Aboriginal Data Report for the South West LHIN Health Links

Executive Summary - August, 2015

Report background

In 2015, the South West LHIN¹ began working with the Well Living House² to assess the state of health and socio-demographic data related to Aboriginal people in the area. The full report was prepared by Michelle Firestone, PhD, and Janet Smylie, MPH, MD. This Executive Summary provides context for and shares some findings, including recommendations for the SW-LHIN as related to Health Links. See full report for additional detail and for:

- A summary of Aboriginal Service Organizations in the SW-LHIN;
- Detailed tables summarizing and characterizing health and socio-demographic data currently available for Aboriginal peoples in the SW-LHIN;
- Tables summarizing upcoming linkages between existing registries or cohorts of Aboriginal peoples and the holdings of the Institutes for Clinical Evaluative Sciences.

Key questions

Key questions for the South West LHIN emerging from this report include:

- o How can data gaps be filled in collaboration with Aboriginal organizations and governments?
- How can Health Links account for Aboriginal individuals who are not accessing care but who are sick and/or dying from potentially treatable causes?
- How can data be collected in a culturally secure way, including in the context of coordinated care plans?
- What kinds of services are Aboriginal people accessing? Where are they located, and what is the quality of care received? How long are people travelling to receive care?
- O What services are Aboriginal people avoiding, and why?
- What are some of the key barriers to accessing care for Aboriginal people?
- o How can mainstream services and service providers contribute to culturally secure encounters?
- What additional resources and services are required to ensure Aboriginal people in the SW-LHIN have access to high quality, culturally secure health care?

Methods

We conducted a comprehensive review of available public data, journal publications and 'grey literature.' We also contacted the Southern Ontario Aboriginal Health Access Centre and Métis Nation of

¹ The South West Local Health Integration Network (SW-LHIN) is responsible for funding, planning and coordinating the delivery of health care and related services in the area from Lake Erie to the Bruce Peninsula, with a population of more than 1 million people. 'Health Links' operate in the context of individual LHINs, and aim to coordinate care for individuals, in particular people with the greatest health care needs. Six individual Health Links are currently at various stages of development in the South West LHIN.

² The Well Living House is an action research centre focused on Indigenous infant, child and family health and well-being. At its heart is an aspiration to be a place where Indigenous people can come together to gather, understand, link and share best knowledge about happy and healthy child, family and community living. The centre is built from a foundation of almost two decades of collaborative work between Indigenous health researchers, front line health practitioners and Indigenous community grandparents. The Well Living House is housed at the Centre for Research on Inner City Health (CRICH), part of St. Michael's Hospital in Toronto. A committee of Elders, the Counsel of Grandparents, guides the operation of the Well Living House.

Ontario to better understand existing First Nations, Métis, and urban Aboriginal health data initiatives involving the Institute of Clinical Evaluative Sciences. Finally, we incorporated data and knowledge from our previous research related to health, health care and Aboriginal peoples in Ontario.

Knowledge Gaps

Currently, there are large gaps in data and knowledge when it comes to the health status and health care utilization of Aboriginal people in Southwestern Ontario. For example, there is little reliable information from the national census, and the health care system in Canada does not routinely collect information related to ethnicity and/or race. In most cases, it isn't possible to ask detailed questions of an entire population³

It is difficult to plan, implement and evaluate effective health programs and services without accurate information regarding the size and characteristics of the Aboriginal population, the prevalence rates of acute and chronic illness, and the rates of use of health care services. Such deficiencies have additional and wide-ranging consequences. For example, the lack of accurate information contributes to damaging stereotypes which feed racism, itself a significant barrier to health care access (Allan & Smylie, 2014).

Even if health care data collection captured Aboriginal patients, the health care utilization and health status of Aboriginal peoples would still go under-documented due to lower hospital admission rates, under-treatment and/or health care 'underuse.' Examples include:

- Hospital admission rates. Evidence from Hamilton suggests that Aboriginal people visiting Emergency Departments are not admitted to hospital at the same rates as the general population despite rates of chronic disease that would suggest the need for treatment (Firestone et al., 2014; Smylie, Firestone, et al., 2011).
- <u>Under-treatment</u>. A recent study in Alberta demonstrated that First Nations persons were less likely to receive a coronary angiogram compared to non-First Nations persons within 24 hours of an acute myocardial infarction (Bresee et al., 2014).
- '<u>Under-use</u>.' Evidence demonstrates that racism can present a substantial barrier to health care treatment (Allan & Smylie, 2015), with Aboriginal people actively strategizing around how to manage negative responses from health care providers in advance of Emergency Department visits (Browne et al., 2011). Evidence also suggests that material barriers such as transportation prevent people from accessing health care services (Firestone et al., 2014; Smylie, Firestone, et al., 2011). The phenomenon of underuse is demonstrated by the premature mortality of First Nations persons in Canada compared to the general Canadian population, including from causes that can be addressed through treatment in hospital such as respiratory tract infection (Health Canada, 2009; Oliver, Peters, & Kohen, 2012; Tjepkema, Wilkins, Senécal, Guimond, & Penney, 2009).

