Decolonizing Indigenous Health Information Systems in Canada

Moving Beyond Patchwork Solutions

April 5th, 2019 University of Otago, Wellington

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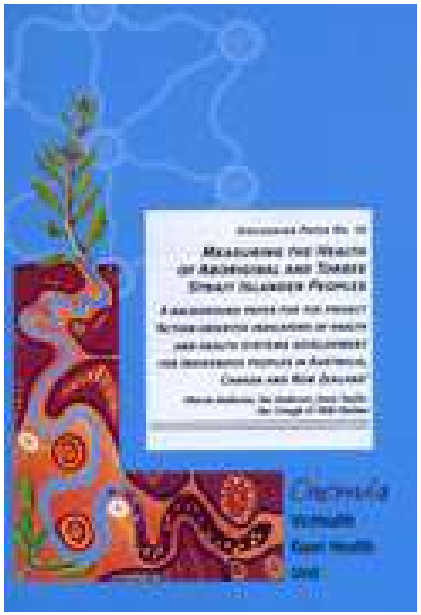
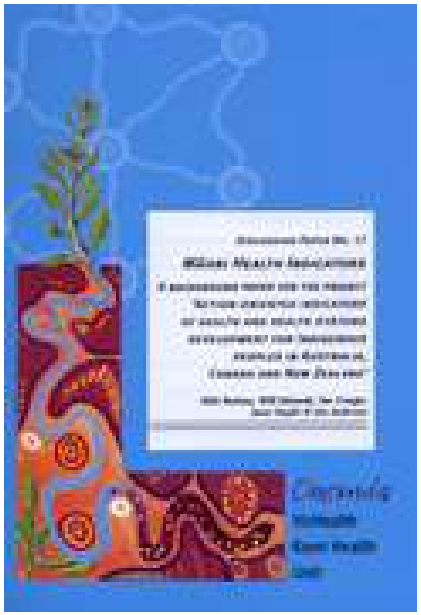
The Well Living House is an action research centre that's focused on Indigenous infant, child and family health and well-being. Our long term vision is that every Indigenous infant will be born into a context that promotes health and wellbeing – at the individual, family and community levels


Welcome
Konroronhk

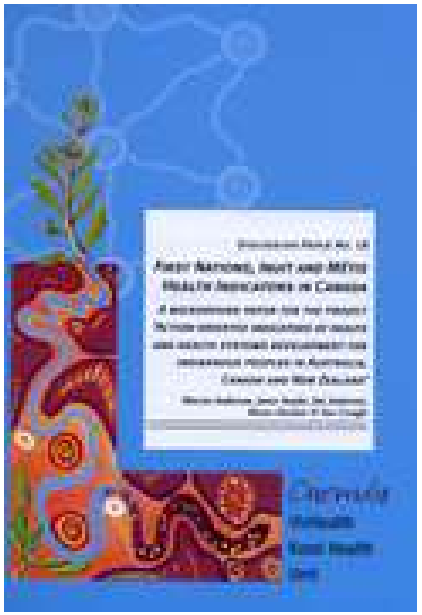
How are Indigenous people involved in data production/use?



Discussion Paper 18: ***Marcia Anderson, Janet Smylie, Ian Anderson, Raven Sinclair & Sue Crengle*** 'First Nations, Inuit and Métis Health Indicators in Canada'



Discussion Paper 17: ***Mihi Ratima, Will Edwards, Sue Crengle, Janet Smylie & Ian Anderson,*** 'Maori Health Indicators'



Discussion Paper 16: ***Marcia Anderson, Ian Anderson, Janet Smylie, Sue Crengle & Mihi Ratima,*** 'Measuring the Health of Aboriginal and Torres Strait Islander People

http://www.onemda.unimelb.edu.au/publications/discpapers.html

Colonizing Data Systems:

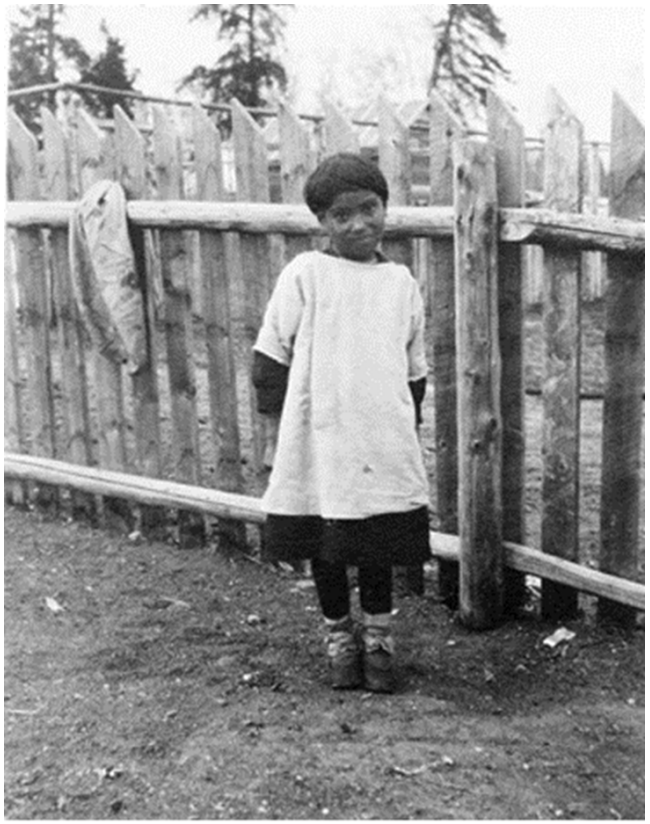
- Maintain control through involuntary counting and tracking
- Protect this control by monopolizing ownership and access to measurement systems
- Dictate who and what will be counted
- Purposefully and systematically undercount and/or discount to advance assimilation and/or maintain unequal distribution of health and social resources
- Are structured to maintain authority over what is a valid count, method, or system.

Involuntary Counting and Tracking

Administering Colonial Science:

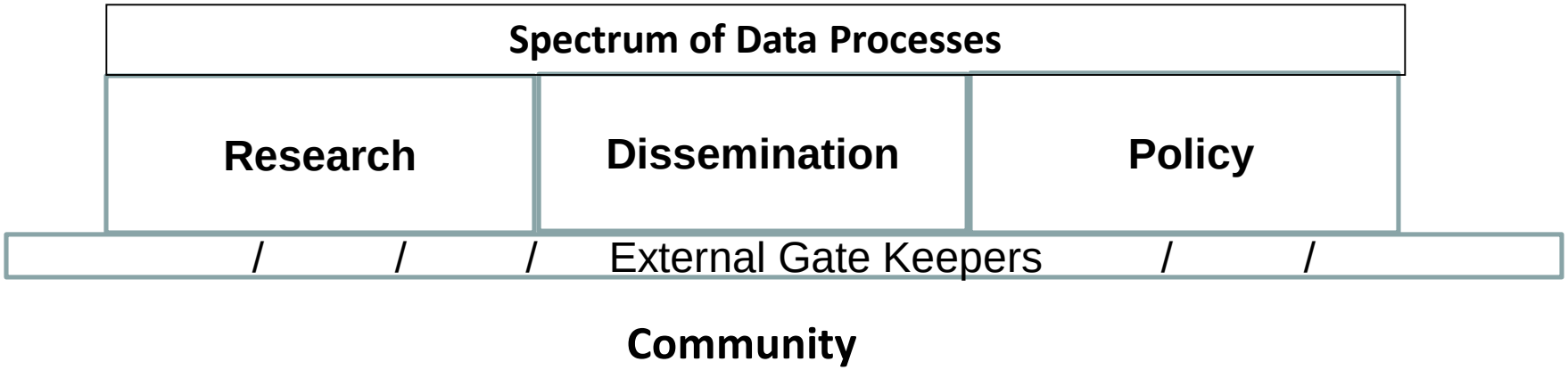
Nutrition Research and Human Biomedical Experimentation in Aboriginal Communities and Residential Schools, 1942–1952

