reason being the lack of adequate, accurate and accessible data and information on Métis health and well-being.<sup>1</sup> Several factors contribute to the lack of Métis health and well-being data/information. This fact sheet explores some of those potential factors.

## Potential Sources of Métis Health and Well-Being Data in Canada

Health data in Canada exists primarily in provincial and federal administrative databases, death and birth registries, health survey databases, and disease registries.

### Surveys—National, Provincial and Local

1. *National surveys:* Several national surveys have been conducted which have included questions on socio-demographics, education, language, labour activity, and health and well-being pertaining to Métis. Examples





- include: Canadian Census, Aboriginal Peoples Survey (APS), Aboriginal Peoples Survey (Children & Youth), Aboriginal Children's Survey (ACS), Canadian Community Health Survey (CCHS),<sup>2</sup> Canadian Maternity Experiences Survey,<sup>3</sup> and the HIV/AIDS Attitudinal Tracking Survey.<sup>4</sup>
2. *Provincial/regional surveys:* Some provincial Métis organizations have conducted local surveys, such as the Métis Nation of British Columbia Survey (2006)<sup>5</sup> and the Métis Settlements of Alberta Census (1997, 2006).
  3. *Administrative databases:* Federal and provincial government agencies maintain several databases related to health and vital statistics, including provincial birth and death registries, hospital administrative databases (outpatient physician visits, emergency room visits, hospital care, drug benefits program utilization, hospital discharge abstract data), infectious disease surveillance, etc.<sup>6</sup>

4. *Academic research:* Researchers in academic institutions engage in research studies that generate health and well-being data. Many of the research findings are published in peer-reviewed journals.
5. *National and provincial disease registries:* Federal and provincial government agencies maintain disease registries. Examples: the Canadian Cancer Registry<sup>7</sup> and Renal Disease Registry.<sup>8</sup>

While these sources of data can potentially provide a wealth of Métis-specific health and well-being data and information, limitations inherent to each source have led to poor data quality, as well as inadequate/non-existent data.

### Limitations of Existing Surveys

While health and other surveys are cost-effective, less time consuming and informative, they are subject to limitations. These include:

1. *Limited scope:* In large surveys such as the Aboriginal Peoples Survey, topics cannot be completely and adequately explored. For example, the mental health section of the questionnaire has 14 questions on mental health, emotional health and suicide attempts to assess the mental health of Métis adults, a small subset compared to the larger questionnaire often used to diagnose mental disorders (Structured Clinical Interview for DSM-IV Axis II Personality Disorders).<sup>9</sup> The validity of the smaller set of questions to accurately capture mental health has yet to be evaluated. Another case in point is the lone question on family violence where respondents were asked if family violence was a problem in their community. The survey fails to probe further to explore other aspects of family violence.<sup>10</sup>
2. *Limited generalizability:* Smaller regional surveys are sometimes plagued by inadequate sample sizes or are based



on incomplete registries, which limit the generalizability of the surveys to the larger Métis population.<sup>11</sup>

3. *Inadequate sample sizes to determine statistics for certain geographic areas:* For many variables in the APS and the ACS, statistics are only available at the national, provincial and select CMA/CA levels. This is especially true for many statistics on Métis living in the Atlantic Provinces. Also, health co-ordinators, program planners, and policy makers at the regional levels often lament the unavailability of health statistics for smaller health regions from the APS and ACS.<sup>12</sup> This limits the usability of the data for the purpose of regional program planning.
4. *Lack of disaggregated data:* Some health surveys such as the Canadian Community Health Survey are unable to provide disaggregated statistics by Aboriginal group (First Nations, Métis and Inuit) as a result of inadequate sample size.<sup>13</sup>

5. *Ethnic mobility:* Ethnic mobility is the phenomenon by which individuals and families change their ethnic affiliation over a period of time.<sup>14</sup> This is suggested to be behind some of the inaccuracies in health status estimates because the number of self-identifying Métis has changed dramatically over time; between 1996 and 2006, the number of self-identifying Métis has increased by 91 percent.
6. *Restricted access to data:* In addition to the publication of research articles, releases, and analytical papers, Statistics Canada offers a number of hours of statistical analysis and dissemination to National Aboriginal Organizations, and provides access to some raw data through their Research Data Centres.<sup>15</sup> However, researchers do not have access to all the data, and often the process for getting access to the data can be lengthy and cost prohibitive. The limited statistical capacity of Métis organizations to analyze raw data

hinders further analysis and use of the data. On the other hand, with regional surveys such as the provincial surveys, access to raw data can also be somewhat restricted by organizations.

7. *Inadequate analysis and dissemination:* The Aboriginal Peoples Survey and the Métis Supplement collected data based on over 250 questions in each cycle. However, only a fraction of the variables often gets analyzed. Findings from regional surveys by provincial organizations are also not always completely disseminated.

## Limitations of Administrative Databases

Administrative databases contain valuable data on usage of health services, hospitalizations, physician visits, mortality, etc. However there are some limitations which preclude easy extraction of Métis-specific information in the existing databases.