³ This is why researchers work to assemble smaller sub-groups or 'samples' with the capacity to represent the whole. To achieve a representative sample, however, you must know the size and basic characteristics of the population in question. That is why it is essential to collect accurate, population-based data for Indigenous peoples in Ontario. Once we have a snapshot of the whole population, we will be able to assemble representative samples, explore people's health care use and experiences, and provide a picture of different patterns related to health status, health care utilization, barriers to service and service gaps.

Current Sources of Data

While large gaps exist, some data for Aboriginal populations in the South West LHIN are currently available. Data from the Census and from Aboriginal Affairs and Northern Development Canada (AANDC) provide some understanding of the socio-demographic profile of the Aboriginal population. One community-based plan offers a snapshot of one community. Smaller, community-based studies contribute to filling gaps in understanding related to local Aboriginal health needs and responses. At the same time, these studies are usually restricted to existing health service users or volunteer participants and therefore do not include people who may have high and/or unmet health care needs. As a result, there are many unanswered questions about health status, health care utilization, barriers to service, service gaps and the determinants of health that operate in Aboriginal peoples' everyday lives.

Recommendations for Moving Forward

- A. <u>Support, in partnership with Aboriginal agencies, better Aboriginal data collection</u> to ensure Health Links impacts and efficacy can be evaluated with respect to Aboriginal people.
 - Pursue core areas for data collection:
 - Aboriginal-specific population based health service utilization data.
 - Aboriginal-specific population based health status data regarding comorbidities and chronic illness; and, complex health needs including mental health, substance use and dual diagnosis.
 - Data regarding key social determinants of Aboriginal health including housing and income.
 - Expand focus of Health Links to include "under-users" by developing and implementing key metrics that address:
 - Unmet health care needs.
 - Barriers to access.
 - Under-treatment (e.g. study in Alberta demonstrating that First Nations people are less likely to receive a coronary angiogram compared to non-First Nations persons within 24 hours of an acute myocardial infarction).
 - Develop and support synergies between Health Links and other research and policy initiatives that impact the SW-LHIN such as upcoming data linkages with ICES.
 - B. Work in partnership with local, regional and/or provincial Aboriginal governing bodies and health service organizations to ensure data collection is culturally secure. Develop a strategy for the culturally secure collection of identity data, including Aboriginal identity data in vital registration and health service utilization data systems. This work needs to be guided by existing domestic and international best practices and led by Aboriginal governing and/or health service organizations. These same principles apply to the creation of Coordinated Care Plans within Health Links.
 - C. <u>Identify and address resources and capacities needed to respond to service gaps for Aboriginal</u> people in Southwestern Ontario

- Time and resources are needed to support the full engagement and action of Aboriginal service organizations and stakeholders who are already stretched to capacity.
- Continue and extend cultural safety training to address institutional racism and trauma,
 and assess how to apply this knowledge appropriately and adequately.
- Increased support and training of Aboriginal health care professionals as well as increased awareness and education for mainstream providers.
- There are important unmet material needs such as transportation that need to be addressed in order to allow equitable access to services for Aboriginal people in the region.

References

Allan, B., & Smylie, J. (2014). First Peoples, Second Class Treatment. Toronto ON.

Bresee, L., Knudtson, M., Zhang, J., Crowshoe, L., Ahmed, S., Tonelli, M.Hemmelgarn, B. et al. (2014). Likelihood of coronary angiography among First Nations patients with acute myocardial infarction. *CMAJ: Canadian Medical Association Journal*, *186*(10), 372–380.

Browne, A. J., Smye, V. L., Rodney, P., Tang, S. Y., Mussell, B., & O'Neil, J. (2011). Access to primary care from the perspective of Aboriginal patients at an urban emergency department. Qualitative Health Research, 21(3), 333–348. Retrieved from

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=21075979

Firestone, M., Smylie, J. K., Maracle, S., Spiller, M., & O'Campo, P. (2014). Unmasking health determinants and health outcomes for urban First Nations using respondent-driven sampling. BMJ Open, 4(7), e004978. doi:10.1136/bmjopen-2014-004978

Health Canada. (2009). A Statistical Profile on the Health of First Nations in Canada: Vital Statistics for Atlantic and Western Canada, 2003-2007 (pp. 1–47). Retrieved from http://www.hc-sc.gc.ca/fniah-spnia/alt_formats/pdf/pubs/aborig-autoch/2009-stats-profil-vol3/2009-stats-profil-vol3-eng.pdf

Oliver, L. N., Peters, P. a., & Kohen, D. E. (2012). Mortality rates among children and teenagers living in Inuit Nunangat, 1994 to 2008. Statistics Canada, Health Reports (Vol. 23, pp. 1–6).

Smylie, J., Firestone, M., Cochran, L., Prince, C., Maracle, S., Morley, M., ... Spiller, M. (2011). Our Health Counts urban Aboriginal Health Database Project: Community Report.

Tjepkema, M., Wilkins, R., Senécal, S., Guimond, É., & Penney, C. (2009). Mortality of Métis and Registered Indian adults in Canada: An 11-year follow-up study.