Ian Mosby



All Saints, Lac La Ronge, SK - Mary Ann Charles, 1924
Photo: General Synod Archives, Anglican Church of Canada

Monopolizing Ownership and Access



Canadian Journal of Public Health
https://doi.org/10.17269/s41997-019-00182-8

QUANTITATIVE RESEARCH

Postpartum depression prevalence and risk factors among Indigenous, non-Indigenous and immigrant women in Canada

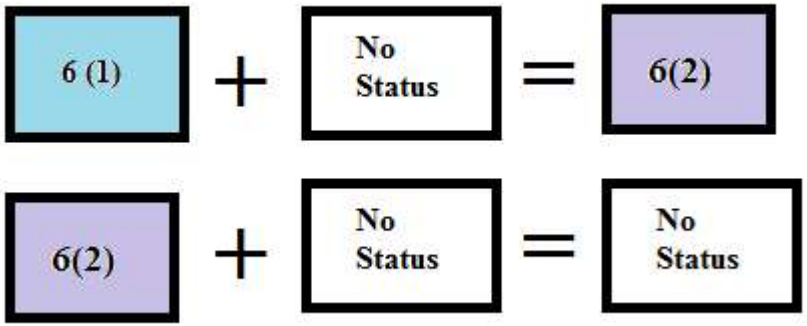
Nihaya Daoud[1] · Kristen O'Brien[2] · Patricia O'Campo[2,3] · Sarah Harney[4] · Evelyn Harney[5] · Kerry Bebee[5] · Cheryllee Bourgeois[5] · Janet Smylie[2,3]

QUANTITATIVE RESEARCH

The Contribution of Socio-economic Position to the Excesses of Violence and Intimate Partner Violence Among Aboriginal Versus Non-Aboriginal Women in Canada

Nihaya Daoud, MPH, PhD,[1,2] Janet Smylie, MD, MPH,[1,3] Marcelo Urquia, MSc, PhD,[1] Billie Allan, MSW,[4] Patricia O'Campo, MPH, PhD[1,3]

Dictate Who and What will be Counted



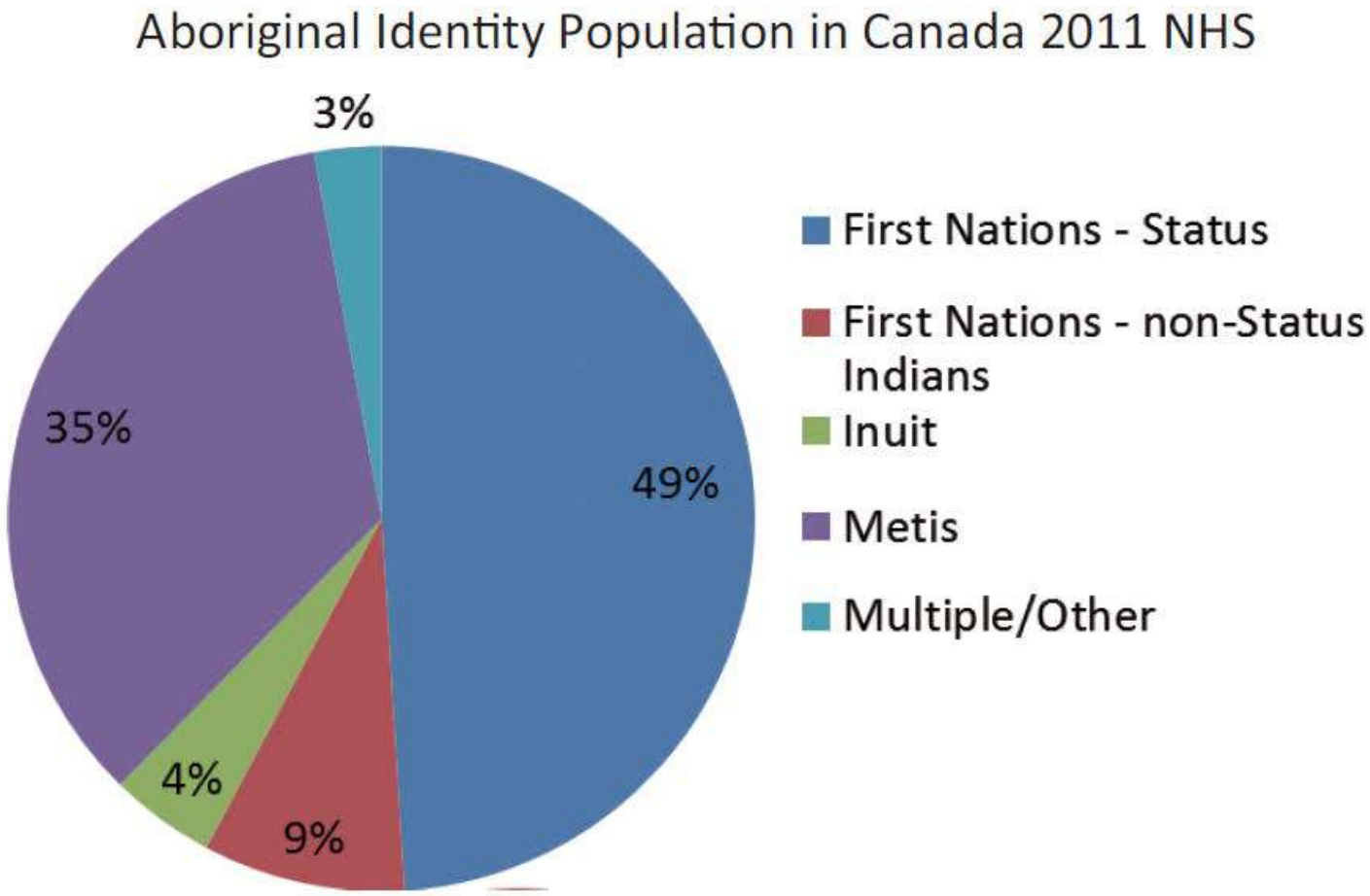


Fig. 1. Core Indigenous Population Groups in Canada (NHS 2011).

Smylie, J. & Firestone, M. Back to the Basics: Identifying and Addressing Underlying Challenges in Achieving High Quality and Relevant Health Statistics for Indigenous Populations in Canada. Statistical Journal of the IAOS. 2015. 31(1):67-87.

The Big Problem for Health Data in Canada:
Indigenous identifiers are missing in source datasets

Data Source	Indigenous Identifier
Census	Removed for 2011, back in 2016
Vital Registration	On birth registration in majority of provinces and territories; on death registration in fewer provinces and territories; inconsistent terms and poor data quality
Primary Care/Hospitalization Records	No – a few provinces/territories have Indigenous identifiers on their health cards, generally not used due to poor quality of these flags
Disease Surveillance/Registries	Limited – inconsistent terms
National Health and Social Surveys	Yes on some - loss of population based sampling frame in 2011, large majority significantly underpowered in their Indigenous sampling and exclude First Nations on-reserve communities

Structured Authority over Validity of Counts, Methods and Systems

Paul Webster (June 9, p 2137)[1]
reports that "For Aboriginal people as a whole, infant mortality is almost 20% higher than among inhabitants in the rest of Canada". This figure is substantially lower than the disparities between Aboriginal and non-Aboriginal infant mortality in Canada that have been cited in recent reviews.[2]
, [3]

Inconsistent or absent identification of Aboriginal people in Canadian health information systems precludes the calculation of pan-Canadian Aboriginal infant mortality rates. However, peer-reviewed studies have revealed infant mortality rates that are 190% higher for First Nations compared with non-First-Nations[4]
and 360% higher for Inuit-inhabited areas compared with non-Inuit-inhabited areas.[5]

Smylie, Letter in the Lancet, 2013

Open Access Research

BMJ Open

Our Health Counts Toronto: using respondent-driven sampling to unmask census undercounts of an urban indigenous population in Toronto, Canada

Michael A Rotondi,[1] Patricia O'Campo,[2,3] Kristen O'Brien,[2] Michelle Firestone,[2] Sara H Wolfe,[4] Cheryllee Bourgeois,[4] Janet K Smylie[2,3]

Data Governance

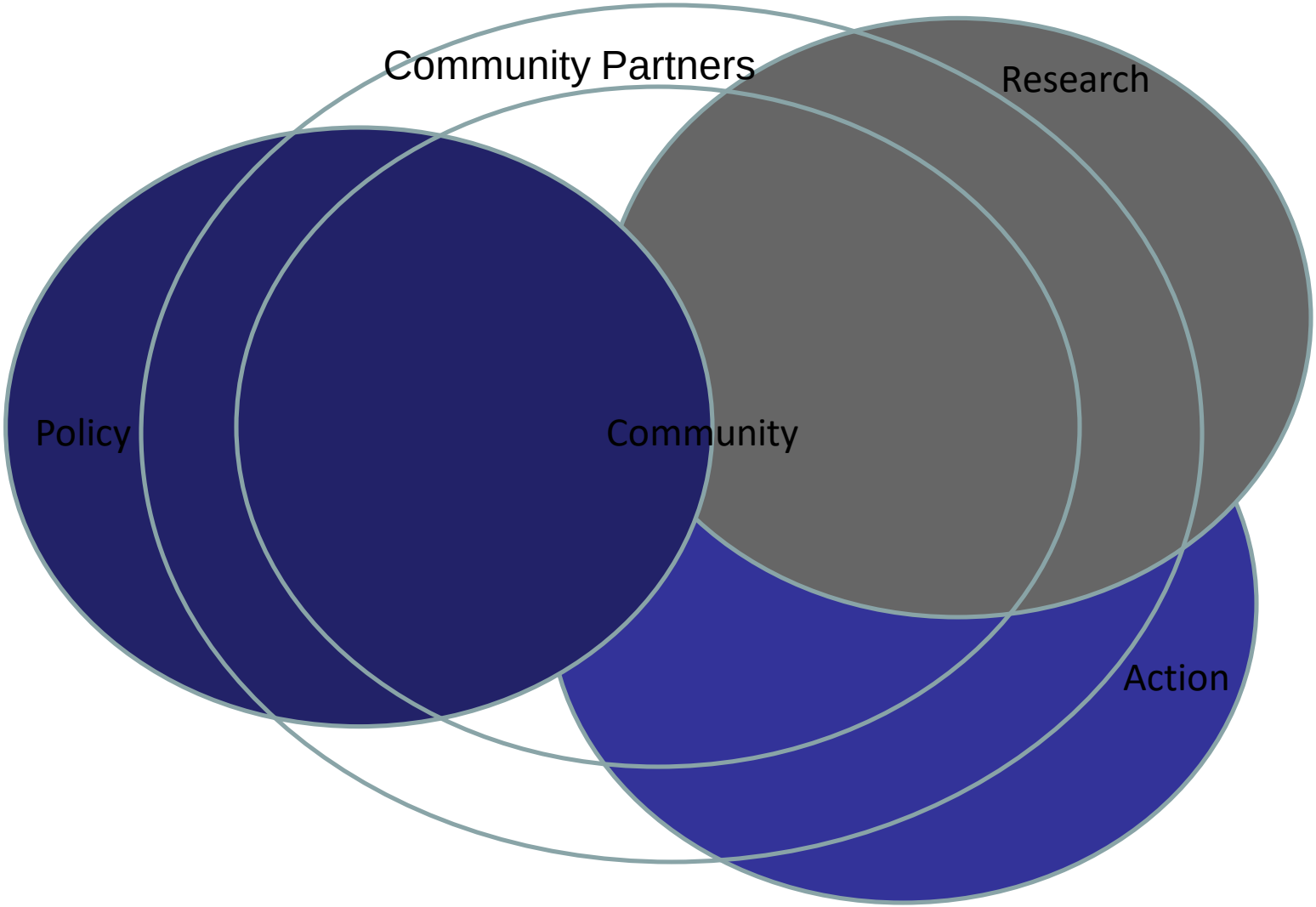
- “Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable.”

Marlene Brant Castellano

Ethics of Aboriginal Research

Journal of Aboriginal Health, 2004; 1:98-114

Data and Data Systems That Support Community Self Determination



Call to Action # 19

We call upon the federal government, in consultation with Aboriginal peoples, to establish ***measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends***. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

Addressing Urban Indigenous Myths

Majority of Indigenous people now live in cities

- in Ontario, which has the largest Indigenous population of any province/territory over 80%+ of Indigenous people live in cities

Inequities in health determinants and health status do not improve with urban residence

- 80-90% of the Indigenous population is living below the low-income cut-off
- Outcomes, including infant mortality, **do not improve** in cities compared to rural/remote residence, and in some cases (ie preterm birth) are worse

There are major barriers in accessing culturally secure care for Indigenous peoples living in Canadian cities

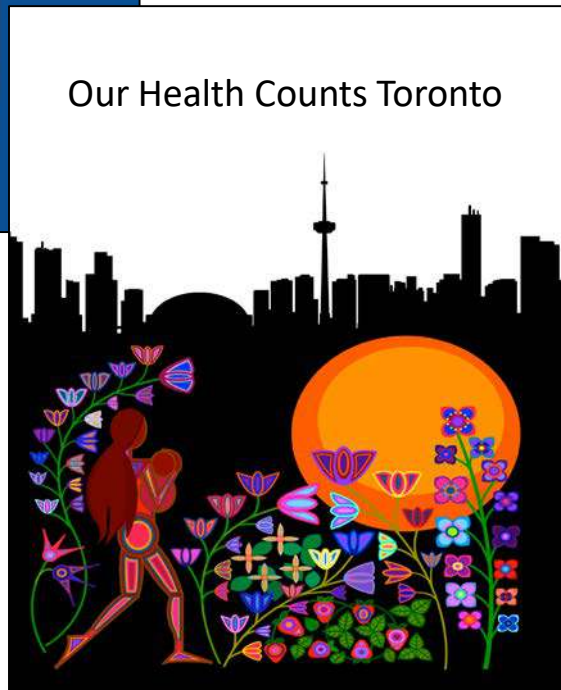
- Includes attitudinal and systemic racism

Data Gaps are Critical for Urban Indigenous Populations

- Existing data sources are biased and/or non-population based
  - non-random convenience samples
  - service or program based
  - incomplete and biased Indigenous participation in census (also limits subsequent census based survey samples)
- Unlike some First Nations on-reserve and Inuit land claim communities there is no inclusive “list” of urban Indigenous peoples
- Existing data tells us this is a sizeable population with significant social and health inequalities

Our Health Counts (OHC)

- Hamilton
- Ottawa
- Toronto
- London
- Thunder Bay
- Kenora



OHC Overview

- Development and application of a baseline population health database for urban Indigenous people in Ontario
- Funders: Canadian Institutes of Health Research (CIHR) and MOHLTC
- Longitudinal multi-site cohort study

Partnerships

St. Michael's
Inspired Care.
Inspiring Science.

Well Living House

ANISHNAWBE MUSHKIKI
COMMUNITY HEALTH & WELLNESS

O.F.I.F.C.

ONTARIO NATIVE WOMENS ASSOCIATION

Tungasuvvingat Inuit

the Métis Nation of Ontario

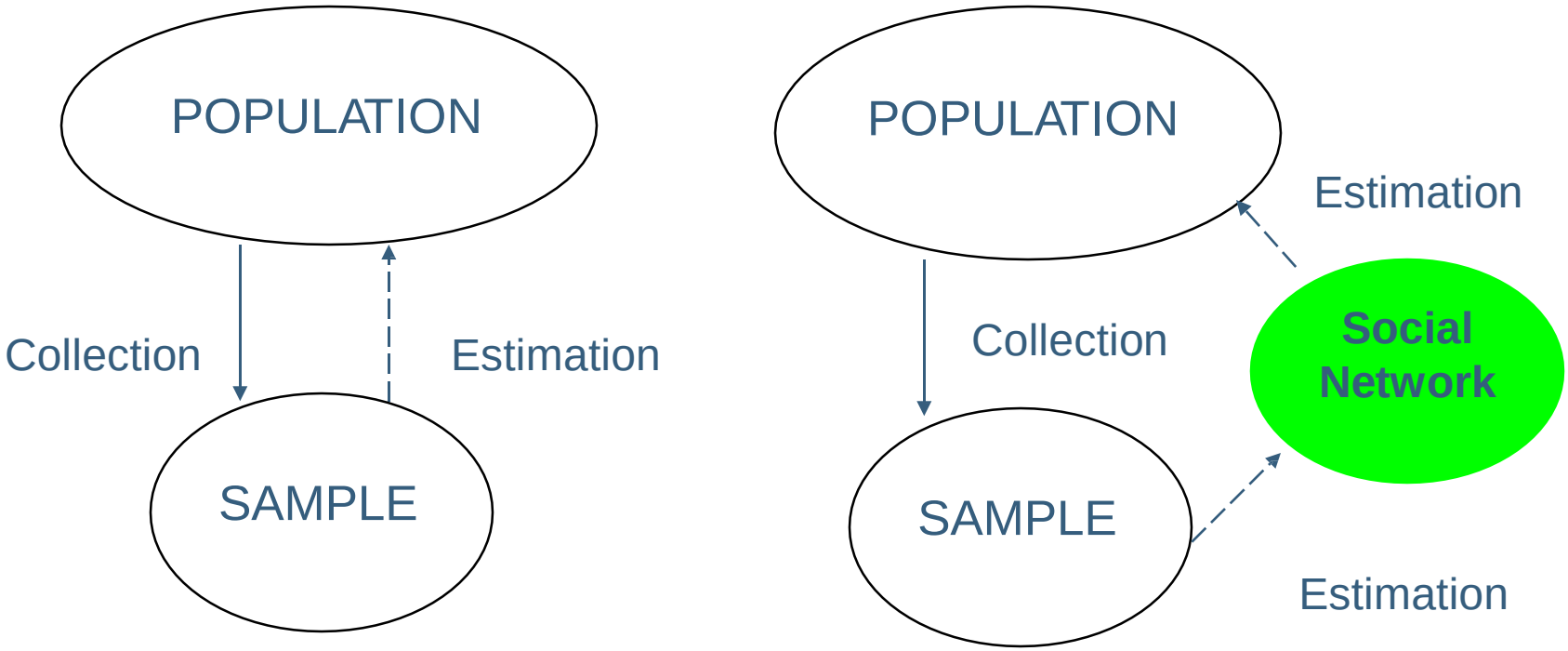
Methods & Key Adaptations

- Community-directed and community implemented participatory action research
- Community Data Custodianship and Control
- Concept Mapping
- Community based Respondent Driven Sampling
- Respectful health assessment survey
- ICES data linkage

Respondent Driven Sampling

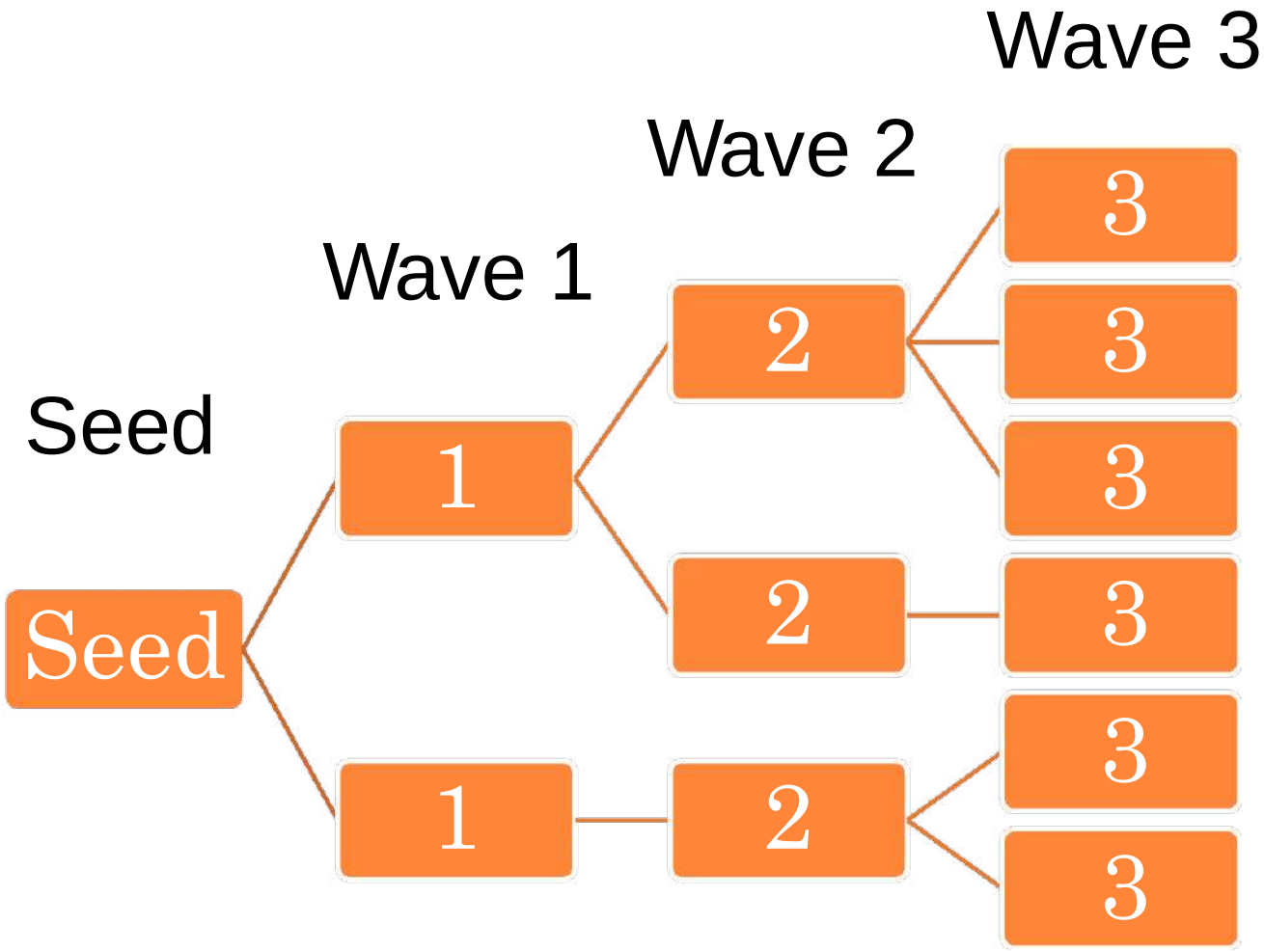
Form of *chain referral sampling*, however, RDS is considered a probability sampling method because probabilities of selection can be calculated

Traditional Probability Sampling vs. RDS



Heckathorn & Salganik, 2004

AN RDS SAMPLE

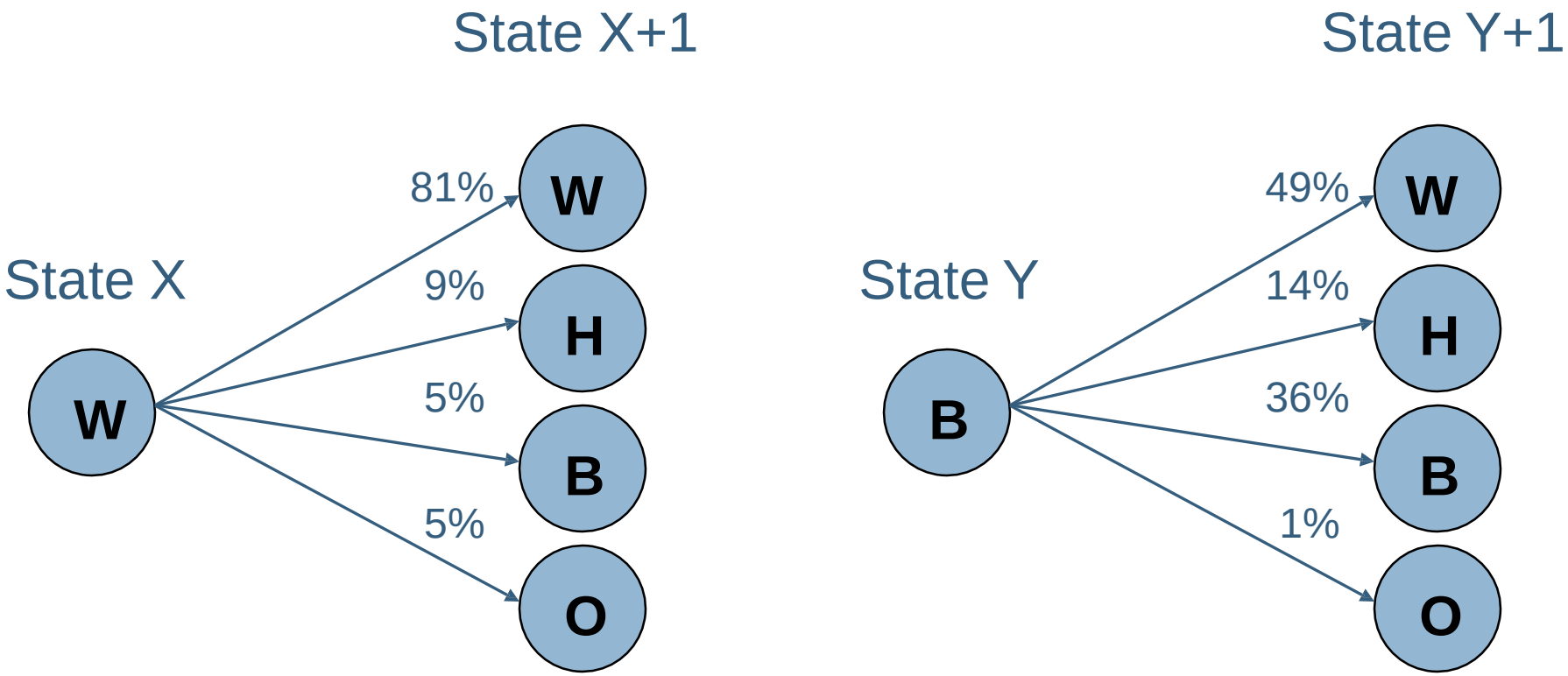


RDS Operational Details

- Respondents are rewarded for both participating and recruiting
- Coupons ration recruitment rights (e.g., 3 per respondent)
- Coupons have unique serial numbers that document who recruited whom

The Markov Model

- Each recruitment is a change in the chain's state, governed by a transition probability (Heckathorn,1997)



W=white, H=Hispanic, B=black, O=other

Resolving Initial Sample Bias: The Markov Model

- Recruitment as a Finite Markov Chain
  - Recruitment can be seen as a stochastic process (ie random probability pattern) in which the social characteristics of each recruiter probabilistically affect who they recruit
  - These characteristics are the *states* of the chain (e.g. four race groups)
  - The transition between states (who recruits whom) is governed by transition probabilities

Two theorems regarding Markov chains are relevant to an understanding of RDS:

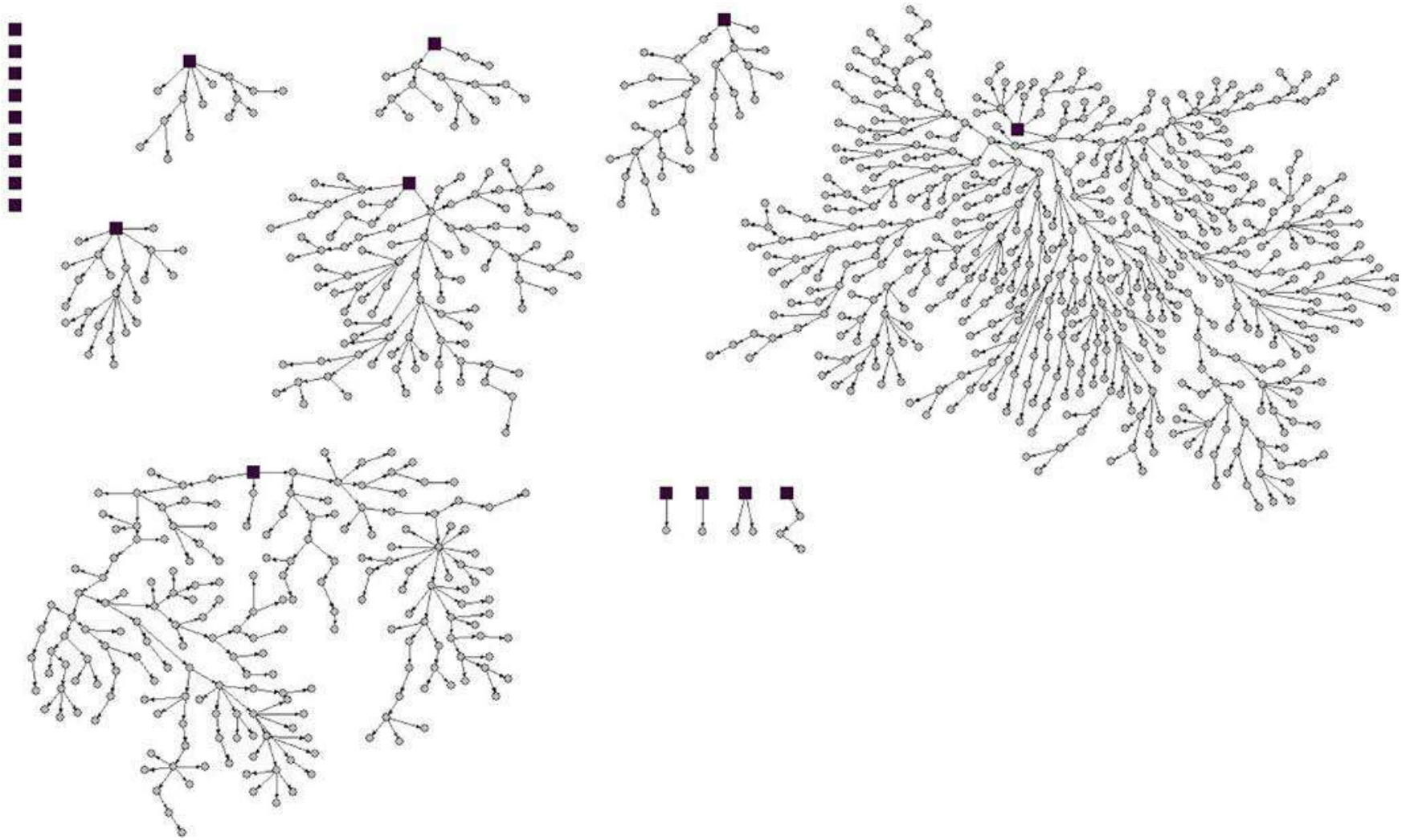
- **THEOREM ONE:** Law of large numbers for regular Markov chains" (Kemeny and Snell 1960)

  Implication: As the sample expands wave by wave, the proportional composition of the sample becomes stable, reaching what is termed *equilibrium,* so bias from the seeds disappears if the number of waves is large enough.

- **THEOREM TWO:** The equilibrium is attained at a geometric (i.e., rapid) rate.

  Implication: Only a moderate number of waves of recruitment are required for the subject composition to reach equilibrium (usually only 4 to 6).

OHC Toronto Recruitment Trees



Sample to Date

- 4 successful samples to date (OHC First Nations Hamilton, OHC Ottawa Inuit, OHC Toronto, OHC London)
- Total Adults (pooled): 2350
- Total Children (pooled): 950
- Two in progress (OHC Thunder Bay and Kenora)
- Application under review (OHC Winnipeg)

Key Findings: Population Size

- The recent Canadian census underestimated the size of the Indigenous population in Toronto by two to four times.
- Specifically, under conservative assumptions, there are approximately 55,000 (95% CI:45,000-73,000) Indigenous adults and children living in Toronto; at least double the 2011 NHS estimate of 19,270
- Similar census underestimates of population size identified by OHC London and OHC Ottawa Inuit

Open Access Research

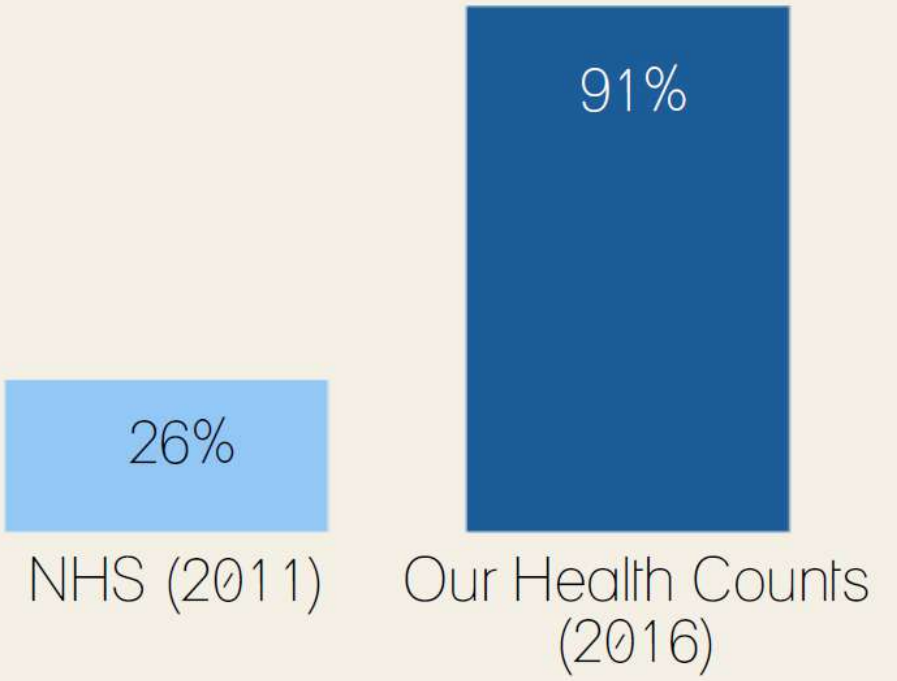
BMJ Open

Our Health Counts Toronto: using respondent-driven sampling to unmask census undercounts of an urban indigenous population in Toronto, Canada

Michael A Rotondi,[1] Patricia O'Campo,[2,3] Kristen O'Brien,[2] Michelle Firestone,[2] Sara H Wolfe,[4] Cheryllee Bourgeois,[4] Janet K Smylie[2,3]

Unmasking of Urban Poverty

Over 90% of Toronto's Indigenous population lives below the (before tax) Low Income Cut-Off (LICO)



When a family spends 20% + more (of their total income) than the average family on food, shelter, and clothing.

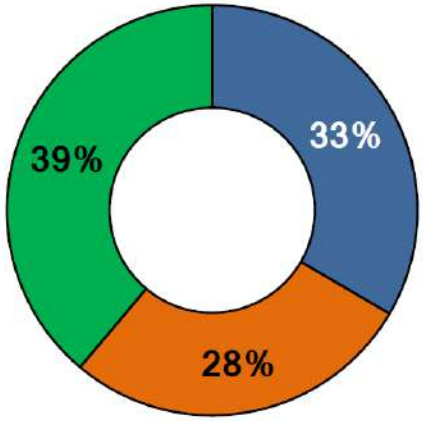
Experiences of Racism

54% of Indigenous adults in the City of Toronto, 15 years and older, reported experiencing racism. This is consistent with the findings of Our Health Counts Hamilton, where over half of Indigenous adults reported experiencing racism.[3]

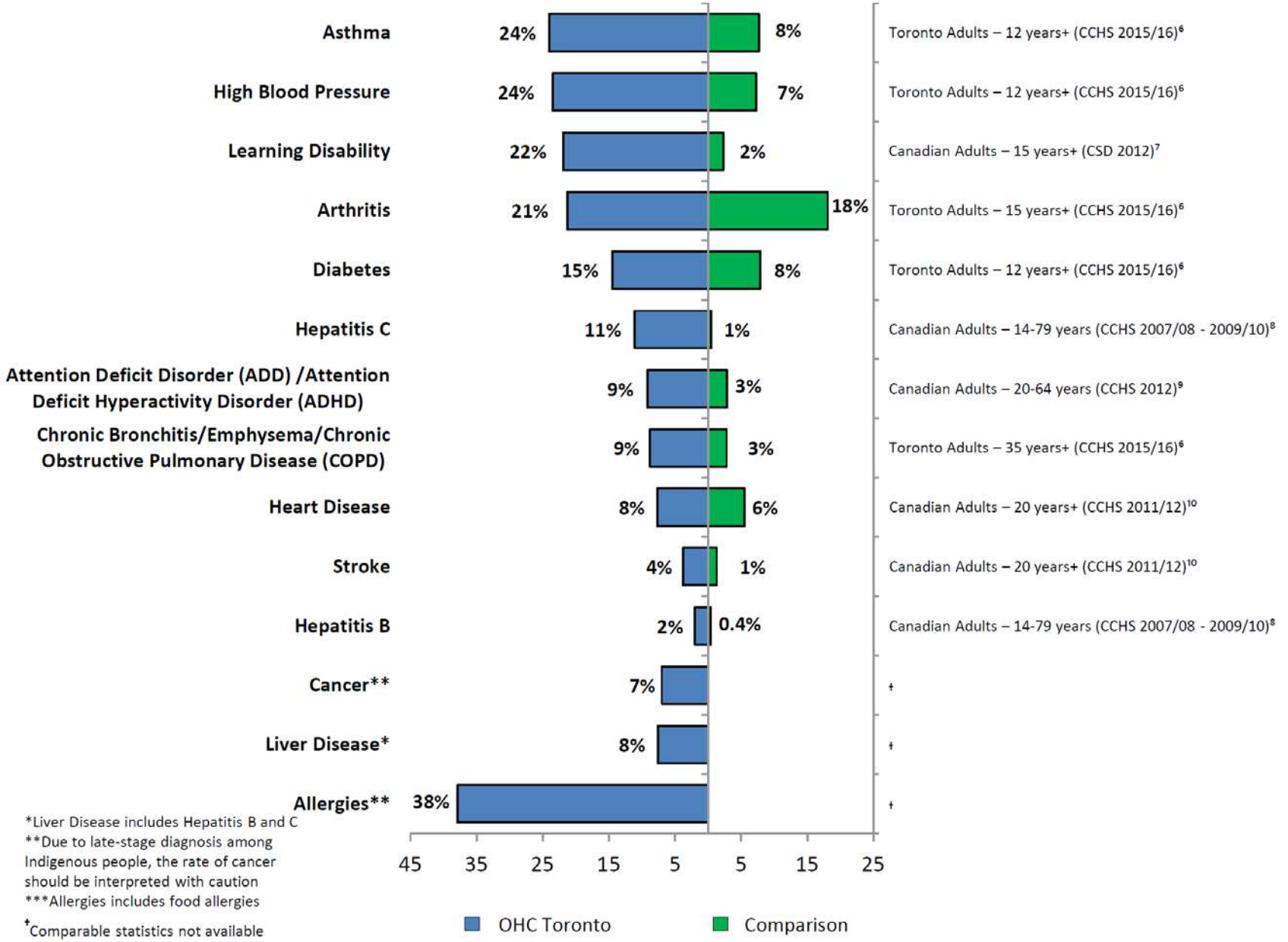
Over half

of adults in Toronto that reported experiencing racism, experienced it over the past year.

- **33%** reported experiencing racism **1-3 times** over the past year
- **28%** reported experiencing racism **4-5 times** over the past year
- **39%** reported experiencing racism **6 or more times** over the past year



84% of Indigenous adults in Toronto believe racism towards Indigenous people is an issue in Toronto.

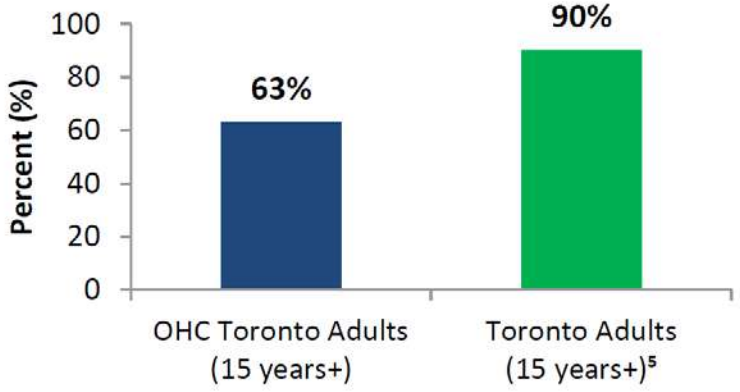


*Liver Disease includes Hepatitis B and C
**Due to late-stage diagnosis among Indigenous people, the rate of cancer should be interpreted with caution
***Allergies includes food allergies

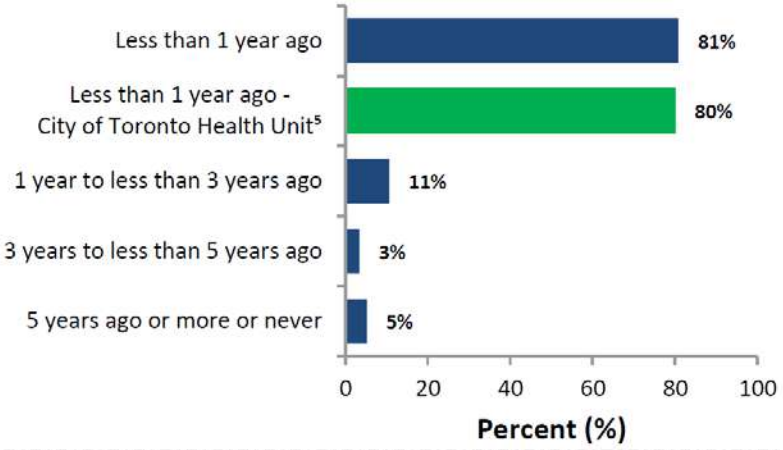
†Comparable statistics not available

Primary Care

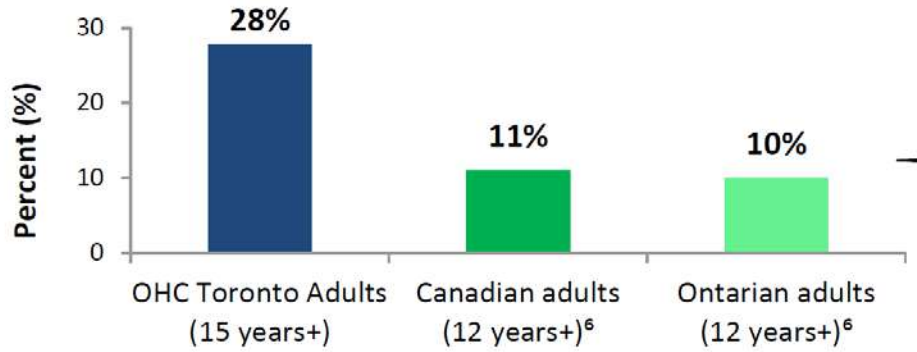
63% of Indigenous adults in Toronto have a regular family doctor or nurse practitioner.
In comparison, 90% of adults in Toronto have a regular medical doctor.[5]



While less Indigenous adults have a regular family doctor/nurse practitioner, many have seen a doctor or nurse practitioner in the last year:



Over 1 in 4 Indigenous adults in Toronto had unmet health needs in the past 12 months.



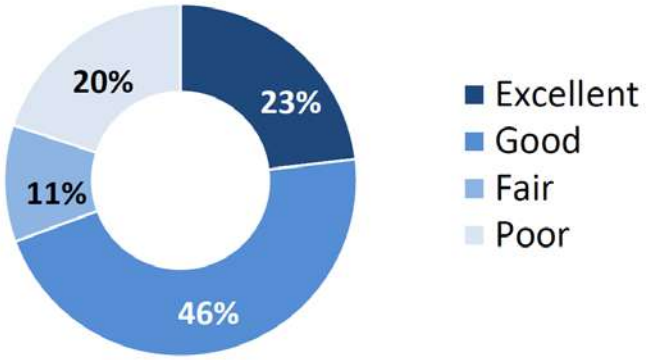
Reasons why these needs were not met:

- Inability to get transportation
- Inability to afford transportation
- Lack of trust in the health care provider

Emergency Care

33% (1 in 3) of Indigenous adults in Toronto self-reported accessing emergency care in the past 12 months, compared to an estimated **19%** of Ontarians.[7]

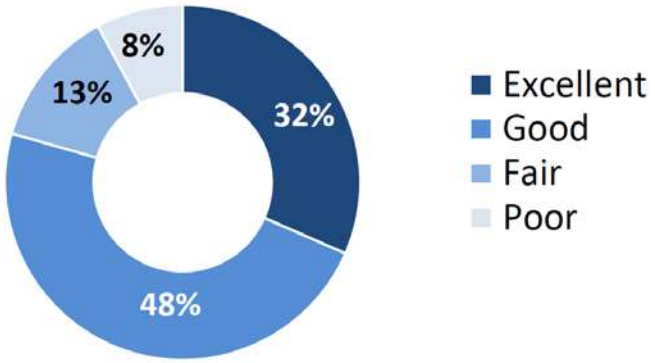
Of people who accessed emergency care, **31%** rated the quality of care as fair or poor:



Hospital Care

40% (2 in 5) of Indigenous adults in Toronto self-reported having spent one night or more in a hospital in the past 5 years.

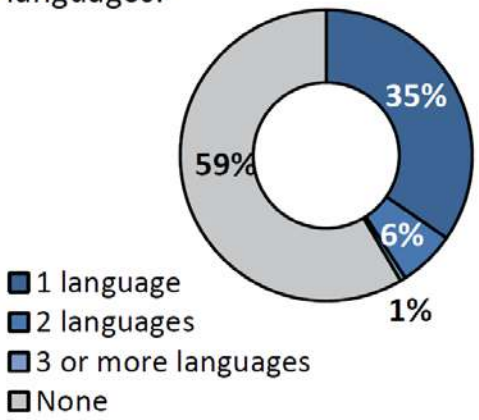
Of people who accessed hospital care, **21%** rated the quality of care as fair or poor:



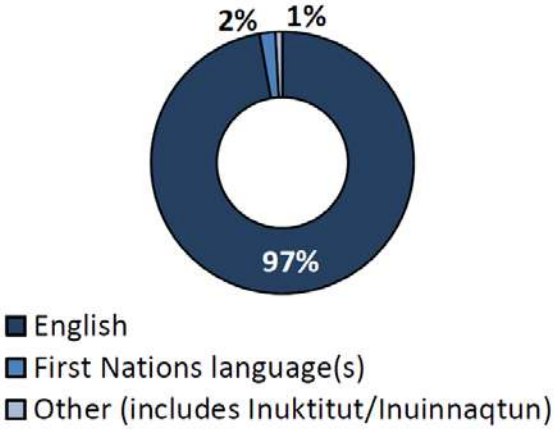
Indigenous Languages

42% of Indigenous adults in Toronto speak an Indigenous language, higher than the TARP 2011 estimate of **19%** of Indigenous adults in Toronto.[3]

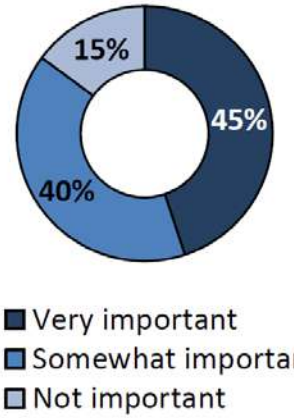
7% of Indigenous adults in Toronto speak multiple Indigenous languages:



The language most commonly used at home by Indigenous adults was:



Most Indigenous adults said that speaking/learning an Indigenous language was important:



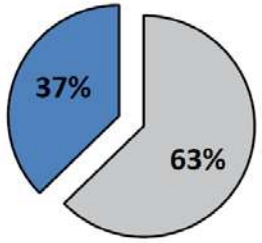
Traditional Ceremonies

2 in 3

(65%)

Indigenous adults in Toronto have participated in traditional ceremonies.

Over 1/3 of Indigenous adults experience challenges in accessing traditional ceremonies:



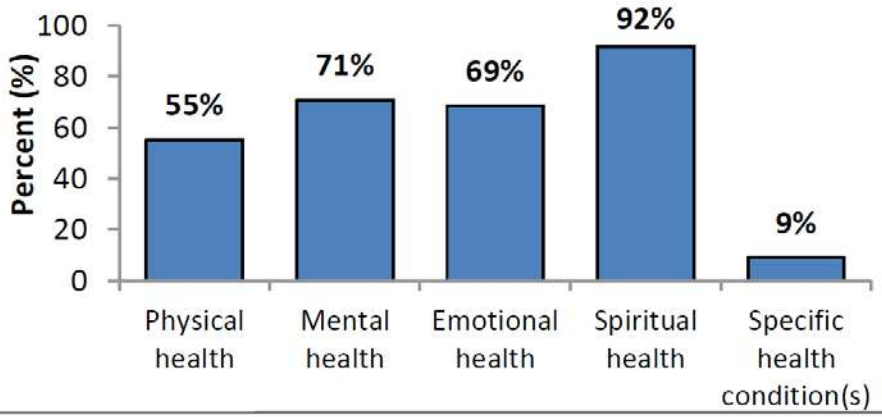
Common barriers faced accessing traditional ceremonies included:

- **Unsure where to access ceremonies**
- **Travel distance**
- **Not knowing enough about ceremonies**

Traditional Medicines

49% of Indigenous adults (2015) used traditional medicines to maintain health and well-being. This is slightly higher than the **33%** of First Nations adults in Hamilton (2009).[2]

Uses of traditional medicines/practices:



Common sources of traditional medicine knowledge and practices were:

- **Elders/Knowledge Keepers**
- **Family members**
- **Other Indigenous people**

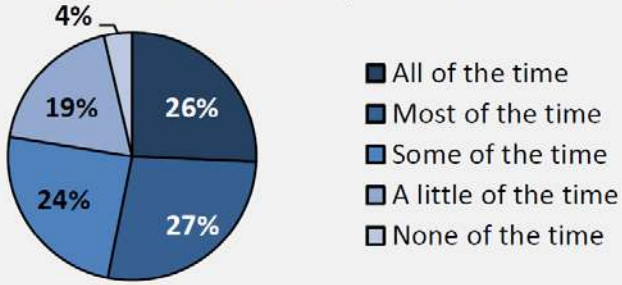
Identity

71% of Indigenous adults in Toronto had a total identity score that reflected a strong sense of identity among the population in Toronto.

74% had a strong identity affirmation factor score and **62%** had a strong identity search factor score.

Connection to the Land

Most Indigenous adults feel a strong connection to the land and Mother Earth all, most or some of the time.



Next Steps

- Working nationally and internationally to decolonize Indigenous data systems
- Build strategic data alliances across jurisdictions and nation groups
- Implement Our Health Counts in other regions of Canada

Discussion