1. *Lack of ethnic identifiers*: Most provincial administrative databases lack ethnic identifiers, or the mechanism by which individuals can self-identify at the point of health service. As a result, it is not easy to derive Métis-specific information on many indicators. A case in point is the infant mortality rate, which is not available for Métis due to the lack of ethnic identifiers in birth and death registries.<sup>17</sup>

2. *Insufficient data linkages*: As a consequence of the lack of ethnic identifiers, data linkages between provincial administrative databases and citizenship registries of provincial Métis organizations are necessary to generate Métis-specific information on health indicators. However, only two of the five Ontario and western provincial Métis organizations have completed linkages with provincial administrative data. Lack of capacity among Métis organizations and insufficient resources have previously contributed to this.<sup>18</sup> However, funding for chronic disease surveillance by the Public Health

Agency of Canada has facilitated other provincial Métis organizations to undertake data linkage studies.<sup>19</sup>

3. *Under-enumeration of Métis in provincial Métis registries*: Registering eligible Métis for provincial registries is an ongoing endeavor. Data linkages using incomplete registries may lead to under- or over-estimation of disease, hospitalization and other related rates.<sup>20</sup>

4. *Jurisdictional issues*: Unlike status First Nations and Inuit, Métis do not have access to federal health services and benefits; instead Métis have to access provincial health care services.<sup>21</sup> As a result, data that is collected via federal programs for First Nations and Inuit is lacking in Métis-specific data.

### Inadequate Métis-Related Academic Research

Well designed and well informed academic studies can be an important source of health information. However, a major limitation has been the severe under-

representation of Métis in academic research studies.

Little academic research has been done on Métis health and well-being.<sup>22</sup> This is reflected in the small number of Métis health and well-being related articles published over the years (see Figure 1). Only about 80 peer-reviewed articles related to Métis health were published between 1980 and 2009. A fraction (12 per cent) of these articles are Métis-specific; only about half of all Métis-related articles have results broken down by Métis.

Compared to First Nations and Inuit research, Métis-related research is woefully under-represented in health sciences and social sciences research. For example, of 254 Aboriginal health-related publications between 1992 and 2001, only two provided data on Métis.<sup>23</sup>

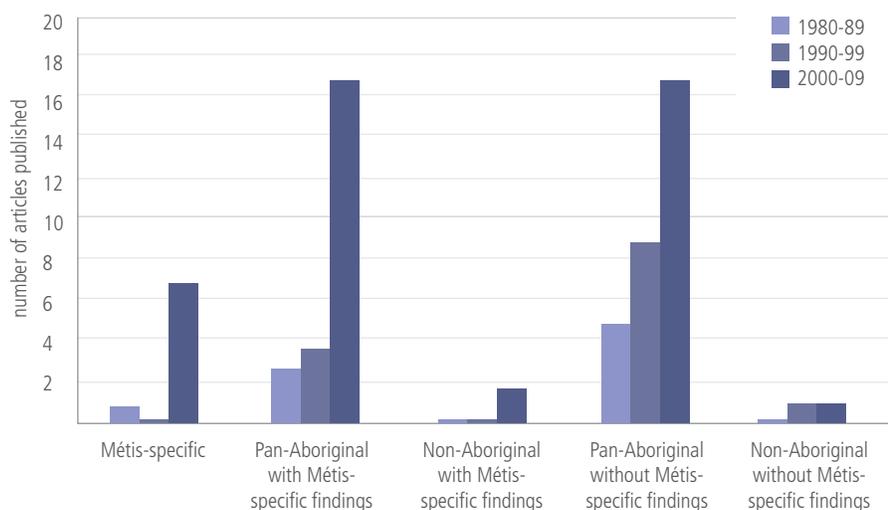
A second limitation of past academic studies has been the inability to provide disaggregated data/information, perhaps as result of inadequate sample sizes. Half of all Métis-related publications in the past three decades did not appear to present Métis-specific findings (Figure 1).<sup>24</sup>

### Barriers to Métis-Related Research

Several factors may have contributed to the under-representation of Métis in academic research studies, including:

1. *Insufficient funding*: Inadequate funding for Métis-specific projects is suggested to have curtailed Métis-specific research. Only 0.4 percent of CIHR funded research studies in 2006 were Métis-specific funding.<sup>25</sup> However, it is unknown whether this under-representation is the result of lack of qualified proposals or current priorities of funding agencies.

Figure 1: Métis health and well-being related articles published since 1980



(Source: National Aboriginal Health Organization, 2009)



2. *Lack of research ethics guidelines:* Métis-specific guidelines for research ethics have yet to be defined, which may contribute to the paucity of Métis research. Academic researchers may steer away from Métis research due to the lack of clear Métis-specific ethical guidelines for research.<sup>26</sup>
3. *Lack of defined Métis communities:* The lack of clearly defined, landed Métis communities, with the exception of the Alberta Métis Settlements, may impede Métis-related research.<sup>27</sup> Clearly identifiable First Nations reserves and Inuit communities may have facilitated more research in the past.<sup>28</sup>

These serve as proximal factors or those that have a direct effect on the ability of different sources to yield Métis-specific

data. However, overarching distal factors (those that may indirectly affect adequate Métis data collection via the proximal factors) may exacerbate the effects of these proximal factors. These distal factors may include: Métis identity issues, inadequate federal and provincial will, insufficient representation of Métis in decision making bodies, the legacy of colonization, and other systemic factors. These systemic factors and, specifically, their role in the paucity of Métis data, need further examination.

### Addressing the Factors Behind Métis Data Paucity

Specific strategies that address both the proximal and distal factors may be necessary. In addition, dedicated streams

of strategies should be incorporated into a larger comprehensive data collection initiative.<sup>29</sup> For example, a dedicated stream to address current limitations of national and regional surveys may include measures to improve the generalizability and applicability of surveys, access to data, and the capacity to access, analyze and interpret data.<sup>30</sup> In the case of academic research, a dedicated stream may incorporate an increase in funding, capacity building, and establishment of Métis-specific ethical guidelines.